

Cultural Commentary: Up in the Clouds and Down in the Valley: My Richness and Yours

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This piece is dedicated to the late Harriet McBryde Johnson, who encouraged disabled people to write not only about the joys we share with non-disabled people, but also about the joys unique to our own types of bodies.

There are so many injustices, large and small, that affect autistic people. None of them are divorced from the injustices that happen to others. None of them are unique. Autistic people are not a special kind of people set apart from all other people. We are just one of many kinds of people, and oppression and injustice take depressingly familiar shapes. My task here is to scale the cliffs of language and shout up to you the pattern of one or more injustices.

Wheelchair accessibility is one that — while seemingly small in comparison to others — galls me the most on an everyday basis. If the powerful people in a society build everything around them, and the powerful people are not wheelchair users, then a wheelchair user will likely face a particular and awful difficulty. We find that no matter where we go, the very structure of the environment excludes us. Counters are too high, staircases abound, curbs end abruptly, ramps exist only in a few places, drinking fountains remain out of reach, and so on and so forth. Despite the fact that few people had the express intention of excluding us, the end result is what Cal Montgomery (1987) (in an essay about more than just wheelchair access) has referred to as "physical and social customs that seem almost designed to shut me out."

What I most want to talk about, however, is language. Like counters, stairs, and drinking fountains, language was built mostly by non-autistic people, with the obvious results, and my biggest frustration is this: the most important things about the way I perceive and interact with the world around me can only be expressed in terms that describe them as the absence of something important.

The absence of speech. The absence of language. The absence of thought. The absence of movement. The absence of comprehension. The absence of feeling. The absence of perception.

Focusing on absence is the easiest way to describe the presence of something much more important to me than what is absent. Many autistic people have even applied these words to themselves. Some of us do this knowing full well that there is so much more that we cannot say. Others are fooled by the language itself into a state of "Nothing to see here; move along now."

What I am writing here is highly personal, but it is not unique to me. I have heard similar sentiments expressed by other autistic people, though they are not universal by any means. I should not have to say this, but in a world where an autistic person's viewpoints are likely to be shoved into the twin oblivions of "But we're not all like that!" and "Thank you for showing me The Autistic Experience TM", it has to be said. Also, try not to assume anything based on what I say. The only one who has seen enough of my life to make definitive statements about what it is like is the cat sleeping snuggled against my right shoulder. She has lived with me day and night for a decade. Check your stereotypes about functioning levels at the door. Sometimes I feel like my writing is smothered by endless disclaimers, but I know that without them my readers' minds will likely be smothered by endless stereotypes.

Jim Sinclair (1987), who is autistic, intersexed, and asexual, wrote a school essay on xyr personal definition of sexuality. It reads, in part (bolded emphasis mine):

Sexuality is when someone tells me that I'm not whole, that my personhood is incomplete, that a relationship in which I give everything I have is not "full." It is hearing that because I have no sexual feelings, I have no feelings; that because I do not feel love in my groin, I cannot feel love at all. **It is when someone who has not even bothered to look at my world dismisses it as a barren rock.** It is being called inferior to "someone who is human." It is the denigration of my experiences, my feelings, and my self. **It is when my unique faculties are thrown back at me as hopeless inadequacies.** Sexuality is reproach.

Substitute language for sexuality and you get closer than any other author I have read to how I feel when my deepest and most profound experiences are described purely as the lack of language, the lack of thought, even the lack of a soul.

Even when they are technically accurate in some sense, to use these words as the main way of describing my experiences is like using them as the main way of describing a Beethoven symphony. "Misleading" is the most polite word I can think of for this practice. And yet, while we have many words to describe a classical symphony, we have few words to describe the ways in which so many autistic

people's minds interact with the world around them. Here are the few words I can manage. I say this not as some kind of self-narrating zoo exhibit, but rather as a political statement in the face of a language that denies my reality at every turn. This is an experience, not a theory, and it is not intended to uphold any theories I have heard, even the ones that sound similar to it. It is an attempt to describe an experience that has been all but erased in the literature on autism.

My long-term memory — like that of many autistic people I have run across — begins when I was very young. My first memories involve sensations of all kinds. Colors. Sounds. Textures. Flavors. Smells. Shapes. Tones. These are short words, but the meaning of them is long, involved, and complex. Some things caught my attention, others did not, but all of them were absorbed into my mind. It is hard to explain to another person the patterns of perception that come before the ones they themselves have. Unless your brain is unusually wired, I doubt you have ever — even in infancy — perceived things the way I most readily perceive them. I don't doubt that this is the reason most people view my way of perceiving the world as an empty hole rather than every bit as rich and beautiful as their own.

These sensory impressions were repeated long enough for me to become deeply familiar with them. This familiarity resolved into patterns that formed the basis for more patterns, and — to this day — all of this continues to form the basis for how I understand things. When I say patterns, however, most people think I mean categories. I don't mean categories in any usual sense. I mean things fitting together in certain ways, outside of me. I mean perceiving connections without force-fitting a set of thoughts on top of them. This is how I handle not only sensory impressions but language itself. This is why I was able to work out which words go with which responses long before I was able to work out the meaning of the words and why — to this day — my ability to fit words into familiar patterns outstrips my ability to understand the words themselves.

Conventional language, however, is based on categories rather than patterns, and it poses a great nuisance to me because of this. If I were merely a speaker of a foreign language, then I might be able to find ways to translate between my system of patterns and another's categories, but as far as language goes, I am something closer to a speaker with a foreign brain.

Most children are already forming things into language-like categories and are thus able to understand the meanings of some words before they're able to use them; however, my first memories of speech involve not only no understanding of the meaning of words but no understanding that words could even have meaning.

I could understand tone, though. This may contradict people's view of autism, but I have observed that many autistic people have trouble interpreting tone of voice simply because they're busy working out what the words mean. Even Temple Grandin admits that she can either hear the tone or the words but not both. I more often hear the tone rather than the words, that's all. On the occasions where I do

understand the words, I can't juggle the tone at the same time. I once met an autistic woman who could sing out the tonal aspects of a conversation without saying a single word, and I understood her precisely because that is how my mind most readily processes conversations.

I can also understand the way strings of words go together with other strings. A simple example is an exchange like "thank you" and "you're welcome." You don't need a great grasp of the meaning of the words to figure out that particular pattern. But I have an extensive and complex map of all kinds of much longer patterns and the situations they go with. Much of this map was developed prior to understanding a single word of English, and while my understanding of words was much delayed, my maps of word patterns continue to flourish far ahead of my receptive vocabulary. This is the reverse of how it normally works, but it's reasonably common in autistic and hyperlexic people from what I'm told.

Language patterns, however, are merely the tip of a larger and far more interesting iceberg. Everything I perceive — from the movements of my body to the smells in the air — goes into my mind and sifts itself into similar kinds of patterns. Some of them correspond to what other people are usually aware of, and some of them don't. I consider these patterns and connections to be more my language than the words that appear on the screen when I let my fingers use the keyboard. And far more my language than the words that have popped out of my mouth throughout my life. They are how the world makes sense to me. Anything else is just the artifact of a shoddy translation.

I also have many forms of communication in addition to, or instead, of language. I have a body language that some others — usually autistic people — can understand. I have the way I interact with things around me at a *particular* time, compared to how I usually interact with them. I have ways of arranging objects and actions that give clues about where my interest is directed and in what manner. I can tap out rhythms in general or those of my favorite numbers. (I really like the rhythm of seven, for example.) I can speak Feline about as well as anyone with my limited human senses.

Not all of these things communicate everything that typical languages communicate, but I don't see any reason they should have to. They are rich and varied forms of communication in their own right, not inadequate substitutes for the more standard forms of communication, and like all forms of communication, some parts of them came naturally to me and other parts I had to learn. Having to learn them doesn't make them any less real or significant than someone's native language, which they had to learn in childhood.

To me, typical language takes place in the clouds, and I have to climb or fly up there just to use and understand it. This is exhausting no matter how fluent I sound or how easy I make it look. The sky will always be a foreign country to me. Sometimes it feels more like I am throwing words up into the clouds but am too

wiped out to fly up or even look up with a telescope to figure out what is going on there. To use my more natural means of communication, I don't have to leave the ground at all.

What has come as a surprise to me is that no matter how consistent I am on the ground, many people measure me by my ability to hurl myself into the sky, whether with respect to language or some other fleeting and insubstantial thing that my body does. So, if I have a certain level of expressive language, then I am expected to comprehend things even if I don't, and if I lack a certain expressive language, then my entire world is supposed to be empty and meaningless.

Another related issue is what most people call thought: the juggling of many layers of symbol and abstraction. As far as I'm concerned, this all takes place in the sky as well. The kind of thought that is right in front of me are the patterns and connections I have described already, but most don't consider these things thought. The reason for this seems to be that people have in mind one thing when they think of thought. They expect thought to take place with a good deal of cognitive fanfare, so that they can hear or see themselves thinking. They expect it to involve abstract and arbitrary symbolism of some kind, and they expect it to reflect back on itself. They don't expect thought to take place so quietly they can barely notice it's there — if at all. They don't expect the much more direct relationships, connections, and patterns formed between one thing and another, and they probably rarely get enough of a break from their louder thoughts to notice any quieter thoughts moving through their minds. But that is how my best thoughts — the thoughts I am most at home around — work. The loud over-thoughts in the sky are nerve-jangling and overloading, and the quieter under-thoughts eventually show me the things I care the most about.

I am telling you these things not to instruct you on the particulars of the mind of an autistic person, but rather to sketch out an image of how I perceive the world, and the richness and worthiness inherent in those ways of perceiving. It is anything but empty, and it is so much more than a simple lack of something that other people have.

When I do scale the cliffs of language, people react to me strangely. They have lived on a mountain so long that they've forgotten the valley I come from even exists. They call that valley "not mountain" and proclaim it dry, barren, and colorless, because that's how it looks from a distance. The place I come from is envisioned as the world of real, valid people minus something. I know, of course, that the valley I live in is anything but desolate, anything but a mountain minus the mountain itself. There are all kinds of trees, many of which can't grow on the mountain. I splash in the creeks, and the smell of the rocks is vivid. I roll on the ground and the smell of the soil is dark and satisfying. Each experience is like a new rainbow for every sense, and each thing fits in a pattern such that I can perceive everything else around it. Of course, the mountain offers a set of experiences, too. Some of them are the same as the valley's, but some of them are

totally different. It's hard for me to climb that mountain all of the time though, so they are more rarely my experiences than those of others. Still so many people from the mountain describe the valley only by what is not there, and that is not anywhere near a thorough enough description.

Someone once saw a photograph of me and said that he felt sorry because I would never know the richness of life that he knows. But I wonder if he is capable of looking around and seeing shapes and colors instead of objects and of mapping the patterns of those shapes and colors. I wonder if he understands my kind of beauty or only that which comes from a different sort of perception: more filtered — perhaps in some ways more efficient — but irretrievably blocking out many things before they hit consciousness. I wonder if he understands the dance of waiting for "launch windows" to line up to make actions possible, and all the things that happen while waiting on the ground for the next "launch window" to open up. I wonder if he understands that with any pain that comes from jerking-around fluctuations also comes a rhythm and beauty. I wonder if any of this makes sense to him.

This is about what is, not what is missing. Forget the notion of a cosmic balancing act where a god of impartiality runs around taking things away but giving one gift for every sacrifice. It is about the fact that those of us who are viewed purely as having had things taken away — as being essentially barren wastelands — are not shut out of the richness of life by being who we are. The richness we experience is not some cheap romanticized copy of the richness others experience. The richness of life is there for everyone, and whether one experiences it or not is not dependent on whether or not one is autistic.

As someone whose cognitive and physical abilities vary widely from day to day, and moment to moment, I know that this richness is just as present when I lack the capacity to differentiate one sensation or moment from another as it is when I am engaging in complex thought. It is just as present when I am fully immobilized as it was when I am rocking back and forth and rapidly typing on my computer. It is just as present when I have seizures every few seconds as it is now when I am virtually seizure-free, and just as present when I am 'bedridden' with pain or fatigue as when I am active and mobile.

The problem with people quantifying that richness is that they completely forget it is infinite compared to the broadest of humanity's finite capacities. A similar problem happens when people try to quantify personhood. The richness I experience of the world is not merely a more limited version of other people's experiences. My experiences have their own richness that other people may not be able to see, and they are far more than a mere lack of movement, conventional thought, speech, language, or perception. But conventional language only allows me those terms, so I have done my best to point out the enormous and beautiful world of experiences that lie between those words and beyond the limits of a language never equipped to describe them.

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