THINKING PERSON'S GUIDE TO AUTISM

Autism news and resources: from autistic people, professionals, and parents

Wednesday, April 20, 2016

Sensory Access Needs Are Human Rights

TPGA is observing Autism Acceptance Month by featuring accounts from autistic people about the differences accommodations (or lack thereof) make in their lives. Today we are featuring a Q & A with **Sara M. Acevedo**, discussing how her well being depends significantly on not being exposed to scented products, yet how infrequently those accessibility rights and accommodation needs are taken seriously, viewed respectfully -- or met.

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[Image: Black-and-white photo of a ponytailed white woman in profile, inside a mist/gas cloud.]

Sara M. Acevedo
sacevedoespinal.wix.com/neurowitching

TPGA: When you need to enter a new room or meet new people, what are some factors you have to worry about?

Sara M. Acevedo: Before attending an event, coming into a new meeting space, or a new social space, there are some things that are not simply relevant, but actually **vital** for me to consider: Among other external factors, my priority remains the exposure to chemical and so-called 'natural' scented products and fragrances (including perfumes, body lotions, deodorants, and hair products among others), as they represent a hazard to my overall well being. In this sense, both the physical/physiological and the psychological/ emotional aspects of my being are impacted negatively by the exposure to scented products.

At the physical level, exposure to these products causes me insufferable migraines, as well as nausea, vomiting and dizziness.

At the psychological and emotional levels, I feel debilitated and exhausted from constantly being forced into positions where I either have to expose and justify my sensory needs, or to educate my non-disabled peers on the concrete causes and effects of chemically induced 'poisoning.' By the same token, I feel isolated as my efforts often result in my peers labeling my sensory experience as 'petty' or my needs as 'inconsequential.'

The truth is that for many people, short-term exposure to chemical products represents a tremendous health hazard due to low to high grades of poisoning resulting in skin rashes, eye irritation, severe migraines, nausea, and vomiting, as well as asthma attacks and even

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respiratory arrest. An array of scientific studies demonstrates that, in most cases, the root cause of these responses to chemical-product poisoning is primarily neurological, and that sensory accommodations are as valid as other forms of access accommodations.

Having said this, I argue that no amount of scientific data should trump embodied testimonies coming from people in our various disability communities -- our sensory access needs and accommodations are not acts of good faith or favors, they are our rights!

TPGA: What can happen to you, if you aren't accommodated?

S.A.: Chronic migraines are a part of my lived experience. I have lived with migraines for as long as I can remember -- all the women in my family suffer from severe pain caused by the chronic inflammation of the hundreds of small blood vessels in the brain.

Chemical scents and fragrances are some of the primary triggers of migraines for me. The root cause of my migraines is indeed neurological. In the past, denial or delay in accommodations around my sensory needs has resulted in prolonged migraine crises. Long-term migraines can and do disable my executive as well as cognitive functions, causing me to miss consecutive days of work and school. In addition, my emotional well being is also compromised due to the feelings of extreme vulnerability and frustration caused by consecutive days of severe pain. From a capitalist/productivity lens, my absence cause little to no inconvenience to an employer; from a human dignity lens, I am left to suffer the material consequences of a social world that remains unaccepting of our embodied experiences as valid and legitimate manifestations of human difference.

If my coworkers/classmates cover themselves in perfumes and colognes and or spray their offices with air ‘fresheners,’ or attend enclosed spaces wearing scented body lotions/deodorants without care for the concrete impact that those products have on my overall well being, I am likely to feel (and have felt) unwelcomed and isolated from my own work space.

If on the other hand, my employer places obstacles and barriers to something as simple as removing high fluorescent lighting sitting directly above my desk (because it represents a ‘safety hazard’) while simultaneously not allowing me to have a warm light system instead (as simple as a standing lamp), I am left with the message that my not only my presence is inconvenient, but also that my body is a liability.

TPGA: When you tell people about the accommodations you need, are they usually respectful?

S.A.: There is usually a sense of complete ignorance around what accommodations unrelated to wheelchair access (for instance) are also covered under ADA, the Americans With Disabilities Act. I am often addressed with questions touching on why I need those accommodations (in terms of ‘diagnosis’ or a medically certified version of my lived experience), as opposed to questions around how external factors such as fluorescent lighting or scents/fragrances affect my physical and emotional well being as a valued member of the community.

Others simply show ‘compassionate’ looks and/or words, only to return heavily scented the next day. I can certainly attest to the lack of care/interest/knowledge around these issues within able-bodied spaces. And, again, way outside the realm of medical diagnosis, our embodied experiences deserve to be valued and respected as they are and for what they are -- as we voice them.

TPGA: What are some simple ways to make more environments not just tolerable but comfortable for you?

S.A.: I wish there was a fabulously mysterious way to simply shake my nose and de-scent everyone as I enter public spaces -- Boom, neuromagic! This is especially so within enclosed spaces such as BART, where my experience of discomfort is much more heightened.

I think that to bring true acceptance around invisible experiences such as sensory sensitivities and needs, multiple voices and perspectives need to join in the conversation.

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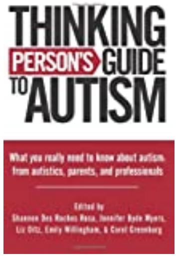

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Collective critical engagement with and action around these issues can lead to concrete changes within the spaces that we inhabit in our everyday. How much more could I accomplish in this fight, if my voice were not the only one? If at each turn, someone else decided to show up unscented to a shared space? If at each turn, someone confronted the use of heavy scents and created mindfulness about entering elevators, and other enclosed spaces? If at each turn, someone would show up for people who remain quiet about their identities and shared a bit of information about the effects of chemical products in libraries, for instance? What would happen if we started by reflecting on how our own individual hygiene practices can potentially affect others in the train, on the bus, in a crowded art gallery, at the office?

I think that ‘tolerance’ is a disingenuous way of engaging with the magic that is difference -- it limits us to think that things ought to remain as they are, for there would otherwise be ‘chaos’-- as if there were no room for the wonderful world of the unfolding within chaos. I think that feeling comfortable for me includes being recognized, being validated, and being valued fully for the person that I am.

Currently, I often continue to be received as an inconvenience within able-bodied spaces. I am convinced that as long as the dominant majority continues to see different forms of embodiment as a liability or as a threat to able-bodied comfort, things won’t start shifting. I will not feel comfortable, even if I am accommodated ‘because the law requires it so,’ until my sensory experience is valid and accepted, as opposed to systematically challenged and devalued.

While I believe that policy is a necessary form of both conceptualizing and concretizing collective struggles for inclusion, access, and full community participation -- my senses also appeal to the very radical idea that different forms of embodiment and experiences are to be valued and amplified without the official boundaries of social institutions -- as an act of mutual recognition and respect.

Posted by Shannon Des Roches Rosa on Wednesday, April 20, 2016

Labels: acceptance, accessibility, accommodations, autism, autism acceptance, autism acceptance month, autistic, chemical sensitivities, migraine, nausea, rights, Sara M. Acevedo, scented products

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Sarah Longstaff · *90 weeks ago*

Thank you for this! I had to quit a job because of scents. For me it's "allergy" type symptoms--everything swells up, from my lungs, larynx, eustachian tubes, sinuses, eyes. I itch. I didn't know it could be neurological. Then my daughter was diagnosed autistic and my son with migraines. As an adult, it's hard to get diagnosed with sensory processing disorder and autism, but I'm working on it, because I would like to go back to work and get a job some day! Thanks for speaking up!

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