

## **Support Group Recap: Minority Survival Skills: Facing Internal and External Ableism**

February 16, 2024

### **Announcements**

- Subscribe for Zoom recaps, updates, and invitations for future events.
  - <https://batemanhornecenter.org/outreach/newsletter/>
- BHC Research is still recruiting for two Long Covid studies. Visit <https://batemanhornecenter.org/research/> to apply or for additional information.

*The following resources and anecdotes were shared by attendees and do not necessarily reflect BHC guidance nor endorsement.*

The support group session was led by Timothy Weymann, LCSW.

**Timothy explained that ableism is prejudice and discrimination** based off of an individual's ability status. It holds that being able-bodied is superior to being disabled. Further explanation:

- Center for Disability Rights: <https://cdrnys.org/blog/uncategorized/ableism/>
- Definition: 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. Ableism is intertwined in our culture, due to many limiting beliefs about what disability does or does not mean, how able-bodied people learn to treat people with disabilities and how we are often not included at the table for key decisions.
- Societal perspective that we are "less than" if not able-bodied.
- It often doesn't come with malintent but rather being generally ignorant about what being disabled entails.
- Disability is traditionally not included in many of the ways we create norms, laws, rules that set up work, set up school, and sometimes even the healthcare system.
- It can be so encompassing that individuals with a disability can adopt ableism themselves when they view themselves negatively and that can come with shame or a self-concept that is mean or dismissive.

**Timothy's examples of experiencing ableism.**

- A medical provider states that there is “nothing wrong with you” when diagnostic tests results are normal. That’s a form of ableism in the sense that the provider isn’t including in their mentality that their tests are limited and just because a test doesn’t pick-up an abnormality, they dismiss the patient’s reports of disabling symptoms.
- Timothy shared that his legs and ankles were in casts when he went to have a blood draw. The facility staff wouldn’t provide him with a chair to sit on while he waited despite his requests. (He ultimately filed a complaint with the ADA.)

### **Participant feedback about experiencing external ableism:**

- Experienced ableism in a group of supportive friends who couldn’t understand why they couldn’t move to a different community.
- Sibling’s use of a wheelchair due to polio is accepted by family while they are dismissive of participant’s need for mobility devices.
- Yes, I’ve experienced this, “it’s psychosomatic”, blame the patient, especially said to women!
- Medical gaslighting
- Social security process
- Family does not understand why participant can’t work.
- Accessibility
  - Not wheelchair accessible
  - Lack accommodations for visual/sensory/auditory stimulation.
- Invalidation
  - “You don’t look sick.”
  - People/family/friends/doctors denying your illness
  - People questioning why you have a placard.
  - Questioning wheelchair use
- People tend to project their own limitations on to other people (example: because I can’t see it then it must not exist).
- When psychosomatic diagnoses are placed on those who have chronic illness.
- When people talk to others about you when you are right in front of them.
- Other people with a different illness can project ableism.
  - I’ve noticed that people with “accepted” chronic illnesses seem more judgmental than others. They seem to think that since they are able to rise above their illness, I should be able too. I’ve had a few tell me to just “work harder.”
- Those who aren’t mindful and respectful of those who have illness.
- Those who mock or disrespect those who wear masks.

### **Participant’s experiences of internal ableism:**

- Shame after being so active and healthy while living in a very active community.
- Blame

- Looking down on yourself.
- Feeling embarrassed by your illness.
- “I don’t have a right to...”
- Internal conflict and inappropriate guilt.
- Internal struggle because you “can” do it, but you pay for it.
  - It can be hard to pace and take care of ourselves when other people are encouraging us to work, socialize etc. (and that's what we want to do too even though we know it is not healthy for us).
  - Feelings of shame for not being able to do more or live up to others' and my own expectations.
- Using rest time to internally criticize self. Once they recognized this issue and changed to focus on truly resting it helped to increase their capacity.

### **Timothy’s shared wisdom:**

- Relationships
  - A lot of pain and hurt in relationships is born of ignorance, not malintent.
  - A common complaint in working with individuals with chronic illness is that certain family members don’t understand and even worse don’t appear to want to understand. This is a form of ableism.
  - Some people tend to project their own limitations onto others. “If I can’t see it, then I tell you it doesn’t exist.” It takes a level of inner strength and resiliency to identify that and understand it is about the other person’s fears. Sometimes it can help to speak to the deeper truth. For example, say, “I appreciate that you have that kind of concern, and I want you to know XXX about my disease.”
  - When things are painful for people they tend to deflect or redirect. (This was in response to a participant sharing that their mother asks for the participant’s spouse’s perspective whenever they share how they aren’t feeling well or isn’t able to participate in something.)
  - Timothy often sees people with chronic illness fixate on the person who won’t or doesn’t want to understand. There is a reasonable expectation of grief over what people can’t or won’t give. This is when we need to realize it is about the other person and develop emotional awareness.
  - Not wanting to understand is a form of gaslighting.
  - Before you argue with someone, ask yourself, “is this person mentally mature enough to grasp the concept of different perspective?” If not, there is no point in arguing.
  - Timothy advises people to look for the vulnerable emotion underneath and to speak to that. For example, say, “You seem really concerned about this and afraid. Is that true? Can you tell me more about that? What I really need is... Are you willing to give that to me?”

- Internalizing
  - Part of coping with chronic illness can be identifying how much we've internalized those messages and then challenging it within ourselves.
  - When we don't regulate our fears, it can come out in an unhelpful way. This is true whether someone is ill or healthy. It's important for us to be aware of fears and speak to deeper needs.
  - Is the shame and embarrassment helpful? If not, then let it go.
    - "I will hate myself into being a better person" or "well person."
  - Accept that the older younger me might be gone but the new me might have a future.
- Dating/Romantic Connection
  - If you are single in this group and you want to date or are dating, and someone rejects you due to illness it means they aren't the right person. It doesn't mean anything bad about you or your possibility because everyone has limitations.
  - There is also a world of people out there who have disabilities that maybe like ours or they grew up in a family with it and have an understanding. Timothy encourages the group to challenge the fears.
  - If you want to have those connections then it just takes extra communication. Be direct in what you want.
- Meta communication
  - Meta communication is when we talk about the way we are communicating.
  - When we are in conversation with someone and it isn't going well we can address the way we are communicating as a way to improve the direction of the conversation. For example, we can say, "I'm noticing you are doing XXX when we are talking about XXX. I need XXX. Are you willing to be more curious about my illness rather than judge it?"
  - Asking open ended questions can make people think and possibly change their perspective.
  - Meta communication is an important skill to use when dealing with difficult conversations and navigating ableism.
- Minority Stress
  - Minority Stress is a result of things you go through that are stressful consistently because you are a minority. Not everyone has ME/CFS, fibromyalgia, or long COVID and so society is structured as if those things don't exist. These stressors build up and we can become overwhelmed.
- Self-advocacy
  - Prompt example: I don't know if you mean this right now, but it feels like XXX because you are XXX would you please XXX (talk to me directly).
  - It's important that we dig into the vulnerability of the discomfort because that's where we learn about each other's experience.

- We often have to be our own advocate in teaching others how to treat us.
- Directly ask for what you want. "What I really need is this, are you willing to give that to me."
- Ableism
  - Identify prejudice for what it is; externalize it and don't let it consume you.
  - Able-ism (along with all the other -isms) are just instances of mental laziness. Rather treat the situation or person as an individual, they revert to categories or groups. It's just easier than being in the moment and relating to the specifics of the situation at hand.
  - Unchallenged oppression becomes internal depression.
  - "That's who he is, that's not who I am."
    - "Ask yourself "who am I?" That's what matters in this life.

### Resources Shared in the Session

- A social justice definition as developed by Talila Lewis
  - <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update>
- Chronic Fatigue and ME documentary free on Tubi.
  - <https://tubitv.com/movies/589832/chronic-fatigue-syndrome-me>
- I consider groups like this to be a community care practice akin to "disability doulas." I've gained tools and language I never had before and it helped me along even when I struggle with "labels" and judgments.
  - <https://19thnews.org/2023/07/disability-douglas-support-newly-disabled-people/>
- Tissue banks
  - Stanford has an ME-specific brain and tissue bank
    - <https://med.stanford.edu/chronicfatiguesyndrome/research.html?fbclid=IwAR26K6jrgJAvRiC5NuM0nYyL-dmt0pIFDqCgXNtL8Oh33vLOcZq1eUqoKbM>
  - BHC's handout
    - <https://batemanhornecenter.org/accelerating-cfs-research-brain-donation/>
- Cartoon explaining PEM
  - <https://themighty.com/topic/chronic-fatigue-syndrome/comic-strip-that-explains-chronic-fatigue-syndrome/>
- Some COVID solidarity wins are listed in this zine on reinstating precautions that might give some hope.
  - <https://www.peopleshub.org/resources>

## General Resources

- [How to Be a Demanding Diplomat as a Severe ME/CFS Caregiver](#) (video)
- [ME/CFS Crash Survival Guide](#)
- Crisis Resources
  - Dial 988
    - [What Happens When You Call 988?](#) (Article)
  - Dial 911
  - [Crisis Text Line](#)
  - [Crisis resource page](#) (BHC)
- Support Groups
  - BHC Support Group 2<sup>nd</sup> and 3<sup>rd</sup> Tuesday at 1 pm MST
    - <https://batemanhornecenter.org/events/>
  - Surviving with ME
    - <https://www.facebook.com/groups/695317212152964>
  - ME/CFS Social Group
    - <https://www.facebook.com/groups/1202428297198122>
  - CFS/ME Friends
    - <https://www.facebook.com/groups/CFSMEFRIENDS>
  - International ME Support Chat
    - 11am-1pm EST/ 5 -7pm GMT / 3-5am Melbourne time & 9-11pm EST/ 3-5am GMT/ 2-4pm Melbourne time
    - <https://us06web.zoom.us/j/84362703704?pwd=bfKmegaCLNhS6KwOUve7fkcsQjs7sB.1>
  - ME/CFS phone support group
    - Occurs on Saturday nights at 8pm, EST.
    - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
  - Massachusetts ME and FM Association Small Group Chats
    - <https://www.massmecfs.org/>
  - #MEAction Living w/ME Support Group
    - <https://www.facebook.com/groups/211058135999671>
  - Caregiver Support Group
    - <https://www.meaction.net/event/me-partner-caregivers-support->

[group/all/](#)

- Health Stories Collaborative Creative Meetups
  - <https://www.healthstorycollaborative.org/creativemeetups>