

Chapter Five

A Dash of Autism

Jami L. Anderson

It seems that for success in science and art a dash of autism is essential.

—Hans Asperger

Some months ago I was sitting on an examining table, working my way through hundreds of questions about our son's developmental progress while my husband and he amused one another. We were all waiting (and *had* been waiting for almost two hours) for a neurologist to arrive. Our son had recently suffered a series of terrible migraines and we had been referred to this neurologist to see if there were any prophylactic treatments available for young children to prevent migraines as there are for adults. I filled out question after question concerning early developmental progress: how old was he when he first sat? stood? crawled? walked? ran? The questionnaire was ridiculously long; by page ten, I was peeved, by page fifteen my answers bordered on science fiction. I had noticed both "migraine" and "autism" listed on the top of my son's forms and I began to suspect that all of this paperwork had far more to do with the neurologist's interests in my son's autism than with a genuine concern for his migraine problems. Finally an intern came in and asked yet *another* round of questions very similar to those on the forms. One of the questions was "When did he start talking in full sentences?" At that very minute our son was signing¹ a song he knew, showing off to anyone who would pay any attention to him. I have long ago become so tired of that question, a question fraught with so much emotional baggage,² I asked, rather snappishly, "Does sign language count as talking? He *signs* complete sentences." The intern stared at the form, mumbled, "I'm not sure," and then wrote something down on the chart. But what did he write if he did not know what the question meant? So this is how research on autism is done by neurologists at world-renowned university research centers, I mused. Then,

the moment we were all waiting for: the neurologist arrived. Within a minute he told us that there was nothing he would give us for the migraines—our son was far too young for migraine medication. But he did suggest that we get lab work done to test for autism. Both my husband and I asked what purpose that would serve. After all, we know he is autistic. The neurologist smiled condescendingly and replied “There is a new genetic test. It was not around when your son was first diagnosed. It will help us find a cure for autism.” He must have been expecting whoops of joy and our lack of interest seemed to annoy him. He turned to me³ and said, rather peevishly, “It is a *simple test*—blood work, no more, and you are done. They check the DNA. (dramatic pause) It is very important.” Getting what can be at best described as complete indifference from us as we organized our bags and coats and readied to leave (while our son continued to sign, sing and lark about the room) he tried again, speaking very slowly and pointedly, “You do want to *CURE AUTISM*, don’t you?” I was surprised to find myself thinking, “No. I do not.”

YOU WANT TO CURE AUTISM, DON’T YOU?

I certainly would not have come to that conclusion six years earlier. Not because I had well-considered views about autism but because I had not given the matter any serious thought and would have been parroting the generally held view of most people: that autism is a sad affliction that causes much suffering for the child, the parents and fellow family members and therefore we must, as a society, do all that we can to eradicate it. I would have thought that such a view was enlightened and reasonable. Before coming to the realization that I do not believe that autism needs to be *cured*,⁴ I have taken what seems like an acid trip through therapy-hazed madness.⁵ I will start at the beginning, which seems to me like many lifetimes ago, but which is not my son’s full lifetime ago.

It seems almost impossible that just under six years ago I knew next to nothing about autism. I had heard the term “autism” but knew almost nothing of what the term meant, knew no one who is autistic (or so I thought), knew nothing of what it was like to live in this society with that label. What I knew (and what can hardly be counted as ‘knowledge’) came almost entirely from an NPR story I heard one morning. It concerned a father who was describing the hardship and pain he suffers from having a daughter who is autistic. What struck me was the heartache he described when he thought of the years laying before him, empty of any affectionate or loving physical contact with his daughter whom he described as “extremely touch adverse.” I am not sure what the ostensible purpose of that ‘news’ story was, but I do know I have at many times thought of that father’s professed suffering, and the public presentation of an autistic child as a profound disappointment for a parent.

Some months later, my husband and I were in a neurologist’s office⁶ and were being presented with the news that our son, then about twenty-eight months old but not yet talking, was, according to the neurologist “without a doubt PDD-NOS.” I felt both sick with shock yet utterly bewildered, having never heard of that condition before. The neurologist then did us the favor of translating: **P**ervasive **D**evelopmental **D**isorder, **N**ot **O**therwise **S**pecified. None the wiser, he explained: PDD-NOS is a subcategory of the Autism Spectrum Disorder⁷ which “makes up an umbrella.” (At this, he waved his hand in a wide arc and for a split second I almost *did* see an invisible umbrella there, suspended, in the room.) He must have talked for a few minutes more, though I have no memory of what he said. While he talked, I watched my son walk around the small examining room, happily making playful overtures to engage with my husband. My son’s tactic was (and still is) to place himself right in front of a person, stare intently into their eyes without blinking,⁸ and then to implant his intentions into their mind. More than once I’ve concluded that, if anyone has telepathic powers, he does, as I often find myself inexplicitly bending to his will, persuaded by the sheer force of his stare. The neurologist ended his emotionally flat patter with a perfunctory, “So, any questions?” In retrospect, it was almost funny. Any *questions*? Had I the power to formulate any *thought*, one question I surely would have asked would have been, “What the hell are you *talking* about?” I do not remember what either of us said but it must have been something about our son’s prognosis, because I do very clearly remember him saying, “His symptoms will eventually disappear but he will always be autistic.” He then wished us good day and left the room.

SO WHAT NOW?

I do not remember the next couple of months very well. Both my husband and I had the astonishing good fortune to be on sabbatical for the whole of that academic year; I am sure neither of us would have been able to teach any classes or attend a committee meeting without falling apart had this diagnosis come during any other year. I had been in the middle of writing a book for which I had a contract with a publisher, but I could no longer concentrate on it. I could not bring myself to care about much at all.⁹ I could not comprehend the total misfit between what I thought I knew “autism” to be—children who were aloof, distant, touch-averse head bangers—and what I knew my son to be—ebullient, joyful, hilarious, cuddly, funny, energetic, loving, and with a wonderful and spontaneous sense of humor. It did not fit. It could not fit. The diagnosis was simply impossible. Indeed the whole idea of a category such as PDD-NOS was *ridiculous*—“not otherwise specified” simply stank of “we do not know what the hell we are talking about.” And every

time I thought of the neurologist's words "his symptoms will completely disappear but he will always be autistic," my mind reeled—what could that even *mean*? If that was the case, why should we care? Why would autism even *matter*?

Not too surprisingly, we could not stop talking about it (with each other, never with anyone else), arguing about it, obsessing about it. After stewing about it for months, we both, independently, devoted all our energy to researching autism. You would think becoming genuinely educated about autism would be relatively simple given how many people in this society are researching, talking and writing about autism. Yet when I entered the world of autism, I entered a colossal, mad, cacophonous circus, one filled with a bewildering number of barkers, each frenetically promising a "complete cure" or "total recovery" all the while warning us to avoid the charlatan in the next tent whose treatments were a hopeless waste of money if not deadly dangerous. In addition to the hundreds, if not thousands of therapies, herbal and medicinal remedies and treatment plans available, there are millions of products parents can buy (if one can afford the hyperventilation-inducing prices) that are designed just for autistic children: special clothing, bedding, toys, school supplies, books and other education supplies, occupational therapy gadgets, videos and CDs—all of which are designed to alleviate, if not eliminate, the symptoms and signs of autism. Product after product features a parent professing that, after purchasing this or that device, their little Johnny or Susie is now "symptom free," "his old self again" or "completely recovered." Some of those things are useful and some are simply fun¹⁰ but a good deal of the stuff is stupefying nonsense. Here are some bullshit autism cures worth mentioning:¹¹

Autism Herbs: For a touch of the Orient, you can try Chinese Herbal Medicine such as Special Brain's Powder. Here is one story: "Joe is 8 years old...[w]hen he first came into our centre [he was] jumping and screaming all over the place and zero communication and eyes contact. He is in his own world, very scared and frustrated, until he hits himself on the head continuously..." But with just 30 days of treatments, two sessions per day, using this Special Brain's Powder Joe was "almost 100% recovered!!!" and Joe and his parents "...went home with a HAPPY HEART!!! NO MORE MEDICINE, WORRY, STRESS, FRUSTRATION, SLEEPLESS NIGHT."¹²

Adult Stem Cell Therapy: One group of audacious clinicians at the Stem Cell Institute claim to treat autism with Adult Stem Cell Therapy. Adult stem cell research is not currently approved by the United States Food and Drug Administration (FDA) nor is it "considered standard of care for any condition or disease." Furthermore, "for most diseases no prospective, randomized clinical trials of adult stem cells have been performed, therefore no guarantee of

safety or effectiveness is made or implied."¹³ Nonetheless it is being offered as a viable treatment for children with autism. Interestingly (alarming?) the treatment is not performed within the borders of the United States but in Panama City, Panama, after one's application—and one's credit line—has been approved.

Testimonials from the parents of survivors of this process attest to the wonders of it: Nine-year-old Kenneth started adult stem cell treatment and within two days his parents saw improvement. "[H]e's more aware of his surroundings. He even remembers birthdays, days of the week and he can tell time. We've just been waiting for the new things and the gains to stop coming and they're not stopping. They're coming every day."

James developed severe autistic symptomatology one month prior to his sixth birthday.

The anguish and pain we felt as our family watched him disappear into the abyss of thoughtlessness is indescribable... The initial round of stem cells significantly improved my son's cognitive skills... Each day we see many subtle improvements like consistently smiling for pictures, allowing his sibling to blow out her birthday candles or understanding that Sunday comes before Monday.

One parent writes of her daughter, "Emma is progressing beyond my wildest dreams."¹⁴

Dr. Wong's Secrets: This manual is chock-a-block full of secrets that will not only teach you how to "defeat" autism but promises a child that will "spring out of bed at 6 a.m. every day to go to normal school, free, refreshed and ready for all the beautiful moments in life you thought autism had stolen from them forever." Dr. Wong warns that his Secrets are not for every parent, though. They are not for those "who don't have an open mind or who are negative people."¹⁵ The subtext of Dr. Wong's "Miraculous Cures Manual" is clear: if the cures do not work, the cause of the problem is not the therapy but with the "negative" parents with closed minds.

Clay Baths: Just one part of the mind-boggling discussion of the benefits of "detoxing" autistic children, clay baths are said to "draw out" the harmful metals, chemicals and other contaminants in the toxic bodies of the autistic child. Amazingly, all symptoms of autism fade in just minutes as these enthusiastic parents testify:

I am absolutely amazed that after a few short baths with...clay, my son's behavior has changed quite noticeably

Our 2 ½ year old son, who is autistic, increased his vocabulary from 4-5 words to 20 words

Keven lost his baby speech at the age of 18 months, right after his vaccinations....A couple of days ago my son Keven came downstairs and told me he was back. So I asked him, "Back from where Keven?", and he said, "I was very far away from you but now I am closer to you." All the while he pointed to his head. "While you were far away from me, where you happy Keven?" And his reply was, "I was alone and afraid." This from a child that walks the same shadow with me from the moment he was diagnosed.¹⁶

After acknowledging that Food and Drug Administration (FDA) regulations disallow claims that taking a clay bath will *cure* autism, they do assert that "many parents of autistic children have seen their child's symptoms reverse or go away entirely."¹⁷

Hyperbaric Chamber Therapy: In short, this is the medical use of oxygen at a level higher than atmospheric pressure.¹⁸ Apparently someone has decided that autistic children would benefit from spending their hours inside hyperbaric machines.¹⁹ What exactly hyperbaric oxygen therapy (HBOT) could possibly offer an autistic child is unclear and the various web page discussions are often filled with obfuscatory explanations of autism and the reasons why HBOT will help. Here is a typical example:

HBOT increases the oxygen tissue concentration which increases cerebral blood flow to an area thus enabling the body to restore brain tissue metabolism of oxygen and nutrients, helping restoration of any areas which are suffering from hypoxia. New blood and oxygen begin to stimulate an area, especially one that has viable, recoverable brain cells that are "idling neurons" not knowing what to do instead of function normally.²⁰

These parents write of their son, Christian, since he underwent his forty sessions of HBOT:

His expressive ability with language is outstanding. He actually talks on the phone and carries on a two-way conversation. His replies are no longer just one word. His desire to use language is much more pronounced. His teachers are amazed and very happy with the changes. They report that he is much better at "talking with" the other children and interacting in general.²¹

If parents are serious about this (and their wallets cooperate), they can purchase their own HBOT chamber for home use. Some HBOT chambers are big enough to hold both the parent and the child (as photos on the website attest) though one may wonder about the wisdom of needless HBOT treat-

ments if one did *not* have "idling neurons." Prices for personal HBOT chambers range from \$5,995 to \$15,995.

Packing: Packing therapy involves "wrapping someone in damp sheets for one hour sessions while the therapist encourages them to notice other sensations."²² Many therapists claim that autistic children benefit from packing. What is typically *not* acknowledged is that the only "packing study" to use autistic children used just six children, and only two of those children were autistic. What is also never made clear is how much or in what way the autistic children benefitted from the packing. That is, in what respect their *autism* improved from the packing and how long lasting these benefits were. As a parent with finite resources, I would want to know: could that hour my child spent wrapped in cold, damp sheets have been have been more productively spent? It seems to me that the study sample was *far too small* to draw any conclusions about autistic individuals, who are a very diverse collection of people and therefore it would be absurd to conclude that this study revealed anything conclusive about autism or the therapeutic benefits of packing for autistic children.²³

Holding: Innocuous enough sounding, holding theory is defined as an intervention in which the caregiver or parent "holds the child very closely and very tightly while speaking in a comforting manner. The caregiver may not release his/her hold until the child 'surrenders' and spontaneously looks into the caregiver's eyes. The caregiver then returns the child's gaze and exchanges affection."²⁴ If the child is particularly reluctant to make eye contact (some children may refuse for hours) parents or caregivers are instructed to resort to "poking" or "prodding of the child's torso and armpits" which is termed "tactile stimulation" by advocates of this approach.²⁵ Defenders of holding therapy claim that autism is not a genetic condition but a "disorder of attachment" which can be repaired by forcing the child to experience and acknowledge the control and authority of an adult.²⁶ There no evidence that this treatments helps autistic children.²⁷

Magnets: Magnetic power is, apparently, essential for maintaining health (or so it is professed on many websites). Thus, the logic goes, a simple magnet sleep pad engineered to mimic the Earth's magnetic field of 4,000 years ago (a more natural and healthy level, *obviously*) will immediately reduce if not eliminate all symptoms of autism. One parent attests:

Our daughter...has high functioning autism and was not sleeping through the night for 7 years! Once we received the sleep pad she has slept all night and wakes up a much 'happier' child. When she does not sleep in her bed we

notice a negative difference in her behavior.... We see such a significant improvement in her behavior that I wouldn't want to give up the magnetic pad!²⁸

Also available are magnetic bracelets, jewelry, body wraps (both firm and flexible), magnetic insoles, magnetic water, as well as products for one's pets.²⁹

Aversion Therapy: Aversion therapy exposes an individual to a stimulus while simultaneously subjecting him or her to a form of discomfort. The purpose is to cause the individual to associate the stimulus with unpleasant sensations in order to stop the specific behavior.³⁰ So, for example, if an autistic child fails to make eye contact with someone, or "flaps excessively," or fails to use age-appropriate sentence structure, he or she would be subjected to such "discomforts." Judge Rotenberg Education Center (JREC), a live-in school for children who exhibit "autistic like behaviors"³¹ uses aversion therapy exclusively, including electric shock, the forced inhaling of ammonia, withholding food and reduced calorie diets to treat autistic (and "autistic like") children.³² JREC uses a "Behavior Rehearsal Lesson" to treat particularly recalcitrant autistic children: The child is restrained and told to misbehave and if the child attempts to pull away, he or she is shocked. If he follows the order and misbehaves, he or she is shocked. I am not sure what the child will learn from this, other than that the staff at JREC are real bastards, but some parents approve, indeed enthusiastically. Here are a few testimonies from parents who praise the Center:

"My son has been [psychotropic] free for 9 years and he is improving."

"It does work! It stops him from being in a padded cell, on drugs."

"[I]s it more humane to drug my son until he can barely stay awake?"³³

The JREC web site describes the Center as having a "colorful and attractive school building."³⁴ I would hope so given that parents are paying over \$730,000 a year for each child despite the Center's long history of lawsuits, recent criminal charges brought against the founder of the Center³⁵ and an inadequately trained staff of over 900, most of whom have only a high school diploma.³⁶

Exorcism: Some parents believe that autism is the result of a "generational curse" visited upon the child for the sins of the parent. Others believe autism to be a sickness curable by the "laying on of the hands." Either way, what the autistic child needs is a healthy dose of exorcism.³⁷

It is tempting to laugh at these "treatments" and conclude that any parent who subjects their child to such experiences is a fool at best. I would never recommend any of the above as a therapy option for autism (indeed would

strongly discourage them), but I can believe that after being informed of an autism diagnosis for their child and then being inundated with *hundreds* of suggestions of therapies, parents can, in a state of half-witted desperation, convince themselves that giving the highly implausible a whirl is better than doing nothing at all. And given what I think of as the Culture of Autism that pervades our society (how autism is presented to parents by so-called experts, how it is portrayed in the media, online, on billboards³⁸), it is not at all surprising, really, that parents feel tremendous pressure to try therapies, even highly dubious ones, for their autistic child.

The primary commandment of the Culture of Autism is "Early Intervention." Picking a therapy plan and getting it underway after diagnosis is *not* akin to deciding whether or not to renovate one's bathroom—something that one can put off year and after year because of the expense and inconvenience. Parents are told that autism is like cancer,³⁹ a problem that you simply do not mess around with. Indeed, once you are handed the diagnosis, you are told to *run*, not walk, to the nearest therapist and begin a therapy program *yesterday*. Once we were given our son's diagnosis we found that every highly recommended therapist within one hundred miles of us was booked solid for months, some for almost *two years*. I felt rage and frustration because, after being told that we had waited far too long to get our son diagnosed,⁴⁰ we were now being put off for possibly two years. What the *hell?* Aren't we in the middle of an autism *epidemic*? What kind of doctors are these people that they do not work evenings and weekends?⁴¹ Miraculously, there was a cancellation⁴² and we were able to jump the queue, securing an appointment with a highly regarded child developmental psychologist in our area near us after waiting only a few weeks.

Selecting and committing to a therapy program is not the end of one's difficulties; rather, it is only the beginning. Because (you are told), if you are going to go into the ring with autism, you have to *combat* it,⁴³ defeat it,⁴⁴ be ready to fight it with every resource you have⁴⁵ and, if you do not give up—maybe, just *maybe*, you just might not see *regression*.⁴⁶

Susan Wendell writes of the guilt-ridden burden felt by individuals with impairments or illnesses when friends and family members offer, surely motivated by kindness and love, endless advice about new treatments, perhaps something they saw on a talk show or advertised on the Home Shopping Network. Wendell writes,

To turn down a suggestion is to risk the judgment that you do not want to get well. To pursue every suggestion is a full-time job (with a price tag instead of a pay-check). For people with life-threatening illnesses, pressures from their loved ones to seek a cure can consume their remaining time in medical and quasi-medical quests.⁴⁷

Wendell correctly points out that a plethora of therapies does not make the ill or impaired person's life better and richer—it makes her situation profoundly worse, for at no point is she permitted to come to terms with her illness or condition and learn to live with it. Because there is always something else to buy, to try, there is always another battle to fight. And these battles are *exhausting*. Wendell's astute discussion concerns adults who are placed in the situation of having to make crucial therapy decisions without complete information regarding their own future outcomes. What is so stressful for a parents of children diagnosed with autism is that they must make therapy and treatment decisions on behalf of their child who is completely vulnerable and cannot (at the age these life-changing options are being foisted upon the parents) play a role in the decision-making process. It is absolutely terrifying.⁴⁸ Lest the parents lose energy, conviction, or confidence, there always seems to be a therapist nearby to spur them on. The first time we met with our son's child developmental psychologist⁴⁹ he said, "It's all on you: if you provide him with all the resources he needs, he *may* become a self-sufficient contributing member of society, perhaps even a brilliant scholar. If you *fail* him, he'll end up living out his days in a group home." I genuinely believe his remarks were motivated not by hostility (though they certainly provoked hostility in me) but by the desire to prompt us to take seriously our task as our son's caretakers, to inspire us to do *everything* we could so that we would keep him safe from the horrors of institutional life which, just a few decades ago,⁵⁰ was the most probable outcome for an autistic child.⁵¹

Although we did settle on a reasonably noninvasive therapy plan with the child developmental psychologist,⁵² I cannot say I felt any sense of relief because I had no time to relax, ever.⁵³ If I was not actively engaging with our son in some sort of therapeutic activity or taking him to a therapist of some kind or other, I discovered that we had to make sure that he was protected at all times from those that might try to hurt him. Because, it seems, there is no shortage of people willing to inflict serious injuries upon autistic children. We discovered when our son was very young, just three and far from being able to verbalize his thoughts, that special education schools are not safe places for autistic children. One day I arrived to pick him up a few minutes early and, standing outside the schoolroom door, could hear the teacher screaming inside. When I turned the knob (but found it locked) the yelling inside suddenly stopped. A few seconds later the teacher opened the door and, looking flustered, she said to my son, (rather saccharinely, it seemed to me), "Look who's here! It's your mommy!" My son, who is normally a vivacious and happy boy, was standing rigidly in the corner, facing the walls—a behavior I had never seen him engage in before. That was the last day he attended that class. I have no idea what was going on in those classes. I think, I hope, my son has forgotten, which means I never *will* know.

Two years later, we tried a different program and a different teacher. Our son, by then five years old, was still not verbal but fairly competent with sign language and this teacher was wonderful⁵⁴—but her paraprofessional ("parapro") was a nightmare. To give but one example: if a child touched or accidentally bumped into a classmate while walking down the hallway on the way to the bathroom, the child lost his or her privilege to use the bathroom. The next year, when he was moved to a "real" elementary school when he was in kindergarten, his special ed teacher, despite acknowledging that he could easily handle a "mainstream" class such as art, kept him in special classrooms all day long. My husband and I thought that trying out one nonacademic mainstream course would have facilitated transitioning him to academic mainstream classes when he was older. Our son's teacher agreed with our plan, yet we noticed that our son was not being moved into any mainstream courses but instead was still spending every day in her special ed classes. One day, in March or so, with most of the school year gone by, we told her that we were fed up with the delays and that we wanted him to be mainstreamed in art immediately.⁵⁵ She furtively looked over her shoulder and whispered, "I *really* don't think that's a good idea. That teacher is really *abusive* to the 'special' kids. He will *not* be safe there. But PLEASE don't tell anyone I said that." I have had special ed teachers tell me the "low down" of our public school district in school parking lots, after work hours ended, in strictest confidentiality, because they feared repercussions. They were horror stories indeed.

Is it a consolation that these tales of woe are not limited to our school district but fairly typical? Not really. Every parent of every autistic child has good reason to be terrified for his or her child's safety at the hands of others. Although students with impairments make up just 14 percent of the nationwide student population, students with disabilities make up 19 percent of those receiving corporal punishment.⁵⁶ Autistic children, perhaps because they are often nonverbal and are therefore particularly vulnerable, are among those children *most likely* to receive corporal punishment in public schools.⁵⁷ Punishment methods include paddling, hitting with belts, rulers, pinching, slapping, grabbing, dragging across floors, being locked alone in an empty room for hours on end, and being slammed into a wall.⁵⁸ Restraints include duct taping an autistic child to a desk, taping their mouth shut, holding them in a "basket hold" or other restraint position designed for adult psychiatric patients.⁵⁹ The consequences of these practices can be devastating to autistic children.⁶⁰ On top of any immediate physical injuries, parents report their children to be too traumatized to go back to school, too afraid to go to stores for fear of seeing teachers or a principal, and report the onset of self-injurious behavior, nightmares, bed-wetting, crying and "meltdowns."⁶¹

As disturbing as the fact that teachers brutalize autistic children is the fact that the children's behaviors that prompt the violence are: failing to answer a

question posed by a teacher, talking repetitively on a favorite theme, rocking and wiggling in a chair, fidgeting in class, spinning while walking down a hallway, and taking shoes off during class.⁶² Each of these behaviors is entirely consistent with a diagnosis of autism and therefore typical for an autistic child to engage in. Thus, being punished for any of these actions is, I think, a violation of the American Disabilities Act and is, therefore, against federal law.⁶³

The hostility does not end there. Among the madding crowd I found parents of autistic children, many of whom lamented their fate, griping about how violent their autistic children are and how burdened their lives are since their child “became” autistic. In her notorious essay “The Monster Inside My Son,” Ann Bauer refers to her twenty-one-year-old son in the most dehumanizing terms: a “gnashing beast,” “the warty monster from a Grimm fairy tale,” and “a night creature.”⁶⁴ In it, too, she describes his behavior as “senseless,” “rampaging,” and “full of rage”—he is an “unspeakably violent” problem that cannot be reasoned with and who is beyond understanding. When a friend misunderstands the nature of her son’s “illness,” she chooses not to clarify, allowing the friend to assume the son has “something like leukemia.” Bauer writes, “I wanted to tell her I would hack off my right arm in return for something *as simple as cancer*. The flickering beauty of a sad, pure, too-early death sounds *lovely*. Instead I nodded, silent and dumb.”⁶⁵ So Bauer would rather have a child dying of cancer than her son who has autism? Hundreds of people commented in response to this essay, and all but a small handful offered their overwhelming support of Bauer. Many wrote that they found Bauer’s essay “brave” and “honest,” an “important” insight into how “painful” and “heartbreaking and home wrecking” autism is.

Autism Every Day, a documentary film sponsored by Autism Speaks, contains the much-commented upon moment in which Alison Tepper Singer states, in front of her autistic daughter, that confronting the challenges of searching for satisfactory schooling for her autistic daughter has prompted her to consider driving off a bridge (thus killing herself *and her daughter*).⁶⁶ And lest one conclude that Singer’s dramatics are just so much talk, stories of parents who kill their autistic children enter the news with pathetic regularity. Karen McCarron, a physician, smothered her two-year-old autistic daughter with a plastic bag on May 3, 2006, just four days after the release of the film *Autism Every Day*. In July, 2010, Saiqa Akhter killed her five-year-old son and her two-year-old daughter because they were both autistic. In her now famous 9-1-1 call, she explained why she strangled both her children with a wire (after her attempts to poison the children failed because the children would not take the poison), “They’re both not normal, not normal. . . They’re autistic. Both are autistic. . . I don’t want my children to be like that. . . I want normal kids.”⁶⁷ Newspapers articles, attempting to make sense of Akhter’s actions, typically include interviews of social workers who explain the high

stress parents of autistic children are under. Apparently the feeling, even hope, for death among parents of autistic children is not unusual. But, these social workers tell us, death is not the solution—additional therapy is.⁶⁸ Just recently, Elizabeth Hodgins shot her adult son, George Hodgins, who was twenty-two years old, because (apparently) she tired of him living at home.⁶⁹ George, who was described as “a delight” by his teachers, did not speak or communicate much. Heather Jauch, the Hodgins’ neighbor for five years said Elizabeth Hodgins had just a few days before the killing mentioned that she found the thought of caring for George for the rest of her life simply overwhelming.⁷⁰

Jean Lewis, a director of FEAT,⁷¹ an organization for parents and family members dedicated to “early autism treatment,” warns that, without treatment, “[K]ids *like this* are usually institutionalized by the time they’re adolescents. They’re living in restraints, living in diapers. They have to have their teeth removed because they bite.”⁷² The belief that autistic children will bite, hit and assault others—and therefore extreme forms of violence can justifiably be used against them to prevent their inevitable attacks—is quite widespread. Initially, one of my son’s teachers resisted quite strongly to allowing him into her classroom despite the fact that his previous teacher had provided him very positive recommendations and that he would be accompanied by a “personal assistant” at all times.⁷³ At one point during our conversation she asked, “Can you *guarantee* that he will never harm the other children?” Considering what I have seen so-called “normal” children do to one another in school hallways and on playgrounds (both during my own childhood and while observing my older son’s earlier school years), found this question astonishing. “Can you guarantee that none of those children will ever, at any time, harm *my* son?” I asked. Of course *neither* of us could make any such guarantee because *no one* can make guarantees regarding the future behavior of any person. Any human is capable of engaging in violent behaviors (in one circumstance or another) including, of course, children. Whether or not the person is autistic is simply irrelevant.

But the correlation between *autism* and *violence* is never irrelevant to the parents of an autistic child. Because even if they know that their child is not prone to being violent, they know that the Culture of Autism is thoroughly soaked with the idea that their autistic child *is* inherently violent—is a “monster” that threatens every classroom and will continue to be a burden for the rest of their life. Is it any wonder, then, that parents of autistic children propel themselves into a frantic search for therapies and treatment programs for their child, if only to save him or her from the malevolent and punitive actions of others. Even more understandable is that parents press researchers to find the Holy Grail of autism: a Cure.

CURING AUTISM

It is generally accepted that there is, at this time, no way to cure or prevent autism. This fact is regarded by most as a great tragedy and, therefore, there is a tremendous demand being made on researchers to find a cure for this complex neurological condition.⁷⁴ But there are two, very different, ways to conceptualize the notion of “cure” and in the frenzied conversations about autism, they get muddled, either unintentionally or, perhaps, not.

One way to conceptualize “cure” is as therapy. I will refer to this as the Therapeutic Cure (TC) model and on this account a cure is a beneficial treatment for the patient that eliminates or ameliorates the harms of the disease, disorder or condition. Modern medicine is rife with examples of cures that fit the TC model. For example, in 1999, The World Health Organization established a goal cure rate of 85 percent of the tuberculosis patients in Russia; these patients were treated with antibiotics. The achieved cure rate was 80 percent.⁷⁵ In contrast, diabetes is typically managed with insulin. Because insulin does not *end* the medical condition of diabetes, insulin is not a *cure* but instead a treatment.

It is difficult to conceptualize what a therapeutic *cure* for autism would be. This is because autism, it is claimed, affects every neurological process of an autistic individual. Dawson *et al.* write:

Few aspects of neurology have not been proposed as being atypical in autism. For example, regions of reported neurofunctional atypicalities range from the brainstem to the inferior frontal gyrus, while reported neuroanatomical atypicalities range from increased white and gray matter volume to more densely packed cells and increased numbers of cortical minicolumns. Neurofunctional connectivity has been suggested to be atypical, and neural resources may be atypically allocated or rededicated. Virtually every fundamental human cognitive and affective process, singly or as part of an overarching model, has been proposed to be dysfunctional or absent in autism.⁷⁶

Indeed, if we are to believe what is published,⁷⁷ the entire “autistic brain” is neurologically atypical. Moreover, these neurological atypicalities begin being structured well before birth. Thus, the only plausible therapeutic cure would seem to be gene therapy.⁷⁸ However, Jill Boucher writes,

Given the complexity of the genetic factors that may contribute to autism and the unknown environmental factors that influence the processes of brain-building, and brain function set in motion by the genes, gene therapy effecting a complete cure is probably only a remote possibility. Equally, the complexity and variability of the neurobiological bases of autism suggest that completely curing all cases of autism by altering patterns of brain chemistry, growth and function is also only a remote possibility.⁷⁹

Boucher’s skepticism is reasonable given what we are proposing gene therapy to accomplish. Despite the fact that parents may not see symptoms (“signs” of autism until a child is two or even three years old (or even later) early triggers begin building relevant brain structures very early in development—perhaps during the earliest stages of fetal development. Moreover since brain development is influenced by environmental factors (such as maternal diet and health, as well as countless other factors), it seems reasonable to hypothesize that environmental factors heavily influence how autism is expressed in each individual. Thus, to cure each and every single autistic person would require not merely understanding the myriad genetic markers that initially *trigger* autism, but would also require addressing the resulting varied brain structures of each autistic person after being influenced by environmental factors.

But let us set aside all those worries.⁸⁰ Even if gene therapy *could* work for *all* the various autistic individuals (who express their autistic symptoms in an astonishing variety of ways), gene therapy would effectively “rewire” each autistic person’s brain—their entire neurological structure—so that was no longer neurologically atypical. I suppose the underlying assumption of gene therapy is that treatment would cease when the autistic person (a) would no longer exhibit any external signs of autism (would no longer *appear* autistic); (b) would no longer have the neurological structures of an autistic individual (would no longer have what is rather bizarrely and entirely misleadingly referred to as an “autistic brain”) which we are meant to believe is verifiable with an MRI; (c) would no longer *cognize*⁸¹ as an autistic individual; and (d) would no longer have the emotional responses (such as social anxieties) typical for an autistic individual.

If it really *was* possible to cure autism using gene therapy, the implications of undertaking such a treatment program are grotesque, given that the identity of a person is intimately connected to their brain structures. Indeed the autistic person’s very being—who they are (their memories, their desires, wishes, hopes, plans) and what they can become—would be altered by this so-called *cure*. Surely such a neurological treatment is deeply unethical. Researchers have concluded that insurmountable practical obstacles have ensured that searching for a therapeutic cure for autism is simply a nonstarter. However, given the ethical implications of a therapeutic cure for autism especially in the form of gene therapy, I think we should be profoundly grateful for those practical obstacles.

There is another way to conceptualize cure. Rather than conceive of cure as therapy as TC does, you strive to eliminate the disease at all costs without regard for the health or well-being of any specific patient. I refer to this as the Negative Eugenics Cure (NEC) model. With NEC, the disease, disorder or condition is considered so deleterious, that preserving the person with the disease or condition has a lower priority than the priority of elim-

nating the disease or condition. There are two approaches the NEC model could adopt to curing autism:

1. Genetic counselors could provide couples who have an autistic child but who are considering having another child with information about the statistical chances that any additional children they may conceive will be autistic. Depending upon the information they receive and how they feel about autism the parents may select to not have additional children and, therefore, remove themselves from the “gene pool.”⁸²
2. Genetic screening is the other possibility, which itself provides two moments for testing, either with preimplantation genetic diagnosis (PGD) or with an amniocentesis test during pregnancy. The idea of PGD is that, were many embryos created and each screened for autistic markers, and only *some* tested positive (but some not), the parents are then in the position to decide to choose to implant those embryos that tested positive for autism *or not*. Likewise, with the amnio, the DNA strand of the fetus is tested for autism markers and, if it tests positive, the mother is in a position to decide whether or not she wants to abort the fetus.

Criticisms of genetic screening for diseases and disorders are not new but worth mentioning briefly. Amnio tests are not 100 percent reliable; they yield a large percentage of false positives (up to around 5 percent for some conditions) and women may, as the result of a false positive, choose to abort a child they otherwise want.⁸³ And, very significantly, even if the test accurately identified autistic markers, what parents really want to know is “how serious the autism is” because, as I have stated above, given the class stratifications within the autism spectrum, there is a clear valuation within the autism spectrum, with a strong preference for Asperger’s (or “Aspies” as they are sometimes known) over the so-called low functioning autistics.⁸⁴ Of course, what parents should be told (because it will be true), is that there is no possible way to predict the future wellbeing of a child based on knowing the genetic markers. Given that environmental factors affect autism and, given how readily some autistics respond to occupational and speech therapy, for example, there is simply no possible way to know at the embryonic stage how successful any specific child will be—or, just as importantly, how generously society will respond to that same child when as an adult he or she is looking for employment or housing. What social supports will be in place? What opportunities will be—will have been—in place for that person to make use of and most benefit from? If a would-be parent is risk averse (as is likely otherwise why genetically screen the embryos for autism?), then it is highly likely that she will implant the embryos that do not test positive for autism.⁸⁵

Of course, at this point in time, a conversation about genetic screening for autism is purely theoretical because, although it is generally agreed that there is a strong genetic basis for autism, one’s genetics do not entirely determine one’s autism. Early reports on twin studies claimed a heritability rate of 95 percent for autism, but now it is generally agreed that those reports were “overstated.”⁸⁶ Nonetheless, the bulk of current research seeking a cure for autism is focused on genetics—and the inevitable outcome of that research, successful, is clear: genetic screening. On February 23, 2005, Joseph Buxbaum of the Autism Genome Project at the Mount Sinai School of Medicine predicted that there would be a prenatal test for autism within the next ten years.⁸⁷ In response to Buxbaum’s statement, disability rights advocates created an Autistic Genocide Clock set for a ten-year countdown.

AN ANTI-CURE PERSPECTIVE

At some point I had had enough. I simply could not stand what had happened to our family since the therapists had, in effect, moved in. Every time our son sat for an hour or two, drawing eggplants over and over (no matter how artistically), I thought “perseveration” and felt slightly sick inside. Every time he toe-walked or flapped, I thought, “regulation problems,” and felt the burden of the need to schedule in occupational therapy hours. Every time I beelined up to his room in search of a book or toy but did not return, presumably having become lost in the joy of playing with his other toys, I would think, “executive dysfunction,” and felt terrible distress. Fortunately, amazingly, I discovered autistic writers, thinkers, artists, and activists, each of whom is critical of the idea that autism is a disorder in need of a cure.

Jim Sinclair is credited with founding the anti-cure movement in the 1980s.⁸⁸ The first foundational claim is that autism is an essential feature of the person, not a contingent feature. Moreover, essential features should be respected much in the way we treat other essential features of persons, like their race identity or sex or sexual identity: with respect. Having a disease such as multiple sclerosis or a condition such as asthma would be, according to Sinclair, a contingent, *nonessential* feature of a person. Therefore, were a person to be cured of multiple sclerosis or asthma, their essential nature, that is who they are as a person, would not be changed. However, unlike asthma or multiple sclerosis, autism is an identity and thus to cure autism (were that even remotely possible) would be to alter the identity of the person. In his seminal essay, “Don’t Mourn For Us,” Sinclair argued:

It is not possible to separate the autism from the person. 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.” Read that again. This is what we hear when you mourn

over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.⁸⁹

Sinclair is credited with introducing the language which many autistic activist organizations promote today, the preferred language of “I *am* autistic,” (or “He or she *is* autistic”) rather than “I have autism” (or “He/she *has* autism”).

This debate is no trivial matter and emotions can get heated. Consider this discussion in a *New York Times* editorial, which describes the agonies felt by some parents distressed by their recalcitrant autistic children. One parent, Kit Weintraub, lamented her eight-year-old son’s choice to be Mickey Mouse for Halloween when normal eight-year-olds wanted to be Frodo from *Lord of the Rings*. Weintraub complained, “I worry about when he gets into high school, somebody doesn’t want to date him or be his friend,” she said, “It’s no fun being different.” Her son, it seems, continues to display “signs” of autism (such as a stilted manner of speaking and, as stated above, the unacceptable preference for Mickey Mouse over Frodo) which, it seems to Weintraub, is evidence of a need for additional A.B.A. treatments.⁹⁰

In her widely circulated blog, *A Mother’s Perspective*, Weintraub, mother of two autistic children, writes:

My children *have* autism; they are not “autistics.” What’s the difference? The difference is that autism refers to a neurological disorder, hereditary in nature. Autism, according to the vast majority of medical experts today, causes *severely abnormal* development, and without appropriate treatment it can condemn those affected to a life of isolation and dependency. “Autistics” is a rather new politically-correct term that I find troubling; it is a label that attempts to define people with autism as members of an elite group of human beings who differ from the rest of us only in terms of their unique talents and their superior way of experiencing the world.⁹¹

Weintraub is clearly concerned. But why? On the one hand, she is convinced that all autistics are severely abnormal yet, on the other, she seems worried that merely the use of a new-fangled term will elevate autistics to an elite corps. Many autistics, adults and teenagers, scorn the views held by parents like Weintraub.⁹² To the anti-cure perspectivists, Weintraub’s allegiance to normalcy reveals not only a profound lack of empathy for the autistic person’s interests and values (which is ironic since nonautistics are allegedly naturally capable of empathy), but also a spectacular intellectual dullness.

Which leads us to the second foundational claim of the anti-cure movement, that society should appreciate and protect *neurodiversity*. The term “neurodiversity” was coined by autistic Judy Singer in the 1990s.⁹³ Valuing

neurodiversity means, at a minimum, accepting that autism has an organ basis. More significantly, it means regarding autistic individuals *as full persons* rather than as broken beings in need of repair. It also means that rather than regarding autistic neurological structures as “defective” or “disordered,” one should regard autistic neurology as worth valuing because each neurological structure contributes to the collective variety of human neurological diversity, in much the same way that each human culture contributes to cultural diversity and each of the hundreds of human languages makes a valuable contribution to human linguistic diversity.⁹⁴

Although one could endorse neurodiversity simply for its own sake, in reaction against sameness, singleness, or narrowness, others argue that autistics create original art, literature, music and are creators of scientific innovation that have cultural worth.⁹⁵ Joseph Straus claims that recent contributions made by autistic writers, artists and musicians make talking of “autistic culture” coherent. Straus argues that autistic culture has three characteristics:

Local Coherence: Although typically pathologized as “obsessive compulsive” or “getting lost in the details and an inability to attend to the whole,” Strauss describes the autistic artist (whether he or she is musician or painter, say) as one who *attends to minute detail* with a preference for complexity rather than confusion.

Fixity of Focus: In medical models, autistics will be described as ritualistic if not bordering on being paralyzed by rigidity or sameness. Straus describes artists as expressing this as a preference for a neatness and orderliness in style and design, often providing them with a capacity to engage in a calm constancy that allows them to engage in repetitive activities over and over again—which may be necessary for completing complicated craft or artistry that requires a tremendous attention to detail.⁹⁶

Private Meanings: Autistic thinking is usually described as idiosyncratic. Autistic artists are often very private, not only in the way they think but also in how they think. Because they are not “caught up in social niceties” they are free to defy social conventions, often with profoundly liberating ways. Autistic art, comedy, literature, and music is *avant-garde*, though not self-consciously so. As Guilla Gerland writes, “This apparent disregard for the convention appears to be brave. In fact, I had absolutely no idea that there were such things as conventions.”⁹⁷

Straus claims that as more and more autistic individuals self-identify as autistic and make their membership in the autistic community known, the fledgling community will become even more vibrant than it already is.⁹⁸

AND, SO...?

What does all this mean? For all my railing against the therapeutic industry, I will hereby admit that I have gained one invaluable insight from our son's child developmental psychologist. During one meeting with him, we were talking about something (I can't remember specifically what now), some behavior of our son's that would be classified as "perseverative" in textbooks. Because I had already internalized the Culture of Autism, I was fretting about the "meaning" of our son's seemingly meaningless behaviors and, most likely, pressing him for a future date when the behavior would, with enough therapy, magically go away. He then asked me if I had ever tried engaging in the so-called "perseverative" activities that my son enjoyed so much *alongside* my son—such as lining up plastic toys, lying on the ground and staring at the sand as it ran through his hands, throwing giant rocks into a pond or pool over and over. I stared at him in bewilderment. "No," I said, "I haven't." "Well," he smiled (reminding me a bit of the Cheshire cat in *Alice in Wonderland*), "Perhaps you should. *He* is clearly having the time of his life. Maybe if you join him, you will find out *why* he is doing what is doing and *why* it makes him so happy." This suggestion shocked me for a number of reasons. Not only did it force me to realize the obvious, that my son had *reasons* for his behaviors (he was not merely a collection of pathologies as the *DSM-IV* implies), but that he may have *good* reasons for what he does. Indeed, it may be the case that, were I to give his preferred activities a try, *I* may find pleasure in them as well. But also surprising and deeply disappointing, was how vividly I realized how utterly dull and adult, how painfully normalized, I had become. I had a view of myself as a radical outsider and yet here I was fretting about my son becoming normal. Where was that coming from? I was never normal when I was growing up and I had never *wanted* to be normal. Why did I think I wanted my son to be normal? What was I *thinking*? I suddenly remembered a conversation I had with my husband years earlier, when our son was first diagnosed, while I was reading something which claimed that with "aggressive intervention an autistic child can live a normal life" and my husband said something to the effect of "But what if they don't *want* a 'normal life'?"

Shifting perspective to a toddler's and, later, preschooler's interests was fascinating and liberating. And it certainly allowed me to rediscover some parts of my own long-lost childhood. When three and four years old, our son was particularly interested in throwing rocks in our pond (over and over), lining up toys, "water play"⁹⁹ and jumping on the trampoline.¹⁰⁰ But he really loved anything that was messy—slimes, doughs, mud, wet sand, glue—any viscous gelatinous substance (even better if it stained fabric) was highly appealing. And he reveled in those globs, pulling, pushing, shoving, kneading them into his mouth, up his nose, into his eyes and hair; he was

living it all the way. Although I was never able to *completely* share his zestful enthusiasm for bodily encounters with slimy substances, I do admit that I was able to overcome my discomfort for having 'icky hands' and was able to enjoy playing in mud, sand and slime with him. Playing in the mud with him also dislodged a happy (and completely forgotten) memory of me taking a mud bath when I was very young and felt no revulsion for wallowing in mud.

I will not pretend that raising a child with autism is easy. Yet despite the difficulties, some parents of autistic children are voicing their concerns for the search for a cure for autism. Virginia Bovell, parent of autistic son, Danny, writes,

To cure my amazing son Danny would be to suggest that there is something dreadfully wrong with him, perhaps even something we, as parents, couldn't live with—but nothing could be further from the truth. If someone took away Danny's autism, it would also take away so much of who he is. And I am certain that many parents of autistic children would agree, because how can I ever tire of watching my son's face light up with joy as he kicks leaves in the park on his way to school? It's a simple pleasure, but Danny—thanks to his autism—has access to a kind of rapture we, as 'normal' people, cannot imagine. He has a level of pleasure way beyond the rest of humanity, and just the simplest of things—sitting behind me on our new tandem bicycle, bouncing on a trampoline or seeing his grandmother—set him off giggling with pure joy. His enjoyment of life stems from simple things, but that is one of the things that make him so special—and to me, curing him would be to take away all that characterizes my beloved son.¹⁰¹

Ken Bruce, parent of autistic son Murray, states, "I believe the world would be a better place if every family had experience of a child with autism."¹⁰² I do not believe Bruce is wishing that every family have a child that is autistic. Rather, I think he is claiming that living with and coming to genuinely understand one's autistic child—developing an empathetic affection for that child, grandchild, sibling, cousin, loved one—makes you a genuinely better human being. And, were every nonautistic person able to have a genuinely caring and affectionate connection with an autistic person, the world would be a far better place. I agree with him.¹⁰³ The difficulties I face do not stem primarily from my son's autism, but from (initially) my complete lack of understanding of autism, from the lack of social supports we had to scramble to find for him and ourselves,¹⁰⁴ from the fact that our public school system is completely unable to educate autistic children,¹⁰⁵ and the lack of adequate federal regulation to protect vulnerable parents from rip-off artists and charlatans selling dangerous medications, "herbal supplements" and "alternative remedies" that are endangering autistic children.¹⁰⁶

When the worries of raising an autistic child seem too much, perhaps it helps, if only slightly, to think of Hans Asperger's words of more than sixty

years ago, “We are convinced, then, that autistic people have their place in the organism of the social community. They fulfill their role well, perhaps better than anyone else could, and we are talking of people who as children had the greatest difficulties and caused untold worries to their care-givers.”¹⁰⁷

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NOTES

1. There is tremendous energy spent debating whether or not autistic children should be taught to sign and years earlier we were thrown right into the storm. One camp advises that pre-lingual autistic children will be “confused” by sign language and this confusion will delay the development of “normal” speech. The other camp advises that children should be taught to sign because it is a visual language and therefore it will be easier for them to learn sign than a verbal language and, so, it will both facilitate immediate communication and will also help verbal communication skills develop later on. With both sides promising that the wrong choice will ruin the child forever and that theirs is the only way, “to sign or not to sign” is just one choice among seemingly hundreds that parents of autistic children must make with almost no reliable empirical guidance available. We sided with the signing side and found resources for him to teach sign to himself (given that we do not know sign) and he LOVED IT. He learned it easily, quickly, and enthusiastically. Though he has just recently become somewhat verbally confident, he still signs every day, often while singing but especially if tired or when not feeling well. But I have come to the conclusion that signing is more than merely a useful tool that facilitates communication; signing is a game, a secret code, a special passage into a world of symbols that, for a child already giddy with delight at the patterns made by letters and with words themselves. Signing is simply a source of delight. For example, signing WATER is so much more than a means to get water: you make a “w” with your first three fingers and you tap your chin—but do you see what you did? Water starts with W and when you sign WATER it’s like the “w” goes right into your mouth and turns into water as you tap your chin. If you think about the sign, you can almost understand a toddler’s delight with signing—a toddler, that is, with a predilection for answering questions such as “What is that?” (when shown a picture of a

cat in a book) with “3-1-20” because C is the 3rd letter, A is the 1st letter and T is the 20th letter of the alphabet. The whole world becomes a visual symbol, a semiotic metaphor, a physically embodied manifestation of thought! What could be better? And signing is still one of his favorite interests, a hobby really, which he has tried to teach to me many, many times. And I have tried to learn, I really have. But there is no way I can keep up with him because his memory is far superior to mine. Anyway, he enjoys showing off what he knows and I do not think it is so terrible a thing that he can outshine his parents at something he loves to do so much. (Our son’s predilection for coding, we were later told, is termed “hyperlexia.” I was continually encountering resistance whenever I described my son in terms of his individual capacities or personality. Therapists were forever reminding me that he would do this or that because of the “autistic tendency for X” or because of the “autistic tendency for Y.” Moreover, virtually everything we said about him would be redescribed as an autistic pathology. Yet, I happen to find hyperlexia (and other autistic “splinter skills” like photographic memory and phonographic memory) quite awesome.

2. By this point in our son’s life I would guess I have spent at least one hundred hours filling out questionnaires for various psychologist and psychiatrists, therapists (of every sort imaginable), and special education teachers and support staff for special education schools and programs concerning his autism. All the questionnaires are the same and all have the same conceptual problems. And every time I have asked, “Does signing count as talking?” the test givers do not know. This is no trivial matter because if they are asking about verbal language development, then it should not. If they are asking about communication development, that is, about whether or not our son initiates and successfully creates complex sentences in any format whatsoever, then I would think it should count as language as a fully signed sentence is a form of social communication. So which is it? Bizarrely, I have been told (when I objected to filling in questionnaires with ambiguous questions) that these questionnaires must be completed entirely despite the fact that neither the person answering the questions nor the person giving the questionnaire understood the questions and that skipping questions is not allowed (on pain of what, one wonders—lost grant money?) and that those administering the questionnaires were instructed to give the stock answer: “Just fill in the bubbles the way you think makes most sense.”

3. I am not sure why he decided to focus his attention on me since neither my husband nor I were giving any indications that we were the least interested in his proposal. Perhaps he had decided on a “divide and conquer” strategy that was to start with me.

4. Now the phrase “curing autism” sounds odd to me, comparable to curing homosexuality—not only a scientifically misguided project but highly ethically and politically suspect.

5. Although (as Orson Welles remarked) we are born alone, we live alone and we die alone, I did not experience this autistic therapy haze alone. While I was always among others and we survived these events together, nonetheless, we each made sense of them in our own way, very much alone. I am writing about my experiences from my point of view only.

6. This was the same neurologist to whom we were years later referred for my son’s migraines. You would think that we would not have gone back to him that second time but I can only say the migraines our son had suffered were horrific and we were desperately hoping that “one of the very top neurologists” in the region would come through for us with something that would ameliorate the pain. No dice.

7. It is debatable that autism deserves the term “disorder” since common “splinter traits” that autistic individuals have are advantageous and highly valuable, such as superior memory. I prefer the name Autism Spectrum Condition (ASC).

8. Is it any wonder that one of his favorite books has always been Maurice Sendak’s *Where the Wild Things Are*? And one of his favorite passages in the book is when Max tames the wild things by staring into their yellow eyes without blinking once. I’ve long been convinced that my son “tames” me, getting me to do his bidding by staring into my eyes without blinking once, and has been doing so since well before his first birthday. It is a powerful skill he has developed and he shows no sign of giving it up as he gets older.

9. To this day the chapter drafts sit, dusty on a shelf in my office. I really do not know if I will ever get back to it. It now seems like a book started by a different person.

10. For example, when our son was three, he did benefit enormously from having very heavy-duty, three-sided colored pencils (rather than standard crayons) to color with until his fine-motor skills developed sufficiently that he could use other writing implements more successfully. Crayons would simply break in his hands and he would get too frustrated to enjoy coloring. Now that he no longer needs those heavy-duty colored pencils, we no longer buy them—which is a relief because they are ridiculously expensive. But I do believe they are important for developing valuable skills. I am sold on mini-trampolines, too; they're great for developing balance and large motor skills and, even better, they're fun. Fortunately (if you do not need to buy the ones with safety bars on the sides) they are not too expensive.

11. I have many ways to waste time, surfing the web is only one. I hereby admit that one perverse web surfing interest of mine is "collecting" bullshit autism cures. Why I do this, I really do not know. I never slow to stare at car accidents and could not possibly care less about the train wrecks that are the lives of most celebrities. So why do I spend my very rare spare time imagining the horror shows that are playing out with sad regularity, like movie schedules at a local cinema, of rip off artists selling these useless if not dangerous treatments to depressed, terrified and misinformed parents who then inflict them upon their vulnerable autistic children?

12. <http://www.autismherbs.com/>.

13. <http://www.cellmedicine.com/pages/patient-application/?menu=footer>.

14. <http://www.cellmedicine.com/testimonials/?catid=17>.

15. <http://www.newautism.com/>.

16. <http://www.clayforautism.com/>.

17. <http://www.clayforautism.com/>. Hundreds of products are marketed to "detox" autistic children. Most are simply a waste of money; some are dangerous if not deadly. "Probiotic-Rx" (a "professional strength formula" that "represents an evolutionary leap in probiotic science") includes 10 vitamins, 8 minerals and 18 amino acids 6.5 times normal strength (though normal strength of what is not made explicit). "BioGuard" professes to restore the autistic child's "bions" to optimal function—whatever those are. These products cost hundreds of dollars per month and have no known efficacy in treating autism. <http://www.helpyourautisticchild.com/products>. On chelation websites, parents testify to self-medicating their autistic child with heavy doses of zinc, magnesium, calcium, mega-doses of vitamins A, B-6, B-12, D and E, taurine, cysteine, sulfate, methionine, selenium and copper. One site sells a FAR Infrared Sauna (FIR) Detoxification Therapy system that will allegedly "enhance your immune system;" this site implies a link between using this sauna and "recovering" from autism. Prices range from around \$1,500 to just under \$3,000 depending on the size and materials used (<http://www.sunlighten.com/?gclid=CNuPx-vWza4CFULrKgod9mlG-g>).

18. This treatment is alleged to be successful for individuals suffering from carbon monoxide poisoning.

19. Research conducted by the Center for Autism and Related Disorders (CARD) found that hyperbaric oxygen therapy has no significant effect on symptoms of autism. But why let the results of research stop you from subjecting your child to this treatment? See Granpeesheh et al. 2009; http://www.centerforautism.com/autism_publications/default.asp.

20. <http://www.balancedhealthtoday.com/Hyperbaire-Oxygen-Therapy-Autism.html>.

21. <http://www.balancedhealthtoday.com/Hyperbaire-Oxygen-Therapy-Autism.html>.

22. <http://autism.healingthresholds.com/therapy/packing-therapy>. One feature of autism (either a defining feature or common symptom) is sensory processing difficulties. The purpose of occupational therapy, one highly regarded form of therapy for autistic individuals of all ages, is to help autistic individuals better "organize" sensory inputs with their cognitive awareness. In short, it helps autistic individuals become more skilled at attending to sensory inputs as well as becoming more physically competent at both fine and large motor skills. Therefore wrapping an autistic child in cold, clammy sheets for an hour and instructing him or her to not focus on what I would imagine would be strong sensory inputs seems to me, then, completely counter to everything that I have learned from our son's occupational therapist and what she set out to accomplish during the four years she and our son worked together.

23. The alleged purpose of the study was to test the therapeutic benefits of packing in response to catatonia. The fact that two of the children were autistic was, actually, irrelevant to the initial purpose of the study. Only four of the six children benefitted from packing, and of

those four, two were autistic. Simply because two of the four children in this study were autistic and this study was widely reported, it has become practically "common knowledge" that packing helps autistic children and packing is considered a standard therapy procedure in many clinical settings (<http://autism.healingthresholds.com/therapy/packing-therapy>).

24. <http://www.asatonline.org/intervention/treatments/holding.htm>.

25. <http://www.psychologytoday.com/blog/child-myths/200909/holding-therapy-and-autism>.

26. Both claims are attributed to Bruno Bettelheim, who did not believe that autism had an organic basis but instead believed it was caused by "refrigerator mothers" who withheld affection from their children. In his book, *The Empty Fortress* (1967), which was immensely influential in the United States, he compared the world of the autistic child to someone in a concentration camp. Holding therapy—forced restraint—would, he claimed, force an attachment between the parent and a child. In fact, it usually caused panic and terror in the child (<http://www.firstthings.com/article/2008/08/006-in-the-case-of-bruno-bettelheim-15>). Temple Grandin, a self-identified autistic and author of *Thinking in Pictures*, developed what she calls the "squeeze box." See: <http://www.time.com/time/arts/article/0,8599,1960347,00.html>. This mechanical device is made out of two big pads that gently squeezes the person within the machine. The essential difference between holding therapy and Grandin's squeeze machine is that holding therapy is forced upon the person by someone else and is, therefore out of the control of the autistic individual—a potentially terrifying experience for the person being held. On the other hand, the "squeeze box" (or, as it is sometimes called, hug machine) is self-controlled and is therefore in no way anxiety-inducing (<http://www.asatonline.org/intervention/treatments/holding.htm>).

27. Indeed, there have been fatalities when overly enthusiastic parents have held down a resisting child and asphyxiated the child or caused the child to go into coronary arrest (<http://www.psychologytoday.com/blog/child-myths/200909/holding-therapy-and-autism>).

28. <http://4optimallife.com/Magnetic-Sleep-Pads-For-Health.html>.

29. <http://www.magnetictherapy.co.uk/>.

30. As with many therapies, the popularity of aversion therapy goes in waves. At one time aversion therapy was commonly used to treat homosexuality. Now, as a treatment for homosexuality, it is regarded by the American Psychological Association as a dangerous practice that does not work. Nonetheless, aversion therapy is still used on children and teenagers if they are suspected to be homosexual by their parents. These children may be "forced to smell ammonia, describe humiliating scenarios, or engage in other uncomfortable acts, while looking at nude pictures, listening to audio tapes describing sexual situations, or describing their own fantasies. In order to measure sexual response, devices such as penile plethysmographs and vaginal photoplethysmographs are sometimes used, despite the controversies surrounding them." In 1992, the Phoenix Memorial Hospital used these methods on children as young as ten. See <http://www.ethicaltreatment.org/arizonarepublic.htm> and <http://www.ethicaltreatment.org/yankowski.htm>.

31. <http://www.judgerc.org/>.

32. JREC pooh-poohs the idea of positive reinforcement and therefore does not use it. Ever. They also seem inordinately pleased that they use only "minimal psychotropic treatments" or the children. But is a parent's idea of minimal usage the same as theirs? Probably not, but there is nothing parents can do about it since parents must waive all rights to interfere with JREC treatment decisions concerning their child (<http://www.judgerc.org/>).

33. <http://www.judgerc.org/>.

34. <http://www.judgerc.org/>.

35. On April 29, 2010, the American human rights organization Mental Disability Rights International filed a request with the United Nations Special Rapporteur on Torture, stating they believed the residents at JREC were being subjected to human rights abuses because of the use of electric shock on children. JREC was court ordered to turn over their security videotapes to the court. However, before the court could view the tapes, those tapes were destroyed. So, in May 2011, Matthew Israel, founder of JREC, was charged with misleading a grand jury over the school's destruction of the tapes, as well as being an accessory after the fact. Dr. Israel resigned in a deferred prosecution plea deal with the Massachusetts State Attorney General:

office (http://articles.boston.com/2011-05-25/lifestyle/29582413_1_shock-case-criminal-case-face-criminal-charges). However, according to the JREC website, Israel resigned because it was “time for [him] to move over and let others take the reins” (<http://www.judgerc.org/>). Interestingly, some inmates of JREC have posted YouTube videos protesting their experiences at JREC. They are rather heartbreaking to watch—though one young man did receive enthusiastic offers of affection from several commenters. The protest videos—and their responses—are a fascinating and wholly unanticipated, but quite inevitable, outcome of JREC’s boast of “A Computer for Every Student.” I cannot help but think.

36. http://articles.boston.com/2011-05-25/lifestyle/29582413_1_shock-case-criminal-case-face-criminal-charges.

37. Exorcism can be risky business as Ray Hemphill of the Faith Temple of the Apostolic Faith Church in Milwaukee, Wisconsin, discovered in 2003 after he killed an eight-year-old autistic boy after attempting to exorcise the autism out of him, an activity that required wrapping the boy (who was known to be extremely touch averse) in sheets while three women, including the child’s mother, sat on the boy’s arms and legs while Hemphill sat on his chest and whispered aspersions at the devil into the boy’s ear. After two hours of such efforts, the boy stopped breathing (<http://www.cbsnews.com/stories/2003/08/25/national/main570077.shtml>).

38. I have been driving past one annoying billboard sponsored by Autism Speaks once a week, sometimes twice or even three times a week, for the past five years. It features a doe-eyed young boy with the text, “Every 20 minutes a child is diagnosed with autism.” Of course there is no reason to believe these children are being accurately diagnosed, but the billboard is sufficiently alarmist, and that is its purpose.

39. “Autism is like cancer” is an analogy that has been used in an Autism Speaks newsletter on their website. Its capacity to terrify parents into frenzied action is likely the reason that Autism Speaks is one of the largest autism organizations in existence, which has raised (they claim) millions of dollars to “fight” autism. They explicitly advocate curing autism though I cannot find statements on their website explaining the exact nature of the research projects they support, such as whether or not they support genetic research that would lead to prenatal genetic testing and, therefore, selective abortion (<http://www.autismspeaks.org/>).

40. We were asked *ad nauseam* “When did you first notice the signs?” Why don’t they get it? We never saw “signs.” Because we exhibit the same “signs”? I don’t know. We would not have ever gone to that neurologist if other people—pre-school teachers, for example—had not suggested to us that we ought to “get advising.” Sometimes I wish we never had gone, but had simply moved far away from civilization instead. The epistemic shift one undergoes when handed a label which, it turns out, is practically meaningless, is nearly impossible to explain. And we can never go back to being P.D. (Pre-Diagnosis)—those wonderfully Halcyon days when you view your child as wholly individual, with a completely open future, rather than utterly essentialized by a condition. Of course, the truth is that your (autistic) child is still wholly individual with as much an open future as any other (nonautistic) child, but I have found that others view autistic children (just as they view all others with impairments) as essentially autistic, and nothing more. Resisting the conception of our son as nothing more than autistic is yet another exhausting battle to wage.

41. These are the kinds of hostile thoughts I had going through my mind during those months. I have heard that adversity brings out the best in people. I cannot say that I saw that happen in myself, particularly.

42. “What an idiot! Apparently they don’t care about their kid!” was my first thought about some anonymous parent. As I said, these were not my best moments.

43. Combat Autism Act of 2006, Pub Law No. 109-416 was signed into law by President George W. Bush on December 19, 2006. This act authorized the spending of about a billion dollars on autism research over five years. It also authorized the Director of the NIH to create an “Autism Czar”—that is the real title, I did not make that up—who would coordinate NIH-based research. Staying true to the theme of war and disaster, Jon Shestack, co-founder of Cure Autism Now (CAN), stated “This bill is a federal declaration of war on the epidemic of autism. It creates a congressionally mandated roadmap for a federal assault on autism” (<http://abcnews.go.com/Health/Story?id=2708925&page=1>, emphasis added). The five years are up. As far as I know, autism has not been combated, defeated, or cured.

44. Defeat Autism Now (DAN) is the name of a rather notorious therapy program, more so since an autistic boy died after being subjected to the treatment plan (<http://www.defeatautismnow.net/>, see also http://www.acsh.org/factsfears/newsID.624/news_detail.asp).

45. Indeed, parents of autistic children are encouraged to spend not only their available resources but to go massively into debt. What decent parent would prioritize their own financial future or secure retirement when their child needs expensive therapy now? Why even bother setting aside for a college for that child if skimping on therapy means that child will never have a chance to go to college—indeed may never have the chance to go to a “normal school” at all? At one “parent support group” I met a couple who decided to spend a small fortune (given their incomes as middle-school teachers at a local public school) on one of their autistic children. They decided it was worthwhile to pay over \$40,000 for the father and his almost three-year-old autistic son to live for four weeks in a hospital facility just over one hundred miles away to learn healthful dietary regimens because the son was a particularly fussy eater. The mother had elected to stay home with the boy’s autistic fraternal twin sister, who was a less fussy eater. At the time I thought the decision was madness. But, as years have gone by and I have thrown away what sometimes seem like a small mountain of uneaten food (the word “NO!” echoes in my mind), I think to myself, “How much money have I wasted on rejected food? And at what point will those dollars total 40,000?” But the better question is: Did the hospital stay work? And, even if it did for them, would it work for us?

46. “Regression” is a term parents of an autistic child are bombarded with over and over again. Every enthusiastic therapist, counselor, book, manual and educational pamphlet, psychiatrist and psychologist has horror story after horror story of the child who “regressed” inexplicably. Typically these children were progressing amazingly—talking, succeeding in school, learning perhaps two, maybe three languages! They were children any parent would dream of having and then—poof!—it all disappeared. They regressed! They were back to acting like toddlers, in diapers again, they “lost” their capacity to talk—they were lumps! The moral of the story is: Everything parents work for can be STOLEN by autism ALL OVER AGAIN in the blink of an eye! I am not sure what purpose these stories are meant to serve in the Autism Mythos except to terrify. And terrify they do. They reel you in, just as when the carnie barker captivates his audience with tales of wonder and intrigue, you find yourself—despite whatever Ph.D.-trained sensibilities you brought with you to the Tent of Wonders—suckered more easily than a child. Any parent who loves their child will do everything to stop regression from happening to their child.

47. See Wendell 1996, 97-98.

48. Never mind that many parents of autistic children have not had a good night’s sleep in years since up to 80 percent of autistic children have difficulty sleeping (<http://www.kennedykrieger.org/patient-care/patient-care-programs/outpatient-programs/sleep-disorders-clinic-and-lab>). Our son did not sleep more than two-hour stretches until he was about five years old. I hardly remember the years between my pregnancy with him and when he was five or so years old when he started sleeping through the night regularly. What little I do remember is veiled with headaches, exhausted caffeine-addled nausea and an itchy-eyed stupor. Is it any wonder that parents of autistic children are especially vulnerable to con artists and charlatans?

49. This psychologist scorned the diagnosis of PDD-NOS given by the neurologist ten months earlier and instead diagnosed our son as autistic. There is, I now know, an informal caste system within the “umbrella” of autism diagnoses. Perhaps not too surprisingly, parents covet the diagnosis of “high functioning autism,” which is sometimes regarded as synonymous with Asperger’s. Yet some want to distance Asperger’s from autism and treat it as a distinct category (class); autism, a lower class, is then divided into high- and low-functioning autism. For obvious reasons, no parent hopes for a diagnosis of low-functioning autism despite the fact that there is no evidence that early diagnosis correlates with later success (or lack thereof). Thus low-functioning autistic children may be “late bloomers” and, in their teen years, acquire language skills of a level that allows them not only to meet but to surpass the skills acquired by so-called high-functioning autistic children. PDD-NOS is sometimes regarded as synonymous with low-functioning autism and sometimes regarded as its own category, distinct from both Asperger’s and autism (both high- and low-functioning). Our son has been diagnosed as PDD

NOS, as mentioned earlier, by a neurologist and by one occupational therapist; low-functioning autistic by the speech therapist, occupational therapist, social worker, and case worker at the special education school he attended when he was pre-K (I was told that this was a “stock label” they gave all their ASD kids so that they would get maximal therapy services from the school district; I do not know if they were trying to console me because of the disheartening label or not); “way high-functioning autism”—whatever that means—by one play therapist; autism, as stated above, by the child developmental psychologist; and “autism but not like anything I’ve ever seen before” by another speech therapist he saw privately for about three years. After a while, it is difficult to take these labels seriously—except that they entirely determine access to therapy services, of course.

50. I write “decades ago” as if institutionalizing autistic children no longer occurs standardly, but unfortunately it still does, though far less often. Part of the motivation for “early detection, early intervention” is, we were told, to ensure that life-long institutionalization occur less often than it did in the 1950s and 1960s, so as to prevent the barbaric horrors those people experienced.

51. Of course, the fact that parents who institutionalized their autistic children were following the enthusiastic recommendations of psychologists and psychiatrists is something that therapists now do not draw attention to. The history of inconsistent claims about autism, the history of useless and dangerous treatments for autistic individuals defended by the American Psychiatric Association, and the barbaric abuses inflicted upon autistic individuals by psychologists and psychiatrists is not something therapists are completely upfront about. Perhaps if they were, parents of autistic children might start thinking that the science of autism is like the Wizard of Oz: just a tiny man behind a curtain pushing a lot of buttons to create the illusion that something really fantastic is happening.

52. By noninvasive I mean that it did not require any biomedical or pharmaceutical products, was in no way connected to A.B.A. (which relies too heavily on aversion therapy for my comfort), and was not cripplingly expensive. It did require learning some bizarre jargon that I never quite mastered and which I now suspect is complete rubbish, designed to (a) get papers published in psychology journals and (b) impress parents. It also required that we tolerate various “play” therapists in our home for three hour stretches while they (1) videotaped us, (2) “shared” with us critiques of the previous play session, and (3) had us make a plan for the next session. I found the play sessions draining and dreaded each and every one. Both my husband and I would desperately hope the play therapist would be a “no show” but, unfortunately, he or she always showed up. (To be fair, I really, really liked them as people and of course I got a lot out of these sessions; otherwise I would not have continued with them for over a year. I just hate therapy sessions and really do NOT enjoy being videotaped, nor do I enjoy having people analyze how I behave while playing with my son while being videotaped for THREE FUCKING HOURS!) At one point, because we were participating in a study funded by a grant and organized by our son’s child developmental psychologist, we had three different play therapists, each coming to our house for three-hour sessions, almost every single Friday for six months. It was a kind of living hell.

53. As with many reputable therapy programs, the therapy plan we chose recommends thirty-five to forty-five hours of therapy for our son every week, divided up between my husband and me, our son’s “personal assistant” (someone who has known him since he was an infant and has gone through the “therapy training” with us), a speech therapist, occupational therapist and music therapist. Music therapy is not typically considered “essential therapy” for autism but, like art therapy, if the child is interested in it and there is a really good therapist, I believe the benefits can be tremendous. Our son has developed an amazingly close relationship with his music therapist. Our son has perfect pitch, was able to read music at a really young age, and is fascinated with musical instruments, particularly the guitar and piano. So, putting all his interests and “splinter skills” together, weekly music therapy seemed the obvious choice for developing his large and fine motor skills, communication and social skills. What turned out to be particularly challenging for him was playing both treble and bass clef on the piano at the same time. But, since he is so highly motivated to succeed, he does not give up. As a result, he plays piano as well as any child his age; more importantly, though, he is inordinately proud of himself when he masters a song (especially holiday songs—Jingle Bells was a particular

favorite). Indeed his attention span with his music therapist is seemingly unlimited; the fifty minutes seem to fly by. Our son never fails to give him eye contact appropriately; he sits calmly in his chair the whole time; and converses (and jokes) with his music therapist about what they are doing. During the rest of the week, our son mentions at least once a day—sometimes many times a day—the number of days until the next music therapy lesson. (Life is a perpetual countdown in our house.) But that same boy, in his mainstream classroom, stares out the window, wiggles endlessly as if he has fire ants in his pants, can’t bring himself to look his teacher in the eyes, and spends his time doodling or talking about buses, sharks, eggplants, or any other idea that pops into his head. His teacher asks me at every parent-teacher meeting, what she can do to “reach him.” The only truthful answer is: “Be as amazing as a well-trained therapist.” But what would be the point of saying that?

54. This teacher, who is a little hard of hearing, signed throughout the day, and worked very well with our son. They were a great team and he adored her. Three years have gone by since he was in her class and he still gets out photos of her and mentions her lovingly.

55. I only mention art here as an example. In fact, we ended up discussing all the possibilities and each one was as bad as the other. But even I knew that the mainstream math class was impossible because I could hear the thirty-odd children yelling and screaming at top volume in that classroom. Our son never would have been able to handle the noise levels of that room—I could hardly stand walking past it to get to his room to drop him off in the morning. Eventually I did reach my limit for the whole damn place and I pulled him out about three weeks before the end of the school year. It all just got too much—for me—not for him. The school was just too miserable and depressing and one day I decided that I could never go there again. By the time he was five years old, I had pulled him out of six separate schools mid-year or mid-program because the teachers, classrooms or schools were simply too horrific or dismal. His older brother, who has always been able to take advantage of “gifted” programs or college prep schools, has never had to go to the city’s most mildewed and dilapidated buildings. Our autistic son is in a school now that is not part of the public school system and it has no special ed program. There are pros and cons to being part of a public school and there are pros and cons to being at a school that is largely ignorant of the “special ed” culture. If I had my druthers he would not go to school at all.

56. <http://www.aclu.org/pdfs/humanrights/impairingeducation.pdf>, page 2.

57. The Human Rights Watch and ACLU study only has statistics on corporal punishment and restraint rates in public schools because they are mandated to report to state and federal agencies. The report notes that it is reasonable to conclude that (a) actual rates are likely to be much higher than reported rates and (b) private institutions are likely to rely on corporal punishment and restraints as well (<http://www.aclu.org/pdfs/humanrights/impairingeducation.pdf>). According to this report by the Department of Health and Human Services Office of Inspector General, state hospitals fail to report about one-third of all “deaths by restraint.” If state hospitals are massaging the numbers, why would private institutions, which are not required to report to anyone, broadcast deaths by restraint? (<http://oig.hhs.gov/oei/reports/oei-09-04-00350.pdf>).

58. Some schools have specially designed paddles for using on the children, many of whom are as young as four or five years old, made from baseball bats that have been shaved flat on one side with holes drilled into them so they hit harder (<http://www.aclu.org/pdfs/humanrights/impairingeducation.pdf>).

59. Using a restraint hold on a child that was designed for an adult is both painful and dangerous for the child. The child’s body is too small and not only bruises easily but their bones, particularly their ribs, are much softer than an adult’s. Numerous incidents of “death by restraint” have occurred in this country when inadequately trained adults have put a child in a restraint hold improperly and caused to the child to go into cardiac arrest if the basket hold is used, or asphyxiate if the prone position is used. Although hospital records are incomplete and private institutions are not required to submit “death by restraint” records to federal agencies estimates place “death by restraint” rates of children in public schools during the year: 1995–2005 at around 150 deaths (<http://www.disabilityrightsca.org/pubs/701801.pdf> and <http://www.gao.gov/new.items/d09719t.pdf>).

60. I suspect they would be to any child.

61. <http://www.aclu.org/files/pdfs/humanrights/impairingeducation.pdf>, 46–47.
62. <http://www.aclu.org/files/pdfs/humanrights/impairingeducation.pdf>.
63. At the time the Impairing Education report was written (in 2009) by the Human Rights Watch, twenty states had laws which permitted the use of corporal punishment in public schools. The Ending the Corporal Punishment in Schools Act (ECPSC) was reintroduced in Congress on September 22, 2011. ECPSC, were it to pass, would place a federal ban on corporal punishment in public schools. Since there is ample evidence that corporal punishment prevents all students, but students with impairments especially, from being able to take advantage of educational services being offered to them in the public school setting, the argument is that any instance of corporal punishment is a violation of both the American Disabilities Act and a violation of Title IX. Unfortunately, given how entrenched notions of authoritarianism within public schools are, particularly where the “worst offenders” seem to be, most people who track rates of child abuse do not predict that ECPSC will pass. Certainly no state laws that have attempted to eliminate or even moderate corporal punishment have ever passed in states that permit corporal punishment. In short, those teachers really want to keep hitting those children, especially children with impairments. See Alice Farmer, a researcher at Human Rights Watch, at *The Hill's Congress Blog* for regular Congressional updates (or lack thereof) regarding these matters.
64. http://www.salon.com/2009/03/26/bauer_autism/.
65. http://www.salon.com/2009/03/26/bauer_autism/ (emphasis added).
66. The film received severe criticism from disability activists. See, for example, Stuart Murray's *Representing Autism: Culture, Narrative, Fascination* (Liverpool University Press, 2008). Despite intense criticism of the film, a forty-six-minute version was given a special screening at the 2007 Sundance Film Festival. A special thirteen minute version debuted at a fundraiser named “A New Decade for Autism” on the Don Imus show on MSNBC and an additional seven-minute version has been created for YouTube (<http://abcnews.go.com/GMA/AmericanFamily/story?id=2286321&page=1>).
67. http://articles.nydailynews.com/2010-07-22/news/27070582_1_capital-murder-children-death-penalty.
68. <http://www.cnn.com/2010/HEALTH/07/23/autism.death.mother/index.html>.
69. Further insights into Elizabeth's motives will remain a mystery as she shot herself dead after killing her son George.
70. March 2012. <http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2012/03/07/BAVR1NH8B4.DTL>
71. <http://www.feet.org/FEAT/tabid/58/Default.aspx>.
72. <http://autismcrisis.blogspot.com/2006/11/dehumanization-specialists.html> (emphasis added).
73. Bitterly disappointed with our experiences with parapros, we hire what we call our son's “personal assistant” to accompany our son while he is at school. She is really a communication facilitator, helping him when communication breakdowns inevitably occur while he is still not comfortable verbalizing his thoughts with people I think of as “non-familiars.” He is a “chatty Cathy” with familiars but not with people he does not know, does not trust or when in new or stressful situations. He can communicate very effectively nonverbally (by writing notes, drawing pictures, and signing) and makes every effort to do so but, I have found, most people are very unwilling to attempt to understand his nonverbal communication efforts. Therefore I believe that a go-between is, at this stage in his life, vital to his success (and safety) at school.
74. There are always stories of “full recoveries” of autism but they are never verified by objective, independent observers and can be more reasonably explained three ways: (1) *Wrongful Diagnosis*—A mistaken diagnosis of autism was made by an overly anxious teacher or physician who believed, say, a nonverbal toddler exhibited “signs” of autism but, a year later after parents threw themselves into various kinds of treatment, those “signs” disappeared once the child started talking as he or she would have anyway; (2) *Wishful Thinking*—A child is autistic and has not actually changed remarkably but developed in ways perfectly compatible with an autistic diagnosis, but parents, therapists and/or teachers are so keen to see progress because of their commitment to a therapy or treatment program, they “see” astonishing progress that others would not (or do not) see; (3) *Quackery*—Individuals lie or exaggerate to

- mislead others into believing that autistic individuals have “fully recovered” or have been “cured” when they have not.
75. <http://www.who.int/topics/tuberculosis/en/>.
76. Dawson *et al.* 2008, 759–72.
77. And I do stress *if*—research done on autistic individuals is often laughably unreliable.
78. Earlier, I mentioned one clinic that claims to be currently treating autistic children with gene therapy. Yet no reputable research institute is claiming that gene therapy is currently available as a therapeutic treatment for autism. At this point, there is simply no evidence that any available existing gene therapy programs could possibly offer any therapeutic results for autism.
79. Boucher 2009, 283.
80. Though apparently there are a just a few researchers who believe it is not completely implausible. See Hu-Lince, C., Craig, D., Huentelman, M., & Stephan, D. 2005. The Autism Genome Project: Goals and Strategies. *Databases and Genome Projects. American Journal of Pharmacogenomics* 5:233–46.
81. I will develop a fuller discussion of the cognitive and affective processes and capacities of autistic individuals later but it is claimed that autistic individuals think very differently from the way nonautistic individuals do. For example, it is often claimed that autistic individuals often fail to understand public associations but, instead, follow reasoning processes that rely on private associations which nonautistics cannot (or, in my experience, refuse to) understand. For example, in the United States a public association is that Christmas colors are red and green—those are the “correct” colors for that season, other colors are “not right.” For an autistic individual, Monday may be square, the number eight may be itchy, October may be loud—anything goes. How one arrives at a private association simply depends on whatever private associations that individual has made between one concept and another. Private associations do not make sense to others but make perfect sense to the person who created them. For examples of autistic college students describing how they think and how they think about thinking, see *Aquamarine Blue 5: Personal Stories of College Students with Autism*, edited by Dawn Prince-Hughes (Ohio University Press, 2002). See also Daniel Tammet's *Born on a Blue Day* (Free Press: New York, 2006).
82. This seems like a fairly innocuous enough model if genetic counselors are neutral in presenting genetic information to parents. Yet a review of literature available presents the decision to not have “defective” children, children with “closed futures” or those who will live a “life not worth living,” as perfectly reasonable, if not ethically obligatory. See Jeff McMahan, *The Morality of Screening for Disability, Ethics, Law and Moral Philosophy of Reproductive Biomedicine* 10 (1, 2005): 129–132; Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future, Hastings Center Report* 27 (2, 1997): 7–15; Julian Savulescu, *Procreative Beneficence: Why We Should Select the Best Children, Bioethics* 15 (Oct. 2001): 414–26. Given the current Culture of Autism, parents may feel pressured to not conceive if they already have an autistic child (or if there are autistic individuals in the family). At another parental support group, I met a young couple who had a four-year-old boy who had been diagnosed as autistic. They had just received the news that their two year old son was autistic. Interestingly, given that everyone there had a child who was autistic, everyone expressed sadness and various words of comfort. Clearly the assumption was that this was very, very bad news. One mother whispered, almost fearfully, pointing to the wife's very pregnant abdomen, “Aren't you worried that your unborn will be autistic, too?” She whispered the word “autistic” as if saying it too loudly might cause the fetus inside to suddenly turn autistic right there in the room. To my amazement the dad said, “Well, we thought about it but I just figure: we have the routine down by now. And the great thing about autism is, if 8 o'clock is bedtime, then that's it, that's when they go to bed. And if they like SpaghettiOs, don't buy 2 cans, buy 20!” He chuckled happily to himself while his wife smiled in agreement and rubbed her tummy bulge contentedly. Everyone else in the room stared at them speechlessly. Even the therapist hosting the counseling session was at a loss—and she was supposed to be offering us help for depression. What was so fantastic about their attitude was that it was a complete rejection of the presumption of negativity and grimness that hung over those group therapy sessions. I never saw two people more at ease in the world. I think of them often. I stopped going to those support groups because,

although occasionally there were amazing people like this couple, in general I found the sessions to be horrifically depressing because they reinforced the attitude that autism is nothing but a terrible grind.

83. See Hubbard, Ruth. 1990. *The Politics of Women's Bodies*, 193–95. Rutgers University Press: New Brunswick.

84. I attended a talk given by Judy Endow, a self-identified autistic who said that she is well aware that she is “merely” a “brown eyed” autistic rather than one of the “blue eyed” Aspies in the autism community, which is an interesting insight for an autistic person to have, given that autistics are alleged to be incapable of understanding social cues. Her very biting social commentary—critical of both the autistic community and “neurotypical society”—was in turns thought provoking, funny and poignant. Autcom Annual Conference: October 15–16, 2010, Milwaukee, WI.

85. Although given how amusing life can be, doing so is no guarantee that the parent will not end up with an autistic child because these tests are, as discussed, unreliable, providing both false positives and false negatives.

86. Sykes and Lamb 2007, 1–15.

87. <http://www.msnbc.msn.com/id/7013251>. “If we get to the point where we have 10 genes that predict risk to some significant degree, then there is a prenatal test,” Buxbaum stated. (emphasis added). The room for error is obvious when put so baldly.

88. Along with fellow autistics Kathy Lissner, Grant and Donna Williams, they formed Autism Network International in 1992, the first organization run “by and for autistic people.” One of the fundamental principles of ANI is that autism should not be cured. See www.autreat.com.

89. <http://nymag.com/print/?/news/features/47225/>.

90. <http://www.nytimes.com/2004/12/20/health/20autism.html>.

91. <http://www.asatonline.org/forum/archives/mother.htm> (emphasis added). Organizations concerning autism neatly divide into two camps: those run and organized entirely by individuals who are autistic and those run and organized by individuals who are not autistic. The tone, politics and goals of the two are entirely different. I have yet to discover an organization that was established entirely by individuals who are not autistic (such as Autism Speaks) that permits autistic individuals to have any influence on how the organization is run or to help set the agenda of the organization.

92. <http://www.nytimes.com/2004/12/20/health/20autism.html>. The slur “curebie” refers to any person who is a particularly weak-minded slave to conformity; it is usually someone who is in favor of finding a cure that will eliminate autism and, thereby, narrow neurodiversity. But it may also specifically refer to someone who is attempting to “train” any evidence of autism out of their child through behavior modification therapies (such as A.B.A., which relies on aversion therapy) so that they appear normal and can “pass” as nonautistic. Thus, just as with race and sexual identities, individuals have much to gain and lose with the politics of autistic identities. No wonder Kit Weintraub says of the anti-cure movement in that same *New York Times* editorial, “I’m afraid of this movement.”

93. Singer is an autistic sociologist. The first published use of the term is credited to Harvey Blume’s use in an article in *The Atlantic*. Blume writes, “Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favor a somewhat autistic cast of mind” (September 30, 1998, <http://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/5909/>).

94. At this point, the conversation becomes difficult and, not too surprisingly, neurodiversity advocates divide. Some believe that conversations about neurodiversity really makes no sense when talking about “low-functioning” autistics and should apply to high-functioning autistics, such as Aspergers, only. The idea is that the neurology of high-functioning autistics is worth preserving, but low-functioning autistics really do need to be “cured” (that is, genetically eliminated). See Jaarsma, P. and Welin, S. 2011. Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis* 20 (1):20–30. Yet, as has been mentioned several times, carving nature at the joints is tricky business and distinguishing between “high-functioning” and “low-functioning” autistics is no-

toriously difficult. (And where are the PDD-NOS’s in this conversation?) As I have also previously pointed out, early diagnosis is no indication of later success. The further problem with this separatist line of reasoning, which should sound familiar to anyone who knows race or gender identity theories, is that from what genetic researchers have so far concluded, genetic markers for autism are not only highly complex, they give no indication whatsoever of how autism will be realized (or expressed) in a person. That is, there is simply no way to (reliably) eliminate the “low functioning” autistics but save all the “high functioning” (valuable) Aspies—either we screen for them all or we screen for none. In other words, the high functioning autistics (or, Aspergers) want to essentialize themselves as inherently different from the low functioning autistics, but there is no genetic or neurological essential difference between the two groups. The difference is in name, and socially constructed privilege, only. Interestingly absent from the conversation is the question of why neurodiversity would not commit one to advocate the mass production of autistic individuals. Perhaps because the standard question is so often about the elimination of autism, the question of increased autism populations does not arise. And, perhaps since most people accept the myth that autistics are asocial (indeed, antisocial) they probably cannot imagine autistics sexually reproducing—yet, have children they do! See Kathleen Seidel’s brief discussion of her attitudes regarding parenting in *New York Time Magazine* (June 2, 2008), <http://nymag.com/news/features/47225/>. Advocates of neurodiversity are not committed to the (rather silly) idea that autistics ought to be created *en masse*. Rather, neurodiversity ought to be regarded as a way to establish protection for individuals who are members of a group with a minority status, not as a means to coerce individuals within a minority group to reproduce to “bulk up” the population or maximize the neuro-variety of that minority group.

95. It is increasingly common for long-dead scientists, literary “geniuses” and innovators to be forensically diagnosed as autistic. Almost every philosopher has been diagnosed as autistic. Certainly Jeremy Bentham, John Stuart Mill and Immanuel Kant would get diagnosed today as “classic cases.” Instead they were allowed to get through their childhood label-free and live perfectly successfully. I have also recently read arguments that Charles Ludwig Dodgson (Lewis Carroll), Thomas Jefferson, Charles Darwin, and Emily Dickinson have been labeled as autistic though there are skeptics.

96. *Threads* magazine featured an article by Alice Korbach who knits beaded purses on sized 00000 needles, using 6 mm beads. She has to design the patterns in advance, stringing 5,760 different colored beads onto the silk thread at one time, so that when they are knitted they end up making the colored pattern. If she miscounts one too many, one too few, the whole pattern will be off. (*Taunton Press* (August/September 1989): 24–29). Althea Merback knits “conceptual clothing.” One Fair Isle sweater, which is smaller than a quarter and complete with inset pockets, and cabled pleats, took her over 500 hours to complete. Some of her cardigans—“micro sweaters”—are 1/144th scale and smaller than a dime. *KnitKnit: Profiles + Projects from Knitting’s New Wave*, ed. Sabrina Gschwandtner (Stewart, Tabori & Chang: New York, 2007, 134–37). “Fixity of focus” is essential for both such artistic endeavors.

97. Straus 1997, 541–44.

98. Straus 1997, 548–49.

99. That is occupational therapy speak for “turning on the garden hose and having a wildly good time in the backyard.”

100. We splashed out on a big trampoline (with a safety net—we’ve seen *The Simpsons!*) and the feeling of flying through the air, suspended, motionless, just before you start to fall is truly thrilling. It makes me almost giddy. But it really is hard on “old knees,” sad to say. Our son is older now and his interests have turned primarily to swimming and biking for “big muscle” activities and reading and drawing for quiet time activities—all of which are easier on my knees and involve a lot less clean-up. But I do miss playing in the mud once in a while.

101. <http://www.dailymail.co.uk/femail/article-1081698/I-wouldnt-change-autistic-boy-world-An-admission-son-ex-wife-author-Nick-Hornby.html>.

102. <http://www.dailymail.co.uk/femail/article-1206734/Ken-Bruce-Why-I-believe-world-better-place-family-experience-child-autism.html>.

103. Although some have argued, rather poorly in my opinion, that autistics are nonmoral persons because they lack empathy, I think, a better moral litmus test that autistics could pass

(and many nonautistics would often fail) is the honesty test. In the autistic world, justice and morality are founded on such categorical imperatives as keeping promises and being honest—not in playing favorites, maintaining social networks, or “working the system.”

104. Our insurance does not cover any autism therapy. Another bit of advice our child developmental psychologist gave us, “If you want good therapy, pay out of pocket.” We were discussing the virtues of private therapy versus public school therapy services, and I think he is right but how many people can foot that bill since a good speech therapist (in our area, at any rate) charges \$75 for forty-five minutes per week and speech therapy is a several-year-long commitment? Never mind all the other therapies that are needed to be paid for out-of-pocket as well. Is it any wonder the headlines read that parents of autistic children are paying on average \$40,000 per year for services? When I read that I snorted, thinking that that was so much “antiautism scare talk,” until I did the math and realized that that is pretty much exactly the amount we were paying for private therapies, including our son’s “personal assistant” to accompany him at school. If insurance does cover therapy, as it does in some states, it will be A.B.A., a type of therapy I am opposed to since it relies on aversion therapy and the evidence of its success is highly dubious.

105. Michelle Dawson *et al.*, argue that cognitive literature is completely incapable of explaining autistic learning. For example, autistics are said to learn passively, a style of learning not favored by nonautistics. Moreover many autistics, such as our son, are “hyperlexic” which will give them “extremely advanced decoding skills.” Discussing a boy with the reading skills of a twelve-year-old but a “mental age” of less than two, they argue, “[E]xisting cognitive accounts are inadequate to account for the development of literacy in this child” (Dawson *et al.* 2008, 759–72). And a typical public school curriculum cannot accommodate such a child, and a teacher has no idea how to educate such a child, either.

106. To protect myself from chicanery, my automatic defense against something, like an “alternative remedy” is to dismiss it. But since there is most likely at least one product or device that might be useful, this is not an optimal approach. (I already mentioned the unbelievably expensive, but really good three-sided pencils that we would never have bought if they had not been suggested by our son’s occupational therapist.) How many other little gems are there out there lost in the dross of inadequately regulated crap?

107. During WWII, Hans Asperger opened a school in Vienna for children with “autistic psychopathy” where he cared for several hundred autistic boys, shielding them from the infamous T-4 policies which certainly would have slated them for extermination. Asperger wrote over 300 publications, mostly about autism; unfortunately, most were destroyed during a bombing. None were translated into English until after his death (Asperger 1991, 37–92). Asperger’s positive outlook for the autistic children is interesting, especially when compared to other researchers who were working with autistic children in other countries during that era, most notably Leo Kanner. After the war ended, Asperger became director of a children’s clinic in Vienna. Later, in 1964, he headed the SOS-Kinderdorf in Hinterbrühl, and was responsible for helping poor, orphaned children who required medical care. Many have speculated that Asperger was “on the spectrum”: he was known to be devoted to the children he cared for, able to “just know” what they needed even if they could not adequately verbalize their needs, yet he was well known to be uneasy among adults. Dr. Fred Stone, a pediatric psychiatrist described meeting Asperger at a conference in Vienna, “He was on duty “welcoming” people—actually, he didn’t welcome anybody, he just sat at the door of the lecture theater...I couldn’t engage him. I think that those who claim that he may have been suffering from the same syndrome that would later bear his name could be right” (Lyons 2007). Asperger’s birthday, February 18, is International Asperger’s Day and is observed by various autism organizations as an unofficial International Holiday.