Abstract:
Since writing this essay in 1998, I've come to believe that the categorization of people into separate boxes labeled "Asperger Syndrome" and "autism" (or "high-functioning autism") is seriously misleading. I prefer to identify myself now as autistic, period, rather than AS; but since this essay shows part of the path by which I reached where I am now, I have not altered it to match my current (as of today, but always subject to change) thinking on the matter. For more on this topic, see the link on my main page to "The Great 'Why Label?' Debate" and/or click on "Defining autism vs. AS" on the Snippets page. (Note added 2002)
Thoughts on Finding Myself Differently Brained

By Jane Meyerding

I used to think all people were alike at the core. Each of us was unique, of course, but unique with an awful lot in common. Various forms of damage, coming from a wide variety of directions and at different speeds, could damage a person so much that s/he would lose track of this basic truth. But whether this person or that acknowledged it or not, the truth remained. Why else would the feeling be so nearly universal: Do not do unto others that which you would not have done unto yourself. What goes around comes around. If I cut you, do you not bleed?

Despite all subsequent riders and challenges to that precociously adopted belief, I continue to see some substantial portion of it as logically unassailable. We humans who are alive today are members of the same single species evolved over millennia on a single planet in an unimaginably vast universe. How can we not see each other as more alike than different? And that for some people this simple fact of kinship is held to be either nonexistent or irrelevant—not to be taken as a basic guide for behavior—continues to strike me as evidence of damage rather than evidence of a potentially legitimate alternate point of view on the subject.

In 1979, an article I'd written the previous year about the intersections between feminism and nonviolence (and anarchism) was reprinted in WIN, a national magazine of nonviolent activism. The responses I received as a result caused me to consider seriously a modification in my one-basic-model theory of humankind. I had written that the willingness to take personal responsibility for the consequences of one's actions (and inactions) is basic to pacifism, feminism and anarchism. In order to do that, I said, we must guard against "the subtly violent dynamics which collectivity often engenders." The seeking individual, I implied, has a much greater chance of finding and holding to the truth than has any formal organization. Therefore, personal (individual) integrity must be the basis for action, rather than, for example, loyalty to the group, theory, or dogma.

The responses I got to that article, which had a much broader focus, all took exception to this single point. They tended to say something along the lines of: "I really liked the article. But you're wrong about individuals being better than groups for finding the truth. I was totally apolitical until I joined [...]. Only in the context of the group was I able to begin to understand the kinds of things you wrote about in your article. Individuals are really self-centered. It's being part of a group that socializes us."

Hmmmm. That conflicted so entirely with my own experience that I had to come up with my first major division in humankind. Some of us are solid core, I decided, and some of us are hollow core. The hollow cores need outside help to find the proper center of gravity that will allow them to orient themselves in society. (If these terms bother you, please think about it again after you get to footnote (6).)

My picture of humankind grew more complicated over the years as I realized more completely how different experiences can give people different ways of thinking. Living as a lesbian gave me a "lesbian-eye view" of the world, which enriched my ability to understand the perspectives I read and heard about from people with life experiences vastly different from my own. But despite the twin-but-opposing claims of post-modernist deconstructionism and post-Leftist essentialism (hollow vs. solid cores again, by the way), I managed to hang on to my belief in the one-ness of us all on some deep, evolutionary level.
Then, cruising an internet news group about Tourette's Syndrome in idle search of information about some of my more carefully hidden peculiarities, I came across an article someone had posted on another subject altogether: Asperger Syndrome. I read that article and saw myself described more clearly than I'd ever imagined possible. Here was the explanation for puzzling incidents dating back 40 years or more. I did a Medline search and probed the resources of the health sciences library at the university where I work. With every new journal article, my discovery was confirmed. It was like finding feminism all over again, only more so: Apparently disparate pieces of the puzzle (the puzzle of my life, my experiences with other people, my inability to "fit" in various situations) began to fall into place, making sense for the very first time.

I was surprised to find myself moving into the realm of neurology. But then, I'd never been satisfied by the usual--the "mainstream" explanatory schemes, which tend to rest heavily on some brand or other of psychology or psychologizing. Psychological explanations have never worked well for me. I could see them working for other people, but when I tried to use them on myself I always felt the result to be a makeshift device, more for show than function. On the other hand, I also realized that politics couldn't explain everything, "the personal is political" not withstanding. I was delighted some years ago to discover moral philosophy as another way to think about humans and our behavior. It felt much more true to me (and true for me) than psychology ever had.

But now here came neurology and the possibility that my brain really was different. If my life matched the descriptions in these articles, then apparently I had a brain that was built to a somewhat different design than the norm. This was something I had to know more about. Did it mean I was wrong to believe all humans are basically alike? If I could understand my life for the first time only by understanding how my brain was different from the majority of brains, how much did I really have in common with all those neuro-typicals (NTs) out there, compared to whom I'd been judged inadequate so many times?

Going On-Line

I am now a member of four on-line groups that have played--and continue to play--an enormous role in helping me learn about myself from this new angle. One of the groups is specifically for people with prosopagnosia (face-blindness), two are for people with a personal interest in what it's like to live with Asperger Syndrome, and one, my "cyberhome," is for people who have felt marginalized by neurologically-based differences.

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1 "Asperger Syndrome: Through the Lifespan" by Stephen Bauer, M.D. You can find this article on the OASIS web site. Another good site is "Ooops... Wrong Planet! Syndrome."

2 Quickie definitions:

- Prosopagnosia: brain-based inability to recognize faces.
- Asperger Syndrome: a constellation of symptoms or characteristics at the "higher-functioning" end of the autism spectrum of "pervasive developmental disorders."
- Central auditory processing disorder (CAPD): a hearing impairment located in the brain (where incoming speech is "processed" and understood) rather than in the ear. Neurologically-based differences include autism, Tourette's, prosopagnosia, CAPD, and many others. Often, two or more "syndromes" (or aspects thereof) are present in the same person.
Like a lot of ACs (autistics and cousins), I find myself able to enjoy "community" for the first time through the internet. The style of communication suits me just fine because it is one-on-one, entirely under my control in terms of when and how long I engage in it, and, unlike real-life encounters, allows me enough time to figure out and formulate my responses. In real-world encounters with groups--even very small groups--of people, I am freighted with disadvantages. I am distracted by my struggle to identify who is who (not being able to recognize faces), worn out by the effort to understand what is being said (because if there is more than one conversation going on in the room, or more than one voice speaking at a time, all the words become meaningless noise to me), and stressed by a great desire to escape from a confusing flood of sensation coming at me much too fast. What’s more, I must assume that most or all of the people around me are NT (neurologically typical), and I therefore feel compelled to hide or disguise ways in which I am different from those norms.

Remember I said I was reading a news group for people with Tourette’s Syndrome? The reason I went there was to find out more, if possible, about what I was calling my need to "decompress." After every social encounter, from interactions with co-workers on the job to political fund-raisers to conversations with store clerks, I go through a period of what seems to be a kind of "letting off steam." I wait until I’m alone, and then, when I am able to relax my shell of control, I twitch and vocalize. My hands jump around, flying this way and that, or gesturing elaborately about nothing. Meanwhile, my voice speaks nonsense. I say "my voice speaks," because the words are involuntary. My conscious, deliberate mind is not involved. I don’t know what I will say until I hear myself say it. Occasionally, I discover that I’m not as alone as I thought I was. The apparently deserted street is inhabited by a man crouching down to inspect the tire of his car, and I wonder for the rest of the day what he thought when this literally jerky middle-aged woman walking by all alone suddenly barked out, "I don’t love you." Or "elaborate retirement options." Or "thirteen purple penguins." Or whatever phrase that non-voluntary portion of my brain happens to be using for decompression that day. Sometimes it’s nothing more exciting than "no, no, no, no, no, no" repeated until I can stop.

On-line interactions don’t build up the pressure in me that requires this kind of release. (I’ve never risked a "chat room" visit; the whole point, for me, is to keep virtual reality different, not "more like" real-time interactions.)

That’s just one part—and far from the largest part—of why I value my on-line groups. With other AS/AC people, who are available to me on-line in a way they never could be otherwise, I can be open about the way I am and I can explore the reasons why. I can find commonalities that help me understand myself and my own history. One thing I find particularly interesting is the way we have tried to explain ourselves in the past. Some of us have accepted labels like "neurotic" or even "schizophrenic." All of us have felt like failures again and again, simply because we didn’t act or react or behave or develop the way people are supposed to. For example, many of us did not follow the normal sequence of physiological, mental, and emotional events that are supposed to mark adolescence. As one man put it, he didn’t "come on line" sexually until he was in his middle twenties. A close friend of my mother persuaded her to send me to a psychiatrist when I was in high school because I wasn’t "growing up" the way a normal girl should. I continued to have no interest at all in my appearance, in clothing, in make-up, or in boys. Fortunately, my good manners and obvious "maturity"3

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3 One characteristic of Asperger Syndrome is markedly uneven psycho-social development. AS kids are often described as "little professors" because they relate on a very mature intellectual level with adults even as they remain years behind in their social skills when compared with their age-peers. For example, I was an expert on radioactive fallout patterns when I was nine, but I was incapable of a normal relationship with my classmates. I couldn’t understand the games they played (games based in large part on non-verbal social cues) and much preferred to play alone or with a child several years younger than I was.
impressed the psychiatrist, and I came up with my own non-psych explanation for my differences: I was a lesbian. My later-discovered differences from people with whom I tried to work politically (activist politics, not electoral) were explained in a similar fashion: I was an anarchist.

I have come to see how right I was in those self-labelings, despite the fact that I am as different from NT lesbians and NT anarchists as I am from NTs in general, and in the same ways. Lesbianism and anarchism are true for me in that they contradict major institutions and assumptions in society that have been trying to contradict me (and, of course, a great many other people) since the day I was born. I’ve been calling myself a "non-aligned anarchist" for decades now, in an attempt to express both my attachment to anarchist beliefs and my inability to be or feel part of any formal or informal group, even if the basis for that group was anarchism. Similarly, I could describe myself as a non-aligned lesbian. (The tag-line "diagonally parked in a parallel universe" comes to mind at this point.)

Imagine my surprise, then, when I realized I was able to feel "aligned" with this disparate group of individuals joined together by neurological differences. It is a select group, of course, and that is a frequent criticism of on-line "culture." Only those with access to a computer and an internet connection are represented in cyberworld. Seeing the resulting population as "white" and middle-class is wrong, because it erases the presence of everyone else who is there, those who are of color and those who have achieved access without middle-class status or security. But it’s true we are a select and self-selected group. For some, that self-selection was the result of great sacrifice, making the internet a priority over other necessities because it is the only source of vital information and support. My own road was easier. I got a home computer years ago in order to co-produce a lesbian-feminist publication, and I’ve been reaping the benefits ever since.

As lots and lots of people are finding out, the internet gives us access to a vast pool of resources: the experiences of individual human beings. Some of them are off the wall, and some of them are playing games, but I remain amazed at the way we are able to make of certain cyberspace neighborhoods a place where we are peers learning from one another. The anarchistic potential of the internet has been noted often before. What’s especially clear in the groups where I have been hanging out is how the internet can empower individuals—-that is, how individuals coming together through the internet can increase each individual’s power—by sheer access to information. And it’s real information, not theory. There is no medical practitioner on the planet who has access to more information on AS than I do, because I am an active participant in daily explorations of what it’s like to be AS, explorations illuminated by hundreds of years of hands-on experience. (I refer, of course, to the accumulated, thought-over lives of all the adults in these groups, plus all the histories of all the AS children whose parents have turned to the internet for answers/knowledge not forthcoming from the experts.)

One hazard I see in participation in on-line groups of this kind is that the thrill of discovery, the rush of empowerment in an area of our lives where we felt especially helpless, and the comfort of a community focused on a mutual concern may cause us to make this focus a larger part of our lives than (perhaps) it deserves. This may be a hazard with its own natural history, though. Just as the newly converted are always the most radical believers, those who have been around awhile usually attain a more balanced perspective. Perseveration 4 is always a risk, a potential for exaggeration or distortion. But it can also be a path to richer understanding, deeper knowledge.

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4 Perseveration (in AS): a tendency to hyperfocus for extended periods (sometimes years) on specific topics of interest - or, as one university professor remarked about me, "you don't like moving off your own dime."
What does it mean to be "different"? And why does it matter?

I used to think I was like everyone else. Now I think I am different from most people, including most of the people with whom I share more or less identical demographics. My brain works somewhat differently from most brains (from "normal" brains). What's more, my brain works consistently enough along the lines described by the diagnosis "Asperger Syndrome" that I feel confident in describing myself by that label. My confidence rests not only on my own investigations and observations but also on the feedback I have received from others who are familiar with the way an AS brain functions. Some of these people have been diagnosed officially as AS, others as HFA (high-functioning autism), others with a grab-bag of labels over the years (including PDD-NOS, pervasive developmental disorder not otherwise specified). And then there are those of us who, like me, are "self diagnosed and peer confirmed."

What we have in common is the experience of feeling, on a very deep level, like an alien in human society. This has been my experience since I was a small child and couldn't understand the others of my age with whom I was lumped by school and custom. They did and said and wanted things that were inexplicable, as far as I was concerned. I was a quiet, passive child who didn't get into much trouble. At home, I got along fine with my family (all older than I), and I could enjoy being with adult friends of my parents. But kids my age were foreign to me. As I grew up, I learned to behave "normal" to a fair degree -- although I was always much more successful in my "passing" with adults than with age peers. Becoming socialized as "normal" when you're not can lead to a particular form of "double consciousness." One on-line friend put it this way:

I wonder what I would be like if I was raised in an Asperger world instead of the "normal" one. How much "normal" have I taken on artificially? How many of my complex problems derive from having two personalities--my genuine AS person and the person I learned to be from mummy and society. I'd like to write a book about a world where being Asperger is the norm. How odd others would seem.

The "others" are sublimely unaware of their own oddities, as seen by AS eyes, but quick to detect the odd in us. Hence the early-learned habit of appearing as "normal" as possible.

My boss and my friends may think it strange that someone as intelligent and capable as I am turns so "clueless" now and then. But they get over it. They never seem to see the pattern inscribed by my "lapses," however, unless I "come out" with it. I've had to explain to a couple of people at work that they must not be so courteous and collegial with me. When they bury their instructions within a "normal" amount of polite chatter, I am unable to "hear" what they are telling me. They think they have conveyed what it is they expect me to do, but they have been speaking in a language my brain doesn't understand. This has led to some unpleasant surprises on both sides, when they discover a week later that reliable old Jane didn't do what she'd been asked to do--because she had no idea she was being asked to do anything at all. Among my small store of real friends, the surprise is more likely to be over something I can't figure out how to do or something I do in a

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5 The adults weren't looking as closely, for one thing, and their communication wasn't dependent on the body language and non-verbal cues so important to "kid culture" everywhere. For the most part, only my age peers noticed that I was oblivious to everything they considered special and important in their communications. Not that this kind of coded interchange is absent from adult contacts. I have a whole mental warehouse full of stories about times when I was there, an active participant, and yet had no idea at all what was going on - or, as friends would tell me later, what was "really" going on. It's eerie to realize that messages are being exchanged all around you, obvious to everyone else, invisible to you alone.
way that seems a weird second choice compared to the way that appears patently obvious to them. When a smart person has no "common sense," it may be because her brain is wired to a less common pattern.

Most of the ways I'm different from the neural norm can be disguised as eccentricities. Even my need for routine(s), rituals, sameness, and spending 95% of my time alone can be seen as within a broadly defined range of normality (partly because I am careful to hide much of my life even from those close to me). In fact, many of us work so assiduously for so many years at appearing "normal" that we become unable to manifest our AS selves sufficiently for our ASness to be credible for outside observers. How does this happen? Try reading the following excerpt from John Stuart Mills' "The Subjection of Women," keeping in mind that "normality" has great authority in this culture, an authority wielded (most often unconsciously) by everyone who can meet the physical and neurologic norms:

It often happens that there is the most complete unity of feeling and community of interests as to all external things, yet the one has as little admission into the internal life of the other as if they were common acquaintance. Even with true affection, authority on one side and subordination on the other prevent perfect confidence. Though nothing may be intentionally withheld, much is not shown....The truth is, that the position of looking up to another is extremely unpropitious to complete sincerity and openness with him. The fear of losing ground in his opinion or in his feelings is so strong, that even in an upright character, there is an unconscious tendency to show only the best side, or the side which, though not the best, is that which he most likes to see....

We learn early to hide our non-normal selves inside a more presentable skin of pretense and habit.

There are times and places where pretense doesn't work, though. For most of us, I've gotten used to being told how I feel (when I don't feel that way at all) or, equally often, told that I can't possibly feel what I do feel (when, accidentally or on purpose, I reveal a reaction that does not fit NT expectations). This must have happened to me countless times as a small child, and I shudder to think of how thoroughly alienated from my AS self I was by the time I began to be willing to think about sex. About having sexual relations with other people, I mean. True to my "little professor" ASness, I knew about sex from a theoretical standpoint long before I thought of it as something in which I might engage myself. When I did (and this was in the 1960s, a time when having sex was easier than not having sex in the leftist circles my family inhabited), a friend immediately told me how I "must" feel about the other person involved. I took a minute to consider her prescription and then told her I didn't feel that way at all. She assumed I was lying.

People often assume I am lying when I report objectively on my inner workings. Or they think I am putting myself down. That latter reaction infuriates me and many other ASers who have to put up with the same thing. Instead of taking our words at face value, NT listeners ascribe some foreign emotional weight to them. They react to their own assumptions about the meaning behind our words rather than accepting our words as meaning what we say.¹ This same NT insistence on their own emotional make-up works against me (and other

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¹ AS folks tend to take things literally. This means, for one thing, that some ASers are seen as having no sense of humor because they don't get jokes that depend on non-literal interpretations of words. I, like a large minority of ASers, greatly enjoy that kind of jokes, so it took me quite a while to recognize that the cause of certain recurrent communication problems was my tendency to be more literal than people expect me to be. Analogously, I have trouble with people perceiving me as "judgmental." They ascribe the normal NT dichotomy of valued/devalued to my observations and assume I am stating a value judgment when I am merely making an observation (another form of being literal). For example, I'm told my reference in fifth paragraph of this article to "solid core" and "hollow core" types of people sounds judgmental (because the reader's assumption is that I must mean to value solid and devalue hollow). No such judgment was meant or implied.
ASers) in many situations. When I describe something unpleasant, such as a pain I am feeling, my voice does not carry an emotional charge recognizable by NTs. Just as I cannot "read between the lines" of NT conversations to "pick up on" the non-verbal signals that form, I'm told, 60 percent of NT communication, neither can I load my own speech with those invisible-to-me tonalities, backed up by body language, gesture, and who knows what-all (I sure don't!) that would convey my meaning exactly enough for NT comprehension. This can be a real problem when I am trying to tell a medical doctor how I feel in order to get the treatment I need. A few times, in extremis, I have had to resort to "acting out" (acting "hysterical") because I could see that my descriptions were too reasonable, too cool, too un-charged with the expected emotional overtones and, as a result, my problem was not being taken seriously.

When I try to tell someone I love what my love is like, I am heard as denying my love. The first reaction is likely to be, "Stop putting yourself down, Jane." That tells me I've totally failed, again, to communicate what I feel, how I think, and who I am. If I persist in trying to achieve communication, I am seen as not loving at all. The only other option I've found so far is to lie, pretend, and try to make my imitation of NTness extend from being my public persona into being a workable "private self." That's what I used to do, before I decided to stop attempting intimate relationships. The NT world says I'm a failure if I'm alone. But if I'm not alone, I'm not entirely myself. On the job, in the grocery store, doing things with friends, participating in political activism...my NT persona is functional enough in all those situations. Where it's not functional is within a relationship where I'm supposed to be sharing the deepest, truest parts of me.

A big part of being AS is experiencing life as a series of failures. Everybody fails now and then, at this and that. When the failures begin to form a pattern and that pattern has a name, a history, and a community, then, if you're lucky, the failures become material with which to analyze the why and wherefores. The failures become pieces in a jigsaw puzzle that shows an illuminating picture, once we get it all put together. Instead of failing to succeed as what you're not, you can start learning how to succeed as what you are--and how to deal with the fact that the rest of the world will continue to see you as a failure no matter what you do.

My emotional equipment works just fine, thanks. The fact that it works in ways that confound the expectations and assumptions of the majority does not mean I have no emotions or that my emotional reactions, as different as they may be, are "wrong." In some ways, my atypical "wiring" works better than the standard model. Nonviolent tactics are easier for me than for many people, because I do not react with fear or hostility to physical aggression. My emotions (especially anger) sometimes get out of hand, it's true, but my intellect is firmly and calmly in control in many situations where NTs are "losing it" all around me. That's not bragging, it's simply an observation based on experience. Similarly, my anarchism doesn't have to struggle against some of the tendencies or temptations that afflict many NTs. "Belonging" has no charms for me, and I am immune to what C.S. Lewis called "that intimate laughter between fellow professionals, which of all earthly powers is strongest to make men do very bad things before they are yet, individually, very bad men." I'm also obsessively punctual and a perfectionist in my work, which makes me a valuable employee and a real pain in the ass for those I work with on political projects.

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7 The best available description of AC-style emotions that I know about is an autobiography written by Edgar Schneider. Although he and I are very different in many ways, I share his style of emotional wiring. Discovering My Autism : Apologia Pro Vita Sua (With Apologies to Cardinal Newman), by Edgar Schneider (Jessica Kingsley Pub, 1999); ISBN: 1853027243.
Thoughts on Finding Myself Differently Brained

Neuro-diversity

One thing we humans all do have in common, as far as I’ve been able to tell, is the experience of alienation. Everyone has times when s/he feels a split between what’s inside and what seems to be required by the outside environment. Most of us, for example, don’t behave in quite the same when we are out applying for a job as we do at home. We “just know” (unless we are AC) that some behaviors are okay here but not there. I think all of us benefit from the chutzpah of the people who deliberately challenge social rules about what is "acceptable." The number or extent of situations and personal attributes that cause us to feel alienated is whittled away by such challenges. Although I’ve never participated in a gay "kiss in" (and never will), I can see the value of making gay public-displays-of-affection as visible as those between people who happily define themselves as opposites. I won’t ever cut my hair in a mohawk, either, nor am I likely to buy myself a man’s suit to wear. But I think my way through public space is eased by women who extend the boundaries of what people get more or less used to seeing in our shared geography.

Similarly, I think all of us (humans) will benefit when our societies acquire a wider appreciation of neuro-diversity. The assumption of neuro-universality is very like a form of ethnocentricity. If an anglo person says of another English-speaking person, "She has an accent," that anglo person is assuming her own accent is what’s "right," the standard against which all others are measured. As Amoja Three Rivers points out in her pamphlet "Cultural Etiquette: A Guide for the Well-Intentioned" (Three Rivers, 1990, p. 11), "Everyone speaks with an accent." Three Rivers recommends the following as one step in converting etiquette into understanding:

Examine what you regard as your own culture as if you were a complete stranger to it. If this proves difficult, find a few people who do not share your values. Ask them to describe your culture to you. Keep quiet and pay attention. Privately imagine yourself to be someone who considers herself different from you. Spend a day seeing the world as they do.

A researcher named Carol Gray helps parents of AS kids get a kind of backwards look into NT society. NT people, she notes, take for granted a great many social skills that AS people lack as kids and must acquire, if at all, through a difficult, conscious learning process. No wonder we don’t perform those social skills as well, and no wonder we sometimes need to make adjustments in our relations to NT society. Temple Grandin (Grandin, 1995, p. 139), probably the most widely known and successful autistic person of the day, writes of herself: "I know that things are missing in my life, but I have an exciting career that occupies my every waking hour. Keeping myself busy keeps my mind off what I may be missing."

Some of what we may be missing, those of us on the autism spectrum, is the ability to adjust to sensory assaults other people accept as normal. We may need to have information presented to us in a different way. Some things may take us longer, or we may accomplish certain kinds of work faster than anyone else but be unable

8 I discovered this term in Judy Singer’s "Why Can't You Be Normal for Once in Your Life?" an essay about being on the autism spectrum and moving "from a 'problem with no name' to a new category of difference." She says of "neuro-diversity": "I'm not sure if I coined this word, or whether it's just 'in the air,' part of the zeitgeist."

9 People on the autistic spectrum must learn through studious application all of the stuff that NT people "just know." This learning is especially tedious because we also tend to have difficulty applying what we’ve learned in one situation to a different situation. I still have trouble with this at the age of 48.
to explain why or how. Our strengths and weaknesses are likely to be unusual when compared to the social norm, and sometimes that will cause us problems in working and living comfortably with those who think the norm should be good enough for everybody. (I'm reminded now of people--and there really are some!--who think a building is wheelchair accessible because there are "just a few" stairs between the sidewalk and the door.) If people on the autism spectrum all "came out" and worked towards increasing institutional flexibility to the point where our "special needs" could be accommodated, the world would be a much more comfortable, less alienating place for everyone else as well. Such a world would be one where the individual got to decide whether the lighting in the workplace was impairing her ability to function. Where bosses would be expected to negotiate with employees the manner in which information and orders were exchanged. Where "the market" would not enforce the notion that being part of a romantically-based couple was the way to become "adult." Where seeking assistance with certain aspects of daily life was not seen as an admission of incompetence. Where it would be as normal for children to have different learning styles as it is to have different colors and textures of hair. Where everyone would "have an accent."

Not everyone on the autistic spectrum is going to "come out" in the immediate future. Not all of us can afford to. One reason I wanted to devote time and energy to writing this essay, though, is that I needed to do some thinking about my own situation. I have it much easier than many of my AS/AC internet friends and acquaintances. For a number of reasons, my upbringing was more friendly to someone growing up "odd" in a society where reactions to oddness range from scorn to hatred. I had a lot of cushions, and I always felt accepted by my family. They gave me a very good start, and my mother continued to help me in many ways until she died in 1995 at the age of 80. (For one thing, she taught me how to help her, too.) Either because of my "environmental" good fortune or because of how my brain developed its helping of genes and chemicals, or because the one reinforced the other, I am less severely affected by AS in daily functioning than are many others. My life might look strange to most people if I let them see what it's really like, but I manage to "pass" as normal or nearly-normal without exceeding my reserves too often.

Nevertheless, I am bothered by the fact that one element keeping me (and lots of others) from "coming out" universally about our place on the autism spectrum is the way society withholds legitimacy from experiences that are not officially reviewed. It's hard enough for people to grasp the distinction between psychology and neurology (hence the continued existence of the "blame the mother" school of thought about autism). If you want someone to make that shift in their thinking, you'd better have some "proof" to offer. Why should they expend the energy if it's all just a bunch of hot air? Without the "legitimacy" of an officially bestowed diagnosis, I pretty much just have to suck it up when people mis-read me and my life. I can't give (or expect them to have time for) an explanation based on "nothing but" my own experience, research, and exploration with others.

Or can I? Maybe this is a way to work towards another kind of shift: of notions about expertise. With the pooling of experiences and information on the internet, maybe we can begin to develop a new set of expectations about who knows what, and how much different kinds of knowledge are worth. Instead of top-down expertise, we can exercise bottom-up expertise. Sounds good to me, from my point of view.

P.S.

I wrote this essay in 1998. About 18 months later, in autumn 1999, I met with a doctor at the Oregon Health Sciences University who confirmed my self diagnosis.
Works cited

