

# Making Invisible Disability Visible

{ By Storee Powell  
{ Center for Persons with Disabilities at USU



CENTER FOR PERSONS WITH  
**DISABILITIES**

**UtahState**University

- ❖ Graduate of USU
- ❖ Worked at the Center for Persons with Disability since 2011
  - ❖ CPD is a state UCEDD for disability research, training, and services (not to be confused with the DRC)
- ❖ Board member of the Cache Valley Women's Wave March
- ❖ Member of Cache Valley 4 Change
- ❖ Worked in radio broadcast and print/online journalism
  - ❖ Winner of UBEE and Society of Professional Journalism awards
- ❖ Specialize in women's and disability issues
- ❖ I LOVE dogs
- ❖ Enjoy anything artsy, craftsy
- ❖ Ghost town hunting

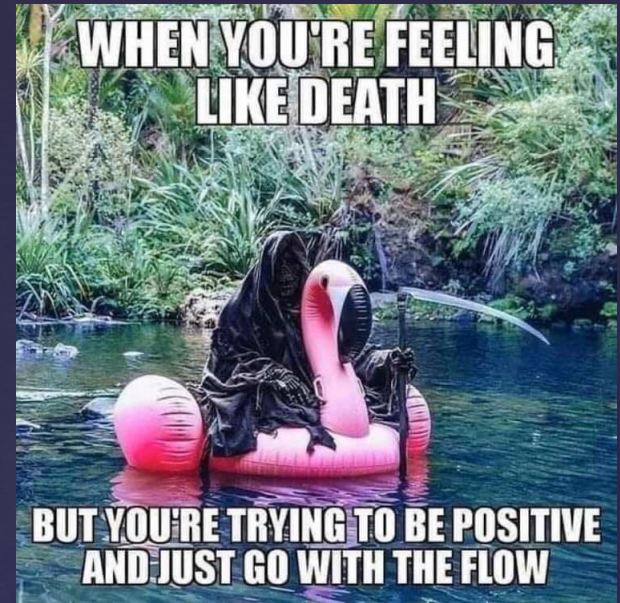


# About Me





- ❖ Started struggling with my health and ability when I transferred to USU in 2008. I faked being well for many years and struggled to live up to the able bodied standards that were put on me.
- ❖ I've been to over 2 dozen specialists, in multiple states. Lots of seemingly unrelated symptoms with multiple body systems.
- ❖ Several misdiagnoses, difficult medications, ambulance rides, ER visits, and SO many needles.
- ❖ Loss of self and identity along with abilities and health status. Impacted every area of my life.
- ❖ Living without a diagnosis meant no treatment, empathy or explanation to those around me.
- ❖ Spent 6 months bed ridden.



# Storee's Story





- ❖ Never ending process of grief. In a state of severe anxiety, depression and complex PTSD.
- ❖ Learning to accept my disability and becoming part of the disability community.
- ❖ Correct diagnosis in 2018 of a rare genetic disorder – Ehlers Danlos Syndrome (EDS) – essentially my collagen is defective. Collagen makes up 30 percent of our bodies.
  - ❖ I have many comorbid conditions including Fibromyalgia, Mast Cell Activation Syndrome, dysautonomia, Raynaud’s Phenomenon, periodical cyclical vomiting and gastroparesis, Irritable Bowel Syndrome, focal nodular hyperplasia, and many more.



# Grief, diagnosis & Acceptance





- ❖ I live with chronic pain, fatigue and physical discomfort. I will do so for the rest of my life. There is no cure.
- ❖ Unable to stand for long periods of time (more than a few minutes).
- ❖ Severe brain fog.
- ❖ Subluxing and dislocation of joints.
- ❖ Nerve pain.
- ❖ Chronic nausea.
- ❖ Muscle spasms.
- ❖ Shortness of breath.
- ❖ Bladder pain and occasional incontinence.
- ❖ GI pain.
- ❖ Severe muscle weakness.
- ❖ Dizziness, poor proprioception.
- ❖ Tongue swelling.
- ❖ Unrestful sleep.
- ❖ Heat intolerance – rash, fatigue.
- ❖ Heart palpitations and racing heart.
- ❖ Arthritis in spine.
- ❖ Inability to control my body temperature.
- ❖ Intolerance to cold – Raynaud's.
- ❖ Easy to become dehydrated.
- ❖ Many more symptoms.



# Life with EDS

# What invisible disability means for my life:

- ❖ I rely on at least a dozen prescription medications to keep me somewhat functional.
- ❖ I have only a few functional hours in a day. I either have to get the necessities done in this time or not do them at all. Daily activities like showering and eating are enormously difficult for me. I live in *crip time and measure my days in spoons*.
- ❖ Since my disorder is rare, finding competent health care providers is extremely difficult.
- ❖ Planning ahead to a week to years is often ineffective as I don't know how I'll be feeling/what my abilities will be.
- ❖ I spend my money on medical bills, expensive prescriptions, adaptive devices.
- ❖ Unable to work more than part time & on location - I earn less, have less career progression.
- ❖ Complicated diet – makes going to social events involving food a real ordeal.



# What invisible disability means for my life:

- ❖ Traveling and going to events is extremely difficult.
  - ❖ Standing in line, places with no elevators or seating are inaccessible to me.
- ❖ Social isolation both because of my inability to participate and the shunning of peers.
- ❖ Loss of independence and quality of life.
- ❖ Constant burden of proof since my disability is invisible.
- ❖ Changed perception of what life means, as well as my ability to trust others.
- ❖ I physically pay for everything I do.
- ❖ Living in fear of my future.
- ❖ Disability pride and self-advocacy.



My invisible disability can make me invisible – keeping me from showing up, being able to advocate for myself and just being visible.



My disability is invisible,  
but I am not.



**If I looked as  
bad as I feel,  
I would scare  
your children.**



# What is invisible disability? What are disability rights?

{ Definitions & theory (the legal & social models)

❖ *Invisible disability* defined from the Invisible Disability Project: **A disability that cannot be easily seen or measured and is often discounted or not respected.**

❖ Your disability may be unseen. But it is not unfelt or unreal. We often lack language to talk about the things we cannot see. A great place to start? Just learn how to define what an invisible disability is, so you'll be better able to talk about it with others.

❖ An "invisible," "non-visible," "hidden," "non-apparent," or "unseen" disability is any physical, mental, or emotional impairment that goes largely unnoticed. An invisible disability can include, but is not limited to: cognitive impairment and brain injury; the autism spectrum; chronic illnesses like multiple sclerosis, chronic fatigue, chronic pain, and fibromyalgia; d/Deaf and/or hard of hearing; blindness and/or low vision; anxiety, depression, PTSD, and many more. We understand the body as always changing, so disability and chronic illness may be unstable or periodic throughout one's life.



This is what invisible disability looks like.



- ❖ *Passing or Masking*: The ability of a person to be regarded as a member of social groups other than their own, such as a different race, ethnicity, social class, gender, age, and/or disability status, generally with the purpose of gaining social acceptance, or to cope with anxiety.

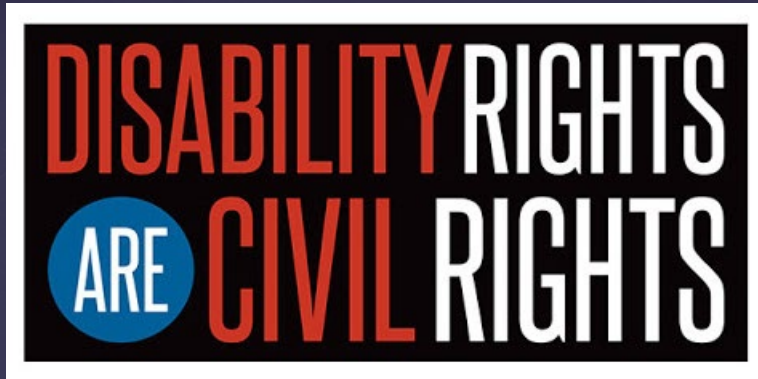


Passing as able-bodied with invisible disability means having able-bodied expectations put on a disabled body.

- ❖ *Social invisibility*: An experience of oneself as unseen by others, not in the literal, physical sense, but rather in a metaphorical, intersubjective one.
  - ❖ This occurs because of the effects of shame, stigma, and marginalization.







# Disability under the law in the U.S.

{ Disability is a protected class.

- ❖ The ADA is a Civil rights law passed in 1990 that prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public.
- ❖ It is important to remember that in the context of the ADA, “disability” is a legal term rather than a medical one. Because it has a legal definition, the ADA’s definition of disability is different from how disability is defined under some other laws, such as for Social Security Disability related benefits.
- ❖ The ADA defines a person with a disability (invisible or visible) as a person who has a physical or mental impairment that substantially limits one or more major life activity (which include major bodily functions). This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.

# Americans with Disabilities Act





- ❖ An employer searches an applicant's name online and learns that she was a complaining witness in a rape prosecution and received counseling for depression. The employer decides not to hire her based on a concern that she may require future time off for continuing symptoms or further treatment of depression.
  - ❖ ADA prohibits different treatment or harassment at work based on an actual or perceived impairment, which could include impairments resulting from domestic or dating violence, sexual assault or stalking

Example of protection  
under the ADA

- ❖ A professor calls the doctor without the consent of a nontraditional student at USU who has an invisible disability to inquire if her (invisible) disability is real. The hurt, distrust and fear of retaliation leaves her in a difficult place.

This is illegal under the ADA.





- ❖ The Rehab Act prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment and in the employment practices of federal contractors.
- ❖ The standards for determining employment discrimination under the Rehab Act are the same as those used in [Title I](#) of the ADA; it protects “qualified individuals with disabilities.” An “individual with a disability” is a person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment or is regarded as having such an impairment. “Qualified” means the person satisfies the job-related requirements of the position he or she holds (or is applying for) and can perform its essential functions, with or without a reasonable accommodation.

# Rehabilitation Act of 1973

Takeaway: People with invisible disabilities have rights under the law.



- ❖ A student with chronic pain and fatigue, who is not a mobility aid user, needs to attend an on-site dig for an archaeology class, but cannot physically access the particular site.
- ❖ The professor tells the student it is the only way to pass the class.
- ❖ The professor must work with the student to either find a way to make the site accessible, or find an alternate site.

Example of protection  
under the Rehab Act.



- ❖ Johanna Hedva (they/them) lays out the need for sick woman theory as an act of destroying all oppressive structures of society, and they push for a centering of all 'Sick Women' in all of our spaces (both physical and ideological).
- ❖ They identify that the notion of 'getting well' and the binary of the 'sick' and the 'well' only functions to uphold violent, oppressive structures that make anyone out of the norm dispensable.
- ❖ They advocate, instead of healing, the idea of 'coping' and surviving through vulnerability and hardship. They aim for a constant community of care and support, not just for those seen as 'sick', but for everyone in their vulnerable bodies.



*Listen to Sick Woman Theory  
and find a transcript at  
<https://vimeo.com/144782433>.*

**Sick Woman Theory (Intersectionality): a  
useful social model to think about all  
marginalized bodies including sick &  
disabled bodies**



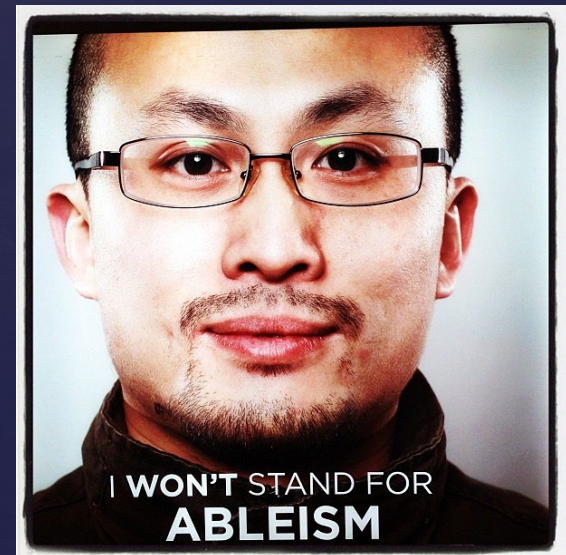
# Defining Ableism

{ What types of ableism do invisibly disabled people encounter?



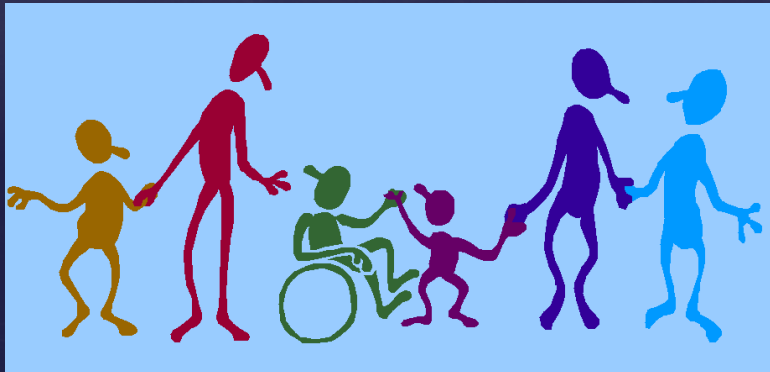
# Ableism defined:

- ❖ From the Invisible Disability Project: Discrimination or bigotry against people considered disabled by mainstream society. The world around you may not always yield to your bodily or neurodiversity. But all bodies and minds have the right to coexist in this world.
- ❖ From the Center for Disability Rights: Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other.



# Why disability inclusion & accessibility matters

{ Disability is diversity.





# Disability inclusion matters.

- ❖ It is not rare:
  - ❖ About 20 percent of college students report having a disability.
  - ❖ About 12.8% percent of the general population in the U.S. has a disability, of which, over half (51%) were people in the working-ages of 18- 64.
- ❖ People with chronic illness or disability are at an increased risk for suicide & mental illness.
- ❖ The stigma and/or oversight invisibly disabled people encounter in classrooms and work places can make learning, participation and job performance incredibly challenging if not impossible.
  - ❖ For example, the graduation rate of students with disabilities is much lower than non-disabled students. Federal data shows fewer than 35% of students with disabilities graduate from four-year institutions within 8 years.
  - ❖ The employment rate of disabled people is 19.1% and 65.9% for able bodied people.



# Ableism faced by invisibly disabled people.

- ❖ Invisible disability brings on not only the struggles of the disability itself, but also the burden of having to prove disability to others – even if it is illegal in the setting. When it is not illegal, and is required to receive accommodations, it can be humiliating and time consuming. It also assumes you have access to healthcare, a diagnosis and a cooperative doctor.
- ❖ Invisibly disabled people face microaggressions, toxic positivity culture, and inaccessible public spaces and policy.
  - ❖ These can affect a person's ability to:
    - ❖ safely and efficiently navigate campus,
    - ❖ feel protected knowing peers and professors won't interrogate them about their disability, and,
    - ❖ Even see themselves represented in university diversity initiatives that include their disability identity and culture.





- ❖ It is not your job or anyone else's to interrogate invisibly disabled people about:
  - ❖ Disability parking tags
  - ❖ What their illness is and if it is 'contagious'
  - ❖ Why they've asked for accommodations
  - ❖ Why they've used the accessible bathroom stall
  - ❖ Why they are using a plastic straw
  - ❖ Why they've used the elevator rather than the stairs
  - ❖ Why they need to take extra bathroom breaks
  - ❖ Why they are wearing certain clothes or shoes
  - ❖ Why they talk so much about their disability or illness



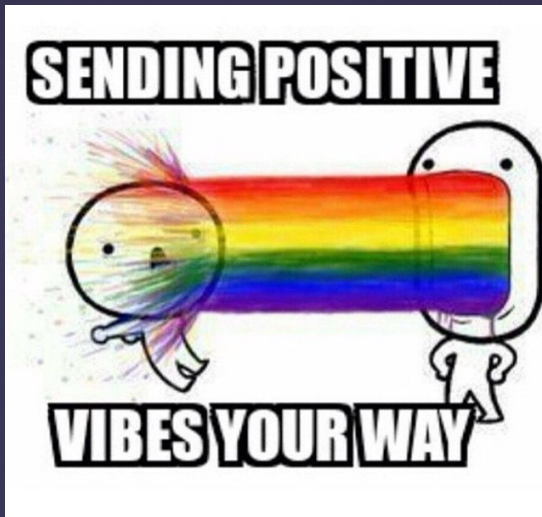
Sam Bosworth     
@\_SamBosworth

Quick guide on how to spot someone faking a disability for a parking spot: you can't. It's none of your business. You have no idea what someone is going through. Some disabilities are invisible. Disabled does not always mean wheelchair. Stop. Go on with your day.

22:00 · 26 Sep 19 · [Twitter for Android](#)



There is no disability police. Invisibly disabled people do not have to prove their disability to you.



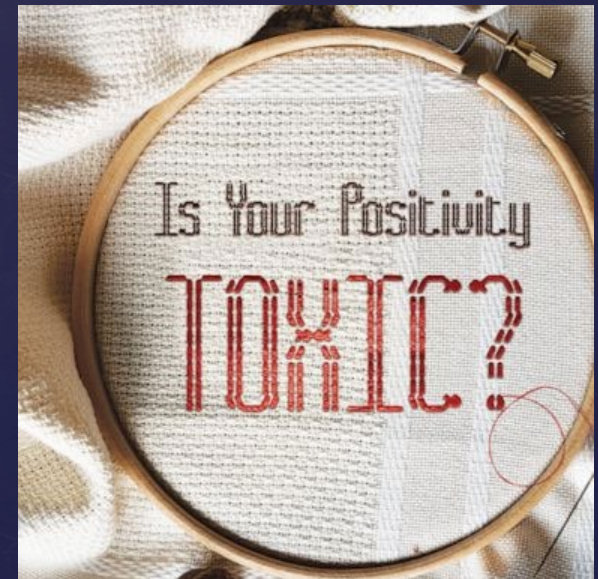
# Toxic Positivity

{ Your toxic positivity is giving me bad vibes.



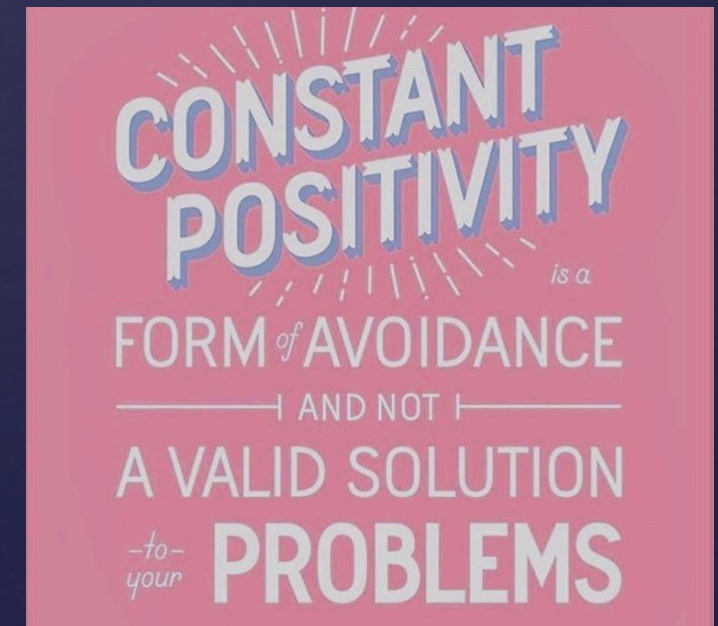
# Toxic Positivity defined

- ❖ *Toxic positivity* is the denial of real and appropriate emotions in the face of competition or adversity, usually accompanied by an admonishment to 'think positive' and how that will make everything be okay again, regardless of reality.
- ❖ Toxic Positivity is:
  - ❖ Victim blaming.
  - ❖ Ableist. It ignores the reality that disability is part of the human experience.
  - ❖ Thinking if someone tries hard enough or does the right things, they can be 'cured'.
  - ❖ Thinking that someone needs to be cured to worthy of love/respect/dignity.
  - ❖ Pushing unrealistic expectations on disabled & sick bodies.
  - ❖ Repressive, oppressive and privileged.
  - ❖ Annoying as hell.



# These ideas & responses are not negative or unhealthy:

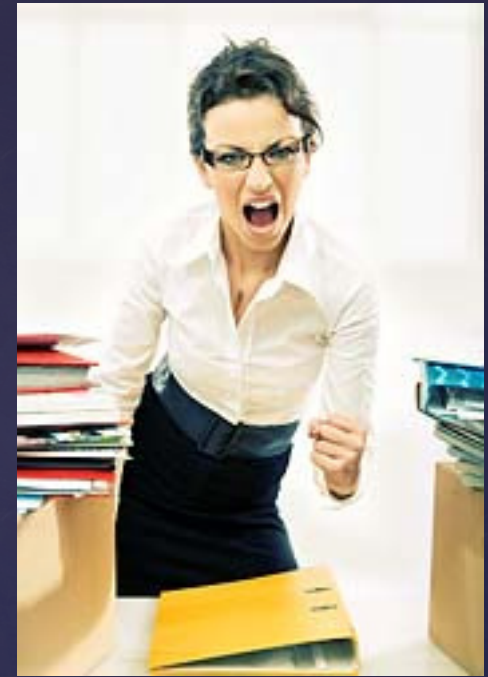
- ❖ Accepting one's disability/illness for what it is (which includes the idea there isn't a cure)
- ❖ Telling someone they are feeling or doing unwell
- ❖ Experiencing grief/rage/confusion/fear about a diagnosis/loss of abilities
- ❖ Planning for long-term medical care
- ❖ Starting to use a mobility aid
- ❖ Not wanting to 'overcome' a disability, but rather live with it.
- ❖ Not wanting or liking your disability.
- ❖ Having pride about your disability.
- ❖ Understanding that





# Ableist Microaggressions

*Microaggressions:* Everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group members. (from Derald Wing Sue, Ph. D.)



{ Well-meaning questions, jokes or invitations can become hurtful and overwhelming – causing isolation, feelings of inadequacy and even fear for physical safety.

- ❖ All you talk about is sick people. Get a life.
- ❖ Disability is not a civil rights issue or a cultural group.
- ❖ He's a truly an inspirational person for living with his disability.
- ❖ You are a good reminder of how great my life is.
- ❖ You're not disabled enough to need accommodations.
- ❖ You could be well if you tried harder/weren't a sinner/tried this cure/just exercised.
- ❖ You're poisoning yourself with all of those prescription meds.
- ❖ It must be so nice to work at home/not work. What a luxury!

# Examples of ableist microaggressions

it's okay if you  
need pills to  
survive + function



(it's also okay if you don't!  
pills don't work for everyone.)



- ❖ Only associate worth of a person with some type of productivity. Example: I was so productive at work today. What did you accomplish today?
- ❖ You're only as sick as you want to be.
- ❖ You are disabled or sick because you are morally flawed (if you'd just go to church you'd get better).
- ❖ Assuming someone doing something a certain way is because they are lazy. Example: someone walking slowly in front of you may be disabled, not lazy.
- ❖ You don't look sick/mentally ill.
- ❖ Hope you get well soon! OR You aren't better yet?
- ❖ You don't have cancer, it could be worse.

# More Ableist Microaggressions

I DRANK ALL THE JUICE,  
I ATE ALL THE  
SUPERFOODS,  
I THOUGHT ALL THE  
POSITIVE THOUGHTS.  
GUESS WHAT?  
I'M STILL ILL.



@natashalipman x @thisthingtheycallrecovery





# Inaccessibility

{ In physical spaces and policy



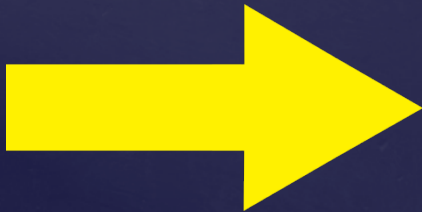
- ❖ Not having options for people to sit or stand at lectures/events.
- ❖ Having bright/flashing lights.
- ❖ People wearing strong fragrances.
- ❖ Waiting lines without options for disability first service.
- ❖ Bathrooms that are far away from an event space.
- ❖ Not having food options for various health needs.
- ❖ Places (like campuses) that require lots of walking between buildings & from parking lots.
- ❖ No elevators.
- ❖ Poor temperature control in buildings.
- ❖ Not using a mic in a large/crowded room.

# Inaccessible Spaces



# Inaccessible Policy

- ❖ CrutchesandSpice.com: ‘When it comes to creating policies, starting the planning process or creating spaces for inclusion, too often, the voices of disabled people are overridden by those of abled allies with mere relational proximity to someone disabled. Where feminists see all-male panels on women’s inclusion in executive spaces, the same happens with disabled people and their able-bodied allies.’ ~Imani Barbarin



## Examples of Inaccessible Policy:

- ❖ Institutional emergency response policies (example: run, hide, fight).
- ❖ Setting up a voting system that allows for one specific time allotment for voting.
- ❖ Planning protest events where physical attendance is the only way to participate.
- ❖ Dress codes that don't allow for functional/sensory friendly clothing.
- ❖ Not allowing for as needed bathroom breaks.
- ❖ Not providing materials in alternative formats.



# How to disrupt Ableism against invisibly disabled people

{ Be a disability ally.



**BREAKING  
SILENCES**

- ❖ Call out ableism in conversations, institutions, policies, etc.
- ❖ Create accessible spaces and policy.
- ❖ Include sick and disabled people in planning.
- ❖ Don't assume someone's ability/disability status.
- ❖ Use the right language (example: disability first or people first).
- ❖ Empathize with those living with disability. Do not pity them or put them on a pedestal (*inspoporn*).
- ❖ Include disability in diversity initiatives.
- ❖ Learn about disability rights and culture.
- ❖ Learn how to support and respond to someone disclosing or coming out with a disability (listen, validate, tell them you are there for them, avoid judgements & offering unsolicited advice).

# How to be Disability Inclusive & a Disability Ally



# References

1. Invisible Disability Project <https://www.invisibledisabilityproject.org>
2. [The Truth Of Disability Employment That No One Talks About](#)
3. [2017 Disability Statistics Annual Report](#)
4. [Center for Disability Rights Blog](#)
5. [ADA National Network](#)
6. [The vast majority of students with disabilities don't get a college degree](#)
7. [Sick Woman Theory](#)
8. [Rehab Act of 1973](#)
9. [Americans with Disability Act of 1990](#)
10. [U.S. EEOC](#)
11. [Toxic positivity vs realistic optimism: knowing the difference!](#)
12. [Toxic Disability Positivity](#)
13. [Disabled People Have an Ally Problem: They Need to Stop Talking For Us](#)
14. [Disabilities Studies Quarterly: Moving Feminist Disability Studies into the Crip Future](#)
15. [I'm a "Spoonie." Here's what I wish more people knew about chronic illness.](#)
16. [Disabled People Are Not Your Feel Good Back Pats.](#)

1. USU Disability Resource Center  
<https://www.usu.edu/drc/>
2. Utah Disability Law Center  
<http://disabilitylawcenter.org>
3. ADA National Network <https://adata.org/>
4. The Mighty <https://themighty.com/>
5. The Invisible Disability Project  
<https://www.invisibledisabilityproject.org/>
6. USU student disability club  
<https://involvement.usu.edu//clubs/bleuclub>

# Resources



## Making Invisible Disability Visible

by Storee Powell

### Glossary of Terms:

- **Crip Time:** it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of 'how long things take' are based on very particular minds and bodies...Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.
- **Ableism:** Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other.
- **Invisible (or Hidden) Disability:** A disability that cannot be easily seen or measured and is often discounted or not respected. An "invisible," "non-visible," "hidden," "non-apparent," or "unseen" disability is any physical, mental, or emotional impairment that goes largely unnoticed. An invisible disability can include, but is not limited to: cognitive impairment and brain injury; the autism spectrum; chronic illnesses like multiple sclerosis, chronic fatigue, chronic pain, and fibromyalgia; d/Deaf and/or hard of hearing; blindness and/or low vision; anxiety, depression, PTSD, and many more. We understand the body as always changing, so disability and chronic illness may be unstable or periodic throughout one's life.
- **Spoon Theory:** Created by spoonie OG Christine Miserandino – Using spoons as a metaphor for units of energy a person has each day. The difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to – these things take spoons for the sick and disabled. The healthy have the luxury of a life without choices, a gift most people take for granted.
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- **Toxic (Disability) Positivity:** is the denial of real and appropriate emotions in the face of competition or adversity, usually accompanied by an admonishment to 'think positive' and how that will make everything be okay again, regardless of reality.
- **Microaggressions:** Everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group members.
- **InspoPorn:** Coined by Stella Young - the omnipresent trope of disability stories that tend to fall into one of three categories:
  - (1) Disabled person does something extremely extraordinary and it's presented as inspiring because the person is disabled, and not because 99% of the total population (disabled and non-disabled) could have never achieved it.
  - (2) Disabled person does something pretty mundane for most people and it's presented as inspiring because apparently disabled people are assumed to be incapable of doing ... anything.
  - (3) Non-disabled person does something not overtly negative or generally discriminatory to a disabled person, and it's presented as inspiring because LOOK AT THE MAGNANIMOUS, KIND-HEARTED (non-disabled) SAINT BEING NICE TO A PERSON SUFFERING FROM A DISABILITY.

#### Resources:

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5. The Invisible Disability Project <https://www.invisibledisabilityproject.org/>
6. USU student disability club <https://involvement.usu.edu/clubs/bleuclub>