

Lessons for the environmental illness community from the LGBT+ struggle for acceptance and civil rights in the United States



There are many similarities between the early years of the LGBT+ struggle for acceptance and the plight of people with MCS or EHS. Here we describe the story and tactics used by the gay community to gain their civil rights. They showed great inventiveness and lots of persistence – an inspiration for the EI community.

Keywords: environmental illness, environmental sensitivity, chemical sensitivity, MCS, electrical sensitivity, EHS, civil rights, acceptance, activism

The story of how the LGBT+ community gained acceptance is instructive for the MCS/EHS community. As it still is today for people with MCS or EHS, the LGBT+ community was scorned by the media, ignored by the politicians and mistreated by the medical industry.

Gays and lesbians were falsely believed to be mentally ill, just as many still falsely believe MCS and EHS are mental illnesses.

When AIDS came along, it was thought to be a gay-only disease and ignored, just as doctors today ignore MCS and EHS. With no help from the medical system, the AIDS sufferers were left with the jungle of unproven treatments. Again, like those with MCS and EHS.

It was mostly gay physicians who were willing to try to help the AIDS victims, just as most doctors who try to help people with MCS/EHS have personal reasons to do so.

Anti-gay commentators claimed that talking about gays in the media could “recruit” people to that “lifestyle,” so it was best to keep a media blackout. There have also been anti-MCS commentary claiming people got MCS from seeing it on television.

The stigma forced many gay people to hide who they were, just as many people with MCS/EHS have to, if they can.

Mainstream civil rights organizations, such as the ACLU, were originally hostile to the LGBT+ people, or at least refused to help. Similarly, MCS/EHS activists have tried asking for help from disability rights organizations, and even the senior organization AARP, but simply been ignored.

And both LGBT+ people and those with MCS/EHS often become estranged from families and friends who refuse to accept them. They are often on their own, unless they can band together with their “own kind,” which can be quite liberating.

There are several other similarities between the early LGBT+ community and today’s MCS/EHS community, such as a focus on just getting along, as well as small, fractured and ineffective organizations.

The following story highlights all these similarities, and the lessons to be learned from their success. We use the term “gay” in the rest of this article, as that was the term used by the sources.

About the picture

The picture on the front page is from a Pride Parade in 1997. What this entry is about is unknown to the author.

The LGBT+ experience in brief

Until 1974, being gay or lesbian was officially a mental disease in the United States, according to the psychiatrist's bible, the DSM. In the decades before, gays and lesbians were sometimes even labeled as psychopaths. Some were forcefully confined to mental hospitals. Medical doctors subjected gays to electroshock, forced vomiting and other forms of failed attempts to "deprogram" them. These "conversion therapies" lacked any scientific foundation, and are today totally discredited.

Most gays and lesbians were deeply closeted. Even people with advanced degrees could not find employment in private businesses or government agencies if they were known to be gay.

There were closeted gays at all levels of society; if they were found out they were instantly dismissed. The armed forces even dismissed retired generals and admirals, who were stripped of their pensions.

Families commonly disowned their gay children.

Until the late 1970s, the media ignored gay people, except when referring to them as "deviants" and "child molesters" (even though gay people were not any more likely to molest children). It was common for gay people to think they were the only ones in the world feeling gay, and they didn't even know there was a name for it.

When television and film started including gay characters, they were portrayed as weird and child molesters, thus reinforcing the common bias.

Many states had sodomy laws that made it criminal to engage in the sexual acts used by gay lovers. The laws officially also applied to straight couples, but were not enforced.

The police occasionally stormed into people's private bedrooms when they knew gay people were having sex and hauled them off to the police station. More commonly, the police would raid well-known gay and lesbian bars or send in undercover cops who arrested anyone who propositioned them.

Gay people started to migrate to areas where other gay people lived, most notably the Castro District in San Francisco and Greenwich Village in New York. Being among their "own kind" meant they could breathe more freely, though the police in both cities was still hostile towards gays and frequently raided gay hangouts.

The state of New York had laws that banned people from dressing as the opposite sex, thereby targeting transgendered and queer people. Many landlords would not rent to LGBT+ people, and if they found out later they terminated the lease.

How did the LGBT+ community turn it around?

The first couple of small organizations started in the 1950s. Additional small organizations sprung up in the next couple of decades. The lesbian organization, Daughters of Bilitis was founded in 1953. By 1970 it still had only 1200 subscribers to its newsletter, and that was one of the largest organizations.

Most organizations focused on how they could all fit in unobtrusively in a hostile society, and did not really work on trying to improve the situation. A few “radicals” wanted to fight for civil rights, and were looked at disdainfully by those who just hoped to get along. People were apathetic about any prospect of improving the situation and most were afraid of being “seen” in the wrong company and perhaps lose their job.

Some people tried to work incrementally through the court system, but it was very tough. The judges had no sympathy for gay people, no matter what the law said.

There was no “LGBT+ community” yet. All the different factions kept to themselves and viewed each other with some suspicion. Gay men treated lesbian women the same way straight men treated straight women, i.e. as subordinate and with secondary needs. This did not go over well.

The Stonewall Inn riot

The Stonewall Inn was a popular gay bar in New York. On June 28, 1969, the police stormed the bar and hauled a lot of people to the police station just for being there. Such police harassment had happened many times before all over the country. The police was used to the gays meekly accepting being jerked around.

This time some sort of critical mass was reached. There were a lot of gay people both inside the bar and out on the street. The weather was pleasant. Suddenly someone decided that was enough and started shouting and resisting the cops. It fed on itself and a riot started. The cops fled the scene, with some of them barricading themselves inside the bar.

As news of the riot spread around New York, more gays came to join. When the police came back in full force, the throngs had swelled. The riot lasted three days.

The Stonewall Inn riot galvanized the gay community. They saw that they were not powerless after all. The memberships of gay organizations swelled across the country and they became more active at demanding their civil rights.

The day was celebrated with a march in New York the next year, and is now celebrated with annual Pride marches across the world.

The Alpine County prank

The press refused to talk about gay issues, unless it was spectacular enough to be considered “newsworthy.” In 1970 an activist in Los Angeles came up with an elaborate prank that briefly made the word “gay” a household word across the country.

He claimed hundreds of gays were moving to tiny Alpine County in California to take it over. If just four hundred gays moved there, they would be the majority which at the next election could vote in a gay sheriff, gay judge and a gay council, so they could live free of persecution. They held press conferences, had flyers and “Alpine or Bust” buttons printed, and took the press on tours to take pictures of a “scouting party” looking at properties in Alpine County. TIME magazine, NBC News, Associated Press, United Press International and other major media gave the hoax full coverage. They even interviewed local residents in Alpine who were distressed about the coming takeover of their quiet mountain community.

For probably the first time, the press mentioned the grievances the gay community had against how they were treated.

Zaps in the 1970s

Activists in New York decided that gays had asked politely for decades to be treated like other people, but had gotten nowhere. They started doing elaborate protests modeled on the 1960s radical feminist protests.

Called “zaps,” they were used to relentlessly harass people in power until they did as asked. It was mainly done to people who harbored some sympathies, since hardliners were considered lost causes.

An early victim was the mayor of New York, John Lindsay. He was pestered at several public appearances, where activists distributed themselves among the spectators and loudly asked Lindsay pointed questions when he worked the crowd. The pressure was kept up for about a year. When Lindsay declared himself a

candidate for president in 1971, his fundraiser in Radio City Music Hall was shut down by 25 zappers. The next day Lindsay finally capitulated and signed an executive order that restricted discrimination against gays in New York.

Another early target of zaps was the head of the agency that issued licenses to taxi drivers in New York. Gay taxi drivers were required to be inspected by a psychiatrist semi-annually and faced other discrimination. Nine activists showed up at the office carrying a couch and with one person dressed as a doctor in a white smock.

The agency head has been in the audience in Radio City Music Hall when Mayor Lindsay was driven off the podium, so he knew the zaps would continue. He ended discrimination against gay taxi drivers within three days.

The company Fidelifacts helped employers screen out gay job applicants. The owner said he could spot gay people, since “if one looks like a duck, walks like a duck, associates only with ducks and quacks like a duck, then he is probably a duck.” Activists showed up in duck costumes to protest.

By the end of 1971, *Life* magazine named the New York zipper’s Gay Activists Alliance the “homosexual liberation’s most effective organization.” The story included a picture of a zap at the City Clerk’s office, where activists carried in a giant wedding cake, with figures of two same-sex couples on top, to protest the marriage ban.

Fighting the psychiatrists

A major problem was that being gay was considered a mental illness. The American Psychiatric Association, APA, listed it as a mental disorder in their diagnostic manual, the DSM. It was essential to prove that being gay was not a mental illness. Everything else would hinge on that.

The first attempt at repudiation was a study done in 1953 by Evelyn Hooker at UCLA. She recruited thirty gay men and thirty straight men who were each given three psychological tests. It was the Rorschach inkblot test and two other tests where the subjects had to make up stories.

The responses were then given to experts in interpreting these tests. Their job was to discern who were the gays and who were the straights. The experts could not separate the two groups. If being gay was indeed a mental disorder, they should have been able to.

Hooker presented her findings at the annual meeting of the American Psychological Association in 1956, but most attendees refused to believe it. It challenged their beliefs too much.

Research funding was hard to get for such a controversial subject, so the study was not repeated. A repeat would greatly strengthen the study findings.

A potent argument that was leveled against the psychiatrists already during the 1960s was their lack of actual science. Instead, they based their opinions on the gay people who came to them for treatment. Of course they'd find mental health issues in gays who came for mental health treatment, as that was a selective group that did not represent the whole community. Their reasoning was circular and not based on reality, but this was generally accepted anyway.

A 1970 poll of psychiatrists showed 90 percent of them believed that homosexuality was a mental disease. Demonstrators at that year's APA conference stormed into the room when one of the prominent agitators for gays-as-mentally-ill was speaking. They also raided an adjacent hall where a psychiatrist talked about using aversion therapy to "cure" homosexuality.

The demonstrators demanded their side to be heard. As a concession, three of them were allowed to speak on a panel at the 1971 conference, but it was scheduled for 9 pm on the last night. That was a clear insult. Demonstrators shut down the conference. In response they were allowed to have a booth at the 1972 conference and a daytime discussion panel.

They wanted a gay psychiatrist on the panel. They knew several gay psychiatrists, but none of them dared to be open about it, since the APA actually had a policy that banned gays from being licensed analysts.

Eventually one gay psychiatrist was willing to be on the panel, but only while wearing a disguise in the form of a Richard Nixon mask. He told the stunned audience that there were more than a hundred gay psychiatrists attending this very conference. His appearance was a great success.

This conference was the first opportunity many mental health professionals had to talk to gays who were not seeking mental health treatment. Many of them expressed surprise that the gays did not think of themselves as mentally sick.

At another conference demonstrators zapped a presentation about aversion therapy (electroshock and induced vomiting), and said they wanted a dialog.

A female psychiatrist defended these methods by saying that they were only helping people who asked for it. When asked if a woman came to her for help to become “shy and retiring,” just as society prefers women to be, would she try? The psychiatrist admitted she wouldn’t.

The pressure was kept up and the psychiatrists slowly accepted the arguments presented, including that the APA’s stance caused blatant discrimination against gays.

The APA delisted being gay as a mental illness in 1974. They did face some interesting questions by the press on this about-face.

(This section is based on chapter 16 in *The Gay Revolution* by Lilian Faderman.)



The gays made many visible demonstrations. Here is one from 1997 celebrating that Disney announced they now welcomed gay couples at their theme parks.

Other activism in the 1970s

Meanwhile, other groups continued to work incrementally through the legal system. They presented the judges with perfect test cases that each were designed to move discrimination back just a tad. The people presented as plaintiffs were the most presentable and flawless people possible. A favorite was highly decorated soldiers who had been thrown out of the military and stripped of their pensions,

simply because they were gay. One of them became the first openly gay person on the cover of *TIME* magazine in September 1975.

Gay people continued to migrate to areas with other gay people. It became possible for gays to hold hands while walking around the gay district of San Francisco, without being physically attacked. If attacks did happen, other people would instantly show up to defend the victims.

The gay community searched for a unifying symbol for a long time. Several were tried, such as the pink triangle, the Greek letter lambda, and a double-bladed axe, but what caught on was the rainbow flag that perfectly symbolized their diversity.

Seeking allies

Gay activists tried to enlist the help of established organizations, but little or no help was offered.

Some lesbians joined the National Organization of Women (NOW), but the organization's leadership wanted to project a "wholesome image" and rejected the lesbians for several years.

The American Civil Liberties Union (ACLU) was initially even more hostile.

Eventually both NOW and ACLU did support the civil rights of gays and lesbians.

The backlash and Harvey Milk

A powerful backlash started with the "Save Our Children" campaign to overturn an ordinance that protected gays against harassment in Miami, Florida. The campaign was spearheaded by a religious glamourgirl who skillfully ran a campaign using emotional scare tactics. She painted gays as psychopaths who wanted to "convert" children to be gay. She got a lot of support from conservative churches.

The pro-gay campaign was slow to realize what it was facing and totally missed the boat. It focused on civil rights, rather than addressing the emotional propaganda. Scare tactics proved to be much more effective than cerebral high-mindedness. The ordinance was overwhelmingly repealed by a referendum.

The "Save Our Children" campaign spurred successful copies in other states. Then this juggernaut arrived in California with the 1978 campaign for Proposition 6,

that would ban gays from working in the schools. Gay school teachers and janitors would be fired if it passed.

San Francisco had just elected the openly gay politician Harvey Milk to city council. He united the factious gay and lesbian organizations into a well-run campaign against Proposition 6.

Harvey Milk and the lesbian woman Sally Gearhart became the faces of the campaign. For the first time mainstream people in California saw intelligent and articulate gays on their televisions, as they debated the opposition in town halls across the state.

Milk's genius was that he convinced gays and lesbians to come out of the closet all over the state, so mainstream people realized they actually knew such people, and they were not like those scary caricatures. It is a lot easier to condemn a group of people you don't really know, than one that turns out to include your neighbors, colleagues at work, and family members.

From a two-to-one lead in the polls, the tide turned and Proposition 6 was overwhelmingly defeated.

Harvey Milk was soon after murdered, together with the liberal mayor George Moscone. The killer was an anti-gay member of the city council.

Other progressive figures of the time had already been murdered (Martin Luther King, Robert Kennedy, Malcolm X, etc.) and Milk assumed that would eventually be his fate too. He recorded a tape to be released in case he was murdered.

When the killer only got a lenient manslaughter charge, San Francisco erupted in violent riots. The police was beaten back by the throngs of angry people. The police force was still openly hostile towards gays and retaliated by attacking random people in the gay neighborhoods in the following days.

ACT UP

In 1981 the infectious disease AIDS showed up in the gay communities in New York and San Francisco. In the start, patients had non-specific symptoms, such as fatigue, so many doctors wrote them off as psychosomatic, until they got visible symptoms.

(In San Francisco, some people with MCS initially thought they had AIDS.)

AIDS was widely believed to be a gay-only disease and was originally called “gay cancer” and “gay-related immune deficiency” (GRID). It was ignored for years by the Centers for Disease Control (CDC) and the Reagan administration. In contrast, the health authorities really jumped on an outbreak of Legionnaire’s Disease a few years earlier, even though it affected far fewer people.

In the first several years of the epidemic it was mostly gay physicians who tried to help the sick, while most other physicians simply refused.

The AIDS epidemic really organized the gay communities. Many sick gays were disowned by their families and did not have the basic support they needed. Organizations sprung up to visit the sick, bring them food, take them to the doctor, etc.

For a decade the annual death toll topped a thousand people in San Francisco alone. Some anti-gay preachers actually celebrated the havoc AIDS wrought on the gay community.

It became clear that the authorities would continue to ignore the AIDS epidemic if their hand was not forced. Some activists preferred calm agitation while others the radical in-your-face approach.

The radicals created ACT UP (AIDS Coalition To Unleash Power) in 1985. It used similar methods as the zap campaigns in the 1970s. They used humor and ridicule to get their message across. That was much more effective than cold factual protests.

ACT UP targeted Senator Jesse Helms when he tried to block a \$600 million AIDS research bill by telling his colleagues that they should not spend money on “a disease spread through immorality.” The prank was a giant inflatable condom draped over Helm’s home.

When a magazine suggested AIDS patients should be branded on their skin, activists created a concentration camp scene on the sidewalk outside the magazine office.

The right-wing tabloid *New York Post* was also targeted, when a thousand people protested the paper’s persistent anti-gay articles.

ACT UP became so well known that they gave their targets ultimatums in advance, though few willingly reformed. Once targeted, several succumbed, such as the National Institutes of Health (NIH), which had a poorly managed, passive,

and bureaucratic AIDS research program that produced little of consequence. Once twelve hundred angry ACT UP activists besieged their headquarters, the NIH leadership was finally changed. When the pharmaceutical company that sold the first AIDS drug, AZT, doubled the drug price in response to the epidemic, ACT UP got the price back down again.

For a long time the NIH refused to talk to the gay community. Then they had informal contacts with the activists, but it took them a long time to get down from their ivory tower and really partner with them. Unfortunately, involving the patient community is still a radical idea today.

A big action against the Food and Drug Administration gained the ACT UP spokesperson an interview on CNN where he sparred with the anti-gay Pat Buchanan.

It took seven years before the White House showed any interest in the epidemic. The reason it finally did was that Hollywood star Rock Hudson got AIDS and died. He was a personal friend of president Ronald Reagan. At this point about six thousand people had died.

The president appointed the Presidential Commission on the HIV Epidemic, which was almost entirely staffed by people with no credentials in this area, and even included some who were openly hostile to gays. It did no work at all. Under pressure from ACT UP the commission got a new leader, a retired admiral who turned it around and actually listened to the AIDS activists and investigated their complaints. The final report was scathing in its critique of the federal response to the epidemic, but was completely ignored.

The AIDS quilt

A different approach was the AIDS Memorial Quilt. The idea was that families or friends could make a cloth panel to memorialize an AIDS victim. The panels were each 3 by 6 feet (1 by 2 meters) – the size of a coffin. It got a slow start, the originator found no interest in his idea the first year.

Some activists hated the idea, since they found it “too passive.” Then he himself made eleven panels and got friends to make two dozen more. He got permission to hang them on the facade of City Hall in San Francisco during a rally. Actually seeing the display convinced a lot of people it was a good idea.

In October 1987 activists displayed 1920 panels on the lawn in front of Capitol Hill in Washington during a demonstration with half a million people. It had taken

hundreds of volunteers and a core group of about ten to do the AIDS Memorial Quilt. It was then taken on a tour of twenty cities.

More panels kept coming in, including some from other countries. In October 1988 they displayed 9,000 panels in front of Capitol Hill. The project was by then managed by a paid full-time staff.

The display was an annual event for several years, but was each year ignored by the presidents Ronald Reagan and George H.W. Bush. After four years in office, president Bill Clinton made the first official presidential visit to the memorial in 1996.

The panels provided a way for families and friends to honor their dead. It was a potent tool to get the attention of the media and a visual shame laid out for the world to see.

Experimental treatments

It took years to determine that AIDS was caused by a virus. Before the discovery, there were many theories. This made it harder to find treatments.

With no treatment for AIDS available from mainstream medicine, the patients experimented on their own. They were desperate and had nothing to lose, as AIDS was a certain death sentence. Anything that even extended life a few months had interest. Several existing drugs were tried and any that seemed to help quickly got a strong following until it petered out, followed by the next. There were a great many such drugs, including Imuthiol, Ampligen, Compound Q, and others.

Activists even traveled to other countries to bring home suitcases full of drugs not available in the United States. AL721 came from Israel and dextran sulfate from Japan. When the border control clamped down on this traffic, bootleggers made their own drugs to distribute through the underground.

Sympathetic doctors, most of them gay themselves, even did small-scale drug trials to get the NIH bureaucrats to look at some of the drugs that showed promise. These efforts were financed by donations, as no public money was available.

Many people experimented with all sorts of alternative treatments, such as herbs, acupuncture, and more.

There were also popular protocols claiming that positive thoughts alone could prevent and even cure AIDS. This inspired the 1995 film *Safe* directed by Todd

Haynes, who was an active ACT UP member. Unfortunately, he used MCS as a metaphor for AIDS and with a self-effacing woman in the leading role, so he inadvertently hurt the MCS community.

Television

Movies and television shows either ignored gays and lesbians, or portrayed them as weird or worse. In 1974 activists complained to the American Broadcasting Corporation (ABC) about an episode of *Marcus Welby, MD* where gays were portrayed as pedophiles.

It was clear that ordinary people needed to see gays as normal, intelligent, and likeable people on their television screens. Otherwise the prejudices would never be reversed. Activists worked on convincing the entertainment industry to give them fair treatment.

The first attempt was the TV series *Will and Grace*, which started in 1997 and became very popular. Soon after, TV host Ellen DeGeneres told her viewers that she was lesbian. Her TV show continued to thrive.

In 2012 the wife of presidential candidate Mitt Romney stated that her favorite TV show was *Modern Family*, which featured a gay couple raising an adopted girl.

A 2012 poll by *The Hollywood Reporter* found that such TV series made viewers much more sympathetic towards same-sex marriage.

Unity

The gays and lesbians joined forces in the late 1980s. A decade later the bi-sexual and transgender people were allowed to join too and the acronym LGBT came to be. Later the queers also joined, so it became LGBT+.

More joined more recently. “Unity makes strong” has always been true, but it took decades for the various factions to come together.

When Congress worked on the Employment Non-Discrimination Act (ENDA) in 2007, the bill’s sponsors thought it couldn’t pass if it included transgender people. Transgender had only been a buzzword for a decade and most politicians were unfamiliar with it. More lobbying was needed before they could be included, the thinking went. But the gay and lesbian groups were not willing to leave the transgender people behind. It was all or nothing.

The bill did pass the House, but died in the Senate. President George W. Bush said he would veto the bill if it passed.

There have been many hate crimes against gays, but the grisly murder of Matthew Shepard shook the nation. Tied to a fence in Wyoming, he was brutally beaten to death in 1998. It took this event to get a hate-crime bill introduced in Congress.

The ultimate acceptance of gays was giving them the right to marry. The first country in the world to allow that was Denmark, in 1989. In the United States it happened slowly, state by state. Massachusetts came first in 2004. The Supreme court's *Obergefell* ruling in 2015 made gay marriage legal throughout the country.

Lessons for the environmental illness community

The struggle for acceptance and legal rights for the EI community will take its own path, though there seem to be many parallels to the LGBT+ story, and lessons to be learned.

Gay activists identified early that the false image of mental illness was a fundamental roadblock towards acceptance and civil rights. It is the same situation for the environmentally ill. Seeking research funding for a cure and improving the air quality in workplaces and medical facilities is greatly hampered when the issue is broadly considered “all in their heads.”

The false image of MCS rests on an equally flimsy foundation. The most prominent study from 1990 included MCS patients recruited from mental health clinics. And it compared them with people who had no health problems, despite it is well established that people with chronic health problems, such as asthma, are more prone to depression and anxiety. Subsequent studies repeated this error, and solidified the echo chamber. They haven't even bothered to study people with EHS before pronouncing them mentally sick.

Another article in a medical journal even postulate that people with MCS or EHS simply want to retire from society and live like hermits. With no evidence provided, other than a couple of newspaper articles about people forced to live in isolation.

Then there are dozens of “provocation studies” with results all over the board, seemingly “proving” people with MCS or EHS react to placebo as much as to active challenges. Those studies were generally very poorly done, and thus very unreliable. They also fail to consider that many fully healthy people feel poorly if

they think they are exposed to a toxic gas. Somehow they demand people with MCS/EHS to be superior to regular people.

It is disconcerting that prejudice can be so strong that it took thousands of deaths before the health authorities got interested in AIDS. That it took the death of a Hollywood star. At the same time there was another ignored deadly epidemic: cigarettes, which killed about 600,000 Americans a year, yet Congress refused to act because of the powerful tobacco lobby.

Similarly, the prejudice against people with MCS/EHS is so strong there is virtually no funding for research. We still don't even know how it causes brain fog or other symptoms.

The gays and lesbians had organizations focused on getting along without challenging anything, some that gently agitated for their civil rights, and some that were loud and in your face. It took all of them to succeed. They each had their purpose.

The message from the LGBT+ campaigns is that presenting an image of paragons of society that just happens to be sick is what sells, whether in a court room, in the media or in front of people and politicians. This means soldiers in uniform with medals on their chests, college professors, business people, professionals, and other accomplished individuals. Sad, but true.

The April 16, 2018 issue of *TIME* magazine published the story of a cute high school girl who lived in the small town of Lorain, Ohio. One picture shows her doing the Pledge of Allegiance. She's anybody's dream daughter and dream neighbor, except she entered the US illegally when she was five years old. Who would want to deport her? Thus the magazine made a powerful statement about immigration issues.

What it took to convince a lot of psychiatrists was when one of their own declared he was gay, and spoke from a podium (albeit wearing a Richard Nixon mask to be anonymous). We need physicians with MCS or EHS themselves to speak out at medical conferences, and it should be required in the medical school curriculum that the students meet people with chronic illnesses who speak to them from a podium (not a hospital bed).

We need stories and TV shows about the majority of EIs who are able to have a job and function in society with just minor accommodation – perhaps living in a house with no carpeting, using no toxic personal care products, and working in an office with an air purifier and no office mate. Otherwise it must be a “normal”

person people can identify with. Viewers can't identify with tinfoil and living in cars.

It is no coincidence that there are no TV shows about homeless people, people who are wretchedly poor, drug users, etc. That is unfortunate, but we have to be realistic if we ever have to gain some traction.

Spectacular displays have their place, such as the AIDS Memorial Quilt and the various attention-getting happenings to get press coverage (otherwise the press will not be interested).

When the Americans with Disabilities Act didn't quite have the votes to pass in 1990, a group of wheelchair users staged a powerful demonstration. The US Capitol building in Washington DC was not wheelchair accessible because of the many steps up to the entrance. Several wheelchair users literally crawled up these many steps as best they could, often in a very undignified way, with the press watching. The law passed a few days later.

Displays where the unreasonableness is graphically evident helps gain understanding. Another classic example is the 1965 civil rights march from Selma, Alabama, to Montgomery, where peaceful marchers were beat up by the police when crossing the Edmund Pettus bridge.

Facts about civil rights abuses do not convince, emotional images do. Unfortunately.

The LGBT+ community eventually chose the rainbow flag as their symbol, as it shows their diversity. The EI community is also quite diverse, we need a better symbol than the tired canary that never got much acceptance, and doesn't really cover our diversity.

The gay rights demonstrators were almost all in their twenties and not sick. In contrast, people who get MCS and EHS tend to be 35 or older, and are a lot more limited. We can't do demonstrations.

ACT UP helped MCS activists in 1990 to shut down a blatantly biased medical conference in San Francisco. It was not possible to do it without their help.

Several studies show that there are millions of people with MCS in the United States. A common number is 15% of the population. With very narrow criteria, for just the severe cases, they still find around half a percent. That is about 15 million people. Where are all these people?

Some don't know what they have thus it is important that the media carry stories about us now and then to tell these people they are not alone, and not crazy. That maybe those psychiatric drugs that leave them in a numb daze are not the answer.

Some people prefer to stay closeted to not appear “weird” to their family, co-workers, bosses, and customers. It's not any different than gays who stay closeted. It can be harmful to a career to admit having MCS or EHS, as it used to be for gays.

The gays got organized after the Stonewall Inn riot. Success breeds success. When people see someone doing things that work, they want to support it. Memberships swelled the organizations, money started coming in so campaigns and lawsuits could be mounted, which again made more gays support the effort. It was a chicken-and-egg problem, which the EI world hasn't cracked yet.

We are still fractious. People with MCS and EHS are mostly separated. We need to come together, just as the LGBT+ folks had to, to be effective. There are many other potential allies, such as people with chronic fatigue syndrome/myalgic encephalitis, fibromyalgia, Lou Gehrig's, epilepsy, autism, hyperacusis, light sensitivity, and more, who sometimes overlap with MCS/EHS and are also often dismissed and ignored.

Sources

The sources for this description of gay and lesbian activism were *The Gay Revolution*, by Lilian Faderman (2015), *When We Rise* by Cleve Jones (2016) and *How to Survive a Plague*, by David France (2016). They are all highly readable and have very little overlap with each other.

The San Francisco MCS demonstration and the film *Safe* are described in detail on the website below.

More information

Other articles about MCS and EHS activism, coping methods, and more are available on www.eiwellspring.org