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Autistics.Org and Finding Our Voices as an Activist Movement

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Deep Origins: Martin Luther King Jr. and the Fair Housing Campaign

Many have said that the first explicitly political act that emerged from the autistic community was the website autistics.org. A few people have said that I, as the founder of autistics.org, am the founding mother of autistic activism.

That's not true. While the community, at the time of the founding of autistics.org in 1998, was oriented toward support groups, political activism was in the air. Some persons active at that time, notably Cal Montgomery, had roots in the broader disability rights, psychiatric survivors, and developmental disability movements, and were posting cogent political positions on Listservs, Usenet, and other now almost forgotten corners of the internet before autistics.org was even imagined. Nothing arises from a vacuum, and neither did autistics.org.

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But if it is necessary to give credit to just one individual for the founding of autistics.org, I know who that person is. The true founder of autistics.org is Dr. Martin Luther King Jr. and he founded it in Chicago in 1966.

In 1966, Martin Luther King moved to Chicago, to lead a housing desegregation campaign. Dr. King was not then seen as the harmless and mostly fictional figure we venerate today. He was a radical agitator, hated and feared by most white people, and considered a criminal and likely communist by the government. The difference between MLK Jr. and more “radical” figures like Malcolm X and the Black Panthers was one of tactics, never of content, and no one during his lifespan doubted or watered down his militancy.

I was nine years old. The Chicago neighborhood I came from, Marquette Park, and the suburb we’d recently moved to, Evergreen Park, were targeted for desegregation marches that summer. People in the neighborhoods were terrified, and many of them prepared to “defend” the neighborhoods, with rocks, bricks, and baseball bats. When the Archdiocese of Chicago announced (in response to the campaign) that it would begin busing African American students to desegregate my school in the fall, violence and threats of violence against African Americans reached near wartime intensity. A house, a few blocks away, was burned to the ground amid rumors (probably false) that it had been sold to an African American family. And gangs of teens had begun patrolling the local mall with baseball bats, seeking out African Americans who dared to go shopping in a white neighborhood.

It was a time when virtually every family watched the 6 p.m. news together, and so I knew about the civil rights movement and the growing anti-war movement. I had not yet formed an opinion about current events, or even an opinion that I should have an opinion. All of it had seemed like stories of faraway events unrelated to my life, told on a 12" black-and-white cathode ray tube in the kitchen.

But during the tumult of that summer, a pattern was emerging. The same persons who were carrying out acts of violence against African Americans were also the worst of my bullies. The few brave families who dared to volunteer as host families for African American kids about to be bused to my school were also among the few who were kind to me, the weird crazy kid in the neighborhood. I did not yet understand much about these

issues, but I knew which side my enemies were choosing. I knew, therefore, which side had to be my side.

I understand racism is not the same as bullying, any more than ableism is bullying. Most of the methods any -ism uses to maintain a power differential between the privileged and the oppressed are subtle, hard to name, and even harder to prove. Many of the methods are baked into the way things are done, so that they can't be uprooted without questioning fundamental assumptions about how the world should work. But in the end every -ism will resort to overt violence, if it must, to maintain itself. The pattern I saw as a kid came about largely because the worst people are inclined to poly-bigotry: they hate everyone not evidently of their own kind.

My Activist Past

Over the course of the next few years, activism became my perseverance and my social crutch. I was awkward and fearful to the point of panic in most social settings, but as an activist I could talk to anyone, speak to any crowd, and act fearlessly. I organized my high school's underground newspaper. I became involved with the Chicago area working-class youth movement *Rising Up Angry*. I read book after book of left-wing theory, identified as an anarcho-syndicalist,¹ and joined the radical syndicalist union, the Industrial Workers of the World. I protested against military recruiters at my high school, I distributed leaflets for the defense committee for the imprisoned African-American anarchist activist, Martin Sostre. I picketed for the United Farm workers union, and I sat on the train tracks in Colorado to shut down the Rocky Flats nuclear weapons facility. I came out as a lesbian in 1974 in my first year of college, and I plunged myself into lesbian and gay politics because, even if I hadn't a clue how to meet women, I did know how to promote political causes. When I was engaged in activism, I was almost normal, or at least I was useful enough for the cause that my shortcomings could be overlooked.

¹A left-wing anarchist who sees revolutionary industrial unionism as the means workers can use to overthrow capitalism.

I was less functional than frantic, less social than busy, and everything I did was as much crushing as it was a social crutch. Sometimes the stress won. Sometimes the weird screwed up everything.

I had a secret. It wasn't much of a secret, but I did my best to hide it. I was a childhood schizophrenic—a crazy person. One of Bruno Bettelheim's² former students had said so. It was a time I wished I could forget but never could. A very bad time, imprisoned in a very cruel place. I knew that crazy people, too, were organizing, and I supported what they were doing, but I did not want that label around my neck because I wasn't crazy, not the way they said I was. I didn't see anything or hear anything and I knew perfectly well what reality looked like. But I wasn't normal. I couldn't hold a proper conversation, or have a girlfriend, and getting a telephone call—not the content of the call, the mere fact of its ringing—could turn me into a blithering panicked mess. A lot of things could do that. I was always on the edge of panic. It was during one of my falling apart times in college, when I could not avoid the open secret that I was dysfunctional, that I came into contact with the office of students with disabilities and, from there, the disability rights movement.

Finding Out About Autism

Fast forward decades later: Though the activism of the 1960s and 1970s had faded, I was still a committed activist. Activism was no longer a crutch, but an ethical commitment, to right what was wrong and to side with the weak against the predations of the strong. I was much more content as a human being, much less stressed, though the weird was never far away. I could answer telephones though I hated them and occasionally destroyed them in frustration. I even figured out how to get into relationships, more or less, though I had no idea how to sustain one.

In the mid-late 1990s, on the early World Wide Web, search engines were absent or limited in power. It was customary to perform a search

²Bruno Bettelheim used fraudulent credentials to misrepresent himself as a psychologist and to obtain an academic position at the University of Chicago. He was exposed for plagiarism, false credentials, and abusive treatment of students after his death in 1990.

by finding a website about your subject matter, then to follow links from website to website until you found what you were interested in.³ What I was looking for that day was electronics parts. Several jumps into the search, I found a home page with a number of useful links, plus links to something even more desirable than electronics: data I did not know.

I love to collect information. If I let myself, I'd spend the rest of my life collecting new facts. So after I explored the links to electronics parts companies, I clicked back to the website where the author had said he had a syndrome I'd never heard of called Asperger's Syndrome. The link led to a website created by a parent of a child on the autism spectrum. I read on...

*So that was what I was*⁴

I plunged myself into the early autistic community, which was spread out over two mailing lists, a few Internet Relay Chat (IRC) channels, Usenet, and a scattering of websites. The focus of the early community was largely self-help. But I, like Cal before me, could not help but apply political analysis to our circumstances.

Political analysis is about power: understanding who has it, who doesn't, how the powerful have taken power over others, and how those rendered powerless can reclaim it. Once you learn how to understand injustice in political terms, you cannot help but apply political analysis everywhere you see human suffering. The skill set works nearly everywhere, because nearly everywhere, when you find a group struggling against disadvantages, you find the same dynamics.

Autistic persons are disadvantaged almost from the moment of birth. Our power to determine the direction of our lives is taken by presumptions about cognition and perception that simultaneously ignore our abilities and make unreasonable demands upon our disabilities. We are rejected by our peers, whose bullying is not merely tolerated, but encouraged, by adults, who themselves may join in the bullying. We are often rejected by our families, and many of us are murdered by them. We are placed into schools and institutions whose very purpose is to wipe us of our identity,

³The Web was a much smaller place then, so this was not as impractical as it would be today.

⁴Later I sought a professional opinion, and the professional thought my childhood development was a closer fit to PDD-NOS. According to the diagnoses of the day. Whatever. We are all Autism Spectrum now.

and whose every “treatment” and “care” is an act of violence against who we are. If we do find work, we are target number one for workplace bullying, and for being fired for autistic traits, regardless of our performance. We are first to be targeted by criminals and among the first to be targeted by police, at least in the US, where every year unarmed autistic people are among those shot by police, and where autistic people are so often stopped while going about our business we have taken to calling this the crime of “walking while autistic.” We are more likely to be the victims of violence, yet we are portrayed in the media and by charities “raising awareness” as dangerous perpetrators of violence. Above all we are isolated from society at every stage as the odd, the weird, the other.

But no matter the exact life path we find ourselves on, oppression comes down to others holding or aspiring to hold undue power over us. Oppression is always the same story, and the same struggle, of the powerless against the powerful. “Injustice anywhere is a threat to justice everywhere” wrote the Great Agitator, King [1], “We are caught in an inescapable network of mutuality, tied in a single garment of destiny.”

What Led up to the Creation of Autistics.Org

I joined the mailing lists and IRC channels where the early online autistic community congregated, including the main mixed parent and autistic IRC channel, #autism on Starlink IRC. There I came into conflict with a few parents over the patronizing and often demeaning way autistic adults were treated in the group (I was, after all, in my 40s, older than many of the parents who patronized me). When I circulated a petition requesting that one parent be removed as an operator for his open hostility toward autistic people on #autism, I was banned from the channel. So I started my own channel for autistics and parents, #autfriends.

#Autfriends quickly becomes a popular channel. In response the owner of #autism approached the owners of a channel for autistic persons and persuaded him to order me to close down #autfriends and tell everyone to rejoin #autism. When I refused, pointing out that he had no authority to give me or anyone else any orders outside of his own channel, and stating again that management at #autism tolerated open abuse of autistic people,

the autistic channel owner banned me from his channel and mailing list, and sent the log of that private conversation to the IRC operators at Starlink IRC, possibly through the owner of #autism.

Never fear an opponent who goes too far. It is at times like this, when one's opponents overreach, that they grant you power, much as when an attacker lunges at a judoka, the force of that attack becomes the power the judo player can use to defeat the attacker. Almost every time a political action I was involved in had succeeded, it had been in part because of gross overreach by the other side.

This attack on #autfriends gave us the moral power and the outrage to create autistics.org. And of course, #autfriends reopened within minutes of the ban on Dalnet, because trying to ban an idea from the Internet is one of the more futile acts imaginable.

Sometimes It Is Allies Who Work Against You

I do not want to go into too many details about the autistic persons who worked with #autism to try to destroy us. I have no reason to stir up ancient conflicts with people who are still around and active in their own ways. No matter what the disputes are between ourselves, it's important to keep one's focus: we are not our own enemies, to be fought to the death, and no one is free from mistakes. What remains important about that incident is the truth that when one takes a stand for what is right, it is often against the objections, not just of your enemies, but of your allies.

Anyone subject to injustice is rightly fearful. It seemed to be a miracle enough that autistic adults with the means to access the net were breaking their isolation and talking to each other. The autistic community was young, small, and fragile. It is understandable why anyone who had been through what we had endured might not have wanted to take any chances, however remote, that this thin connection to humanity might be broken.

But you can't preserve a community by tolerating hostility toward it, and you can't fight injustice by succumbing to your fears. You have to learn to take a deep breath and will yourself past a pounding heart and sweaty palms to take your stand, to disrupt things as they are, and you have to have confidence in the power of truth. I had learned, over decades as an

activist, to overcome fear. My objectors had little experience as activists aside from, to their credit, playing an important role in the early autistic community.

I'd been attacked more than once for my political activism. I was one of a scant dozen LGBTQ activists picketing outside a nightclub in 1976 when a much larger group of hostile counter-protesters rushed the thin police line separating us. I've had local police look for any way to arrest me on anything, real or not (I survived, but one of my fellow activists at that time was framed with heroin possession). I've been knocked down and dragged out of a public meeting by an official who did not like my political cartoons, with the culprit slamming the door shut on my arm, hard, after he was done (and then was charged afterwards, though charges were dropped when the culprit bragged about what he did to the press). I've lost a job. I can't even begin to count the number of death threats I've gotten over the years. I'd even survived an attempt to set fire to my college dorm room.

In comparison, the attacks against #autfriends were silly, and there was never a question in my mind to persist. The only strong impression they made upon me was how, if I had been seen as a middle-aged adult, gray hair and all—in other words, the way I was seen in the real world—none of it would have happened. It would be seen as an outrageous violation of boundaries to order an independent adult not to express an opinion, even in private, on the Internet, as my opponents tried to do. But I was being treated as the defective child that so many of the regulars in #autism imagined autistic adults to be, and so in their minds there were no boundaries.

Letter from a Birmingham Jail was an open letter, not to enemies of the civil rights movement, but to supporters who objected to Rev. King's tactics. "History is the long and tragic story of the fact that privileged groups seldom give up their privileges voluntarily," King wrote to his critics who had argued for negotiations instead of protests. "Individuals may see the moral light and voluntarily give up their unjust posture; but as Reinhold Niebuhr has reminded us, groups are more immoral than individuals." Politely asking the operators of the Judge Rotenberg Center to stop torturing inmates will make little headway, as all of their interests, and that of the many other centers of power that oppress autistic people, lie in the direction of continuing to do so. But picketing the home of the

head of the US Food and Drug Administration to demand that shock devices be outlawed (as the disability rights organization ADAPT, in an action organized by Cal Montgomery, did recently) can begin to dislodge that evil. And before you can get to political action, you need to give voice to truths not spoken.

Autistics.Org

Autistics.org came directly out of this tumult around #Autfriends. It was envisioned as a compilation of support and resources for autistic adults, in contrast to providing resources only for parents of autistic children as #autism did. But, even as such a compilation proved too difficult for us at that time, inspired by the outrageousness of the attacks against us, speaking truths not spoken became our mission.

One of our more popular truth-telling sections was ostensibly a medical institute operated by autistic researchers, the Institute for the Study of the Neurologically Typical (ISNT). ISNT turned the tables on the dehumanization done to autistic people by autism researchers. Several contributors to that site picked apart characteristics of neurotypical individuals in the same patronizing, pathologizing, voice in which traits commonly held by autistic people are described, with feigned obliviousness to how such traits might also be useful, and no concession that neurotypicals might not be carbon-copy identical. The point of ISNT (if I can presume to speak for multiple authors here, though I do think this was a universal goal among us at that time) was to shine a light on how we are treated. Some people to this day take it literally as an assertion of autistic superiority, which leaves me wondering how deeply ingrained are their assumptions about our supposed inferiority, that they cannot recognize satire.

Understand, though, that I am not upset about claims of autistic superiority, even though I don't believe in anyone's intrinsic superiority. Every oppressed group struggles to reclaim a sense of intactness and worth, and phases where some members of the group claim superiority and even attempt to separate from the mainstream, "inferior," society are a normal stage in the reclamation of human dignity. We don't need to worry

about oppressed groups with little to no power singing their own exclusive praises, so much as we need to worry about the oppressors, people who have actual privilege and who wield real power, who drive oppressed people to that degree of exaggeration in search of their own worth and a little space where they can feel safer.

Another popular feature was the graphics we produced. One of my life's proudest accomplishments was designing the original "I am not a puzzle/I am a person" graphic with a human-shaped puzzle piece inside a red circle crossed with a slash—the "not" symbol used on road signs. The original still hangs on my living room wall. Every time I see this design reused, probably by people who know only that it is a classic image of the autistic civil rights movement, I am reminded that I do have children who will carry on the values I imbued them with long after I am gone: that graphic is one of my progeny.

We encouraged autistic people to write for our library, where we posted essays that did anything but reaffirm that we were defective children whose job it was to obey. It was in the library where we most clearly spoke truths that had not been often said: that almost all autism treatment is based on false models of autism, that the institutions that have grown up around autism engage in violence, sometime subtle violence, and often overt violence, against autistic people in order to obtain compliance, that parents are often part of the problem—that bearing an autistic child makes no one, *ipso facto*, a saint, and that actual parents of autistic children are, if anything, more inclined to engage in abusive behavior toward autistic persons than the average parent, as illustrated by the many cases where parents of autistic children murder their own children. Of course, there are also many allies of ours among the parents of autistic children. The point is that no one automagically becomes an ally by virtue of merely existing—if you want to be an ally of any oppressed group, and you have privilege, you have to choose to be an ally, educate yourself, and work at it. Just thinking that you deserve to be counted among the good guys is *always* insufficient.

The End of Autistics.Org?

I began this adventure in middle age at a time when I was beginning to have significant health problems, and aging is no friend of chronic health issues. Eventually I could no longer maintain the website. I put it first into an archived state, trying to preserve what was already there. Unfortunately over time even this has decayed, so that the domain autistics.org currently links to an empty directory and autistics.org lives on only at the wayback machine. I still have the files, and if I have the opportunity I will try to restore them. But I am looking for people who would like to continue what we started. I don't consider autistics.org dead, and I certainly don't consider the domain to belong to me personally (as you might imagine I've had many offers to buy the name from parent-led charities and commercial entities), but to the autistic community. Perhaps the domain autistics.org will rise again, under the leadership of a new generation.

During the years when autistics.org was actively maintained, we were anything but organized. Initially we tried to operate the website on shared hosting, but the volume of traffic got us shut down, more than once. So we moved the site to the cheapest dedicated server I could find. I tried (and sometimes failed) to manage the server, on the strength of having been an early adopter of Linux. Amelia (Mel) Baggs wrote prolifically for the website. Joelle Smith tried to make sense of the mess I sometimes made of Unix. Phil Schwarz was around from the beginning to nearly the end. Many others contributed, technically, financially, and through content. I apologize that I don't remember all of your names, and almost certainly there would not be space here to give everyone credit. Feel free to point to this article and tell others "I was there," because what you did changed the world.

We are tied in a single garment of destiny. Autistic activism is but one branch of an eternal great struggle, to set right what is wrong, to lift up those who have been pushed down, and to make space for joy in this world.

Reference

1. King M. L., Jr. (1963). *Letter from Birmingham jail*. Retrieved April 16, from https://wikilivres.org/wiki/Letter_from_Birmingham_Jail.

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