

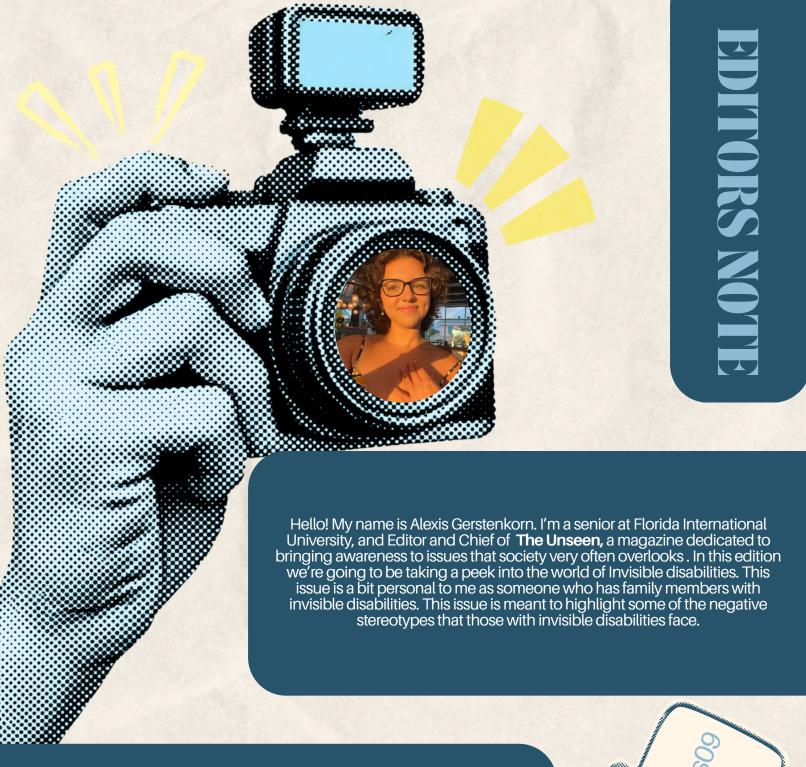


**ALICE WONG** 

### STORIES FROM EVERYDAY HEROS INVISIBLE DISABILITIES

From Alice Wong's book, Invisible Disabilities, A collection of stories from disabled individuals in the 21<sup>st</sup> century.





Now I'd like to make a quick disclaimer, though I have family members with invisible disabilities, I myself am not a part of this community. The content within this magazine is based off of my own research into the matter. It is not my intention to offend or spread negative or false information, that being said I am human and prone to making mistakes so if you find any information within this magazine which you believe is false please feel free to reach out to me via my email.





Here are four individuals. Each of them have been diagnosed with a formal disability, can you identify them?















### **BUT CAN YOU SEE ME?**

SO WHAT IS AN INVISIBLE DISABILITY?

When we think of an individual with a disability we often might think of someone who uses some sort of physical aid like a wheelchair, medical aid, or prosthetic limb. Something that, to others, can be easily used to identify them as disabled.

Now lets take a moment to first identify what a disability is. The term "disability" is meant to describe an ongoing physical or mental challenge (whether short or long term)<sup>1</sup>. Just because a person has a disability doesn't mean they are necessarily disabled, many with a disability are still living full and active lives. Disabilities come in a range of manageability.

Invisible disabilities, as the name implies, are much harder to spot. They are "conditions, illnesses, and structural or biomechanical anomalies that are life limiting but not readily discernible to others," meaning just like our little "game" earlier you more than likely would not know that an individual is disabled just by looking at them<sup>1</sup>.

Just like visibly disabled individuals they still face many challenges within their day to day, yet, despite this their stories are often left out in the conversations surrounding disabilities.

Joni Eareckson Tada, an international disability expert, explained her experience with an visible disability to someone with an invisible disability saying, "People have such high expectations of folks like you [with invisible disabilities], like, 'come on, get your act together.' But they have such low expectations of folks like me in wheelchairs, as though the thought is that we can't do much" 1. She shows the stark difference between how society views invisible disabilities.

There are many conditions and illnesses that fall under the "Invisible disabilities" umbrella but here are just a few to help you develop a better understanding of what invisible disabilities are.

### MENTAL DISORDERS

These may be both mental heath related (Depression, ADHD, anxiety, bipolar disorder, etc.) or Neurological disorders like autism or dyslexia. These can come either from birth or from traumatic events /injuries later on in ones life.



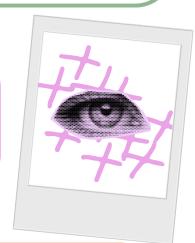


### CHRONIC ILNESS/PAIN

Conditions like arthritis, fibromyalgia, chronic fatigue, and diabetes are examples of a chronic illness. While chronic pain can look like migraines and nerve pain, all of these issues can be debilitating to ones day-to-day but are rarely outwardly noticeable. <sup>2</sup>

### **VISUAL IMPAIRMENTS**

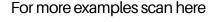
Visual impairments fall under sensory impairments and don't just mean a complete lack of vision but rather come in a spectrum. Many, unlike someone with complete hearing loss, are much more dificult to recognize. <sup>2</sup>





### HEARING IMPAIRMENTS

This also falls under sensory impairments and again doesn't only include those with a complete loss of hearing?





Hello, and thank you so much for joining me today! It's an honor to get to interview you, will you share who you are with our audience?

Hi! I'm Rachel Bender, I'm 21 years old and I'm an influencer on Instagram where I share my life and advocate for invisible disabilities.

Yes, I see you've been speaking about issues surrounding invisible disabilities for a few years now. Tell me what inspired you to dedicate your page to this cause?

Well, I was diagnosed with juvenile arthritis when I was about 18 months old. Since then I've received dozens of treatments, and have been diagnosed with POTS and Chrohn's disease, all of which have affected my quality of life. Many think that just because I look "normal" on the outside that my health issues aren't as severe as I say they are, so I wanted to use my platform to bring awareness and educate others on the reality of having an invisible disability.



I see, but with so many invisible disabilities out there how can you possibly bring awareness to all of them?

Oh? Tell us more!

Well sometimes I do advocate specifically for those with juvenile arthritis like myself, but I try and make my page a place for everyone in the community. Obviously I can't bring attention to the needs of every single individual with a disability, so I try to cover issues, information, and resources that I know will affect all of us in the community.



**@RACHCUTIEPIE** 

One major issue I've been talking about a lot on my page recently is the budget cuts to programs like Medicaid and the ACA (Affordable Care Act). These programs help individuals like myself pay for medications and treatments to manage our disabilities, without them the cost of our care is going to rise significantly. This hurts all of us, and may force some to choose between paying for food and paying for life-saving meds.

I had no idea the government was allowing these kind of cuts! But, how can we help to stop this?

It's really simple. Call. Your. Senators. Even if you yourself don't have a disability. It may seem that in the face of all these major decisions there's nothing we can do, but if we bring our voices together we can push the people in power to make positive changes. Also, educate yourself on what's going on and spread the word! The more voices we have, the more powerful our message.

Great advice, which actually leads me into our next question. What advice would you give to non-disabled people to be better ally's to the community?

I think the best advice I can give is to just listen. You never know the kinds of struggles someone may be going through, even if they look "fine" to you. Take the time to actually sit down and hear their story. By doing this you'll have a better understanding of what they're going through and what they may need.

## RACHE



For my final question, do you have any words of wisdom for other influencers who want to use their platform to address social issues like yourself?

Just do what works for you! I like to share a lot of my personal journey which helps to spark conversation, but you can also do skits or share infographics. Even just reposting other stories or posts about an issue can be helpful to bring awareness!

Well thank you so much for joining me today! It's been a pleasure!

Of course! And if you guys check out my page be sure to check out the other organizations linked in my bio!

Arthritis Foundation Jingle Bell Run

Protect Ostomy and Catheter Supplies



We've all had that experience, you get up one day with a horrible stomach ache or a cold, but when you tell your parents or a teacher you're met with, "you're fine, you just want to skip school," or "maybe you shouldn't have \_\_\_." Though you're in pain your feelings are downplayed or dismissed entirely. It was probably frustrating having other people tell you how you're supposed to feel, even after making it clear that you were struggling. Now, imagine having to deal with that same situation every day of your life, that is how many individuals with invisible disabilities are forced to live every single day.

As Dr. Amrita Sen Mukherjee, an advocate for invisible disabilities in the medical field, perfectly stated in her ted talk, "people with disabilities not only bear the weight of living life with their unseen conditions, but they face further burdens. They have to contend with the daily struggle of living in a world that does not fully acknowledge, recognize, or understand their needs." In a society where looks essentially rule how you're to be treated, those with invisible disabilities are often not taken seriously and/or treated unfairly because they don't "look disabled enough."

The general consensus among the able bodied community is this idea that those with invisible disabilities are "faking it," or using it as a cover for their own laziness. these assumptions are extremely harmful as not only can it have mentally and even possibly physically damaging effects on disabled individuals. these negative stereotypes can prevent people from accessing proper resources and makes it even more difficult for laws that mandate how disability rights are carried out . This is because with the assumption that disabled individuals are "faking it" then comes the argument that proper accommodations would allow them an unfair advantage.

What many don't understand is that accommodations allow individuals to participate fully in school, work, and in daily life. Without them many would have to deal with added barriers on top of dealing with personal ones. All disabilities can significantly impact a persons life, one way or another, and just because you can't see it doesn't mean they can't feel it.





In Disability Visibility by Alice Wong we hear stories from real individuals with both invisible and visible disabilities.

These individuals come from all walks of life. From different races, ethnicities, and economic backgrounds, each share their story about living with disabilities.

Now Wong makes it clear these stories are not meant to bring about a sense of pity but to bring awareness and help other young disabled people come together to fight for themselves and their community.

However, this book does so much more as it reveals not only brought by having a disability but how those struggles may be amplified based on your standing within society. These highlight how issues within the disabled community are intrinsically linked to so many other aspects of our lives. Here are just a few of the stories shared.

### KITAY D. DAVISON

Davis was a proud black, disabled trans man who spent his life advocating for multiply marginalized people with disabilities. For those like him who not only faced barriers because of their disabilities, but also because of their race, sexual orientation, gender, or economic background. He famously said, in a letter to his community.

"Advocacy is not just a task for charismatic individuals or high profile community organizers. Advocacy is for all of us." <sup>5</sup>



### JEN DEERINWATER

A citizen of the Cherokee Nation of Oklahoma, Deerinwater describes her experience as a disabled woman trying to receive treatment while having to deal with extreme anti-native racism. She goes on to explain the appalling state of medical care within native reservations. The *Indian Health Service* (IHS) is consistently ranked as the worst healthcare provider in the US due to poor funding. This already makes access to proper healthcare very difficult but it makes it next to impossible for disabled individuals.



### June Eric-Udorie

A young black woman born with congenial idiopathic nystagmus. Udorie recounts the clash between her disability and her religious upbringing, Her disability was seen as something she was just waiting to be "healed from" and her feelings and medical needs were largely ignored due to this belief. This led Udorie to be embarrassed about her condition and neglect to seek programs or accommodations that could have eased her daily challenges. 5



Disabilities have posed immense challenges for individuals for centuries, but to marginalized groups, like people of color, those in the LGBTQ+ community, women, and immigrants, it adds another complex layer onto pre-existing issues. Though this article doesn't have the capacity to touch on all these intersections it is important to take a moment to acknowledge these stories and histories. The following excerpt hails from the *Disability History Series* brought to you via the **National Park Service.** Like my magazine they were unable to go in depth into the complexities of these issues, however they sum them up nicely while also providing the following resources, which I will provide as well.



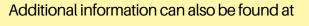
- Women and Disability: Women have faced discrimination based on misguided beliefs
  of their intellect and capability throughout American history. In the late 1800s and early
  1900s, there were several cases of women who were institutionalized at psychiatric
  hospitals. Some of these diagnoses included promiscuity and hysteria, which
  physicians often blamed on heredity, country of origin, or education.
- Immigration and Disability: There are many accounts of immigrants who arrived at Ellis Island and other entrance stations, only to be turned away due to their perceived "disabilities." Certain populations were regarded as more "inferior" or "defective" than other groups. This kind of categorization led to the Immigration Act of 1924, which relied on quota systems to cap the number of immigrants from various countries of origin, and similar legislation.







- Inclusion of people with AIDS in the Americans with Disabilities Act: After much debate within federal government in 1990, it was decided that AIDS would be recognized by the ADA, meaning discrimination against people with AIDS was prohibited in all areas of public life.
- Race and Disability: People of color were often placed in segregated psychiatric institutions in the late 1800s and early 1900s. These hospitals and asylums rarely followed the rule of "separate but equal."







- Listen to their conserns and issues with empathy and understanding.
  - Try and educate yourself so that you don't allow stereotypes to drive your understanding. 4
- Go out and find disabled activist/ creators to support.<sup>5</sup>
  - Take a stand when you see oppression, just because you are one person doesn't mean your voice doesn't matter.<sup>5</sup>
- Allow those with disabilities to come to you for help rather than assuming their needs.
  - Allow them to use their accommodations without judgement.

People with disabilities make up the largest minority in the United States, yet their stories are often ignored or untold. In the late 1700's and early 1800's people with disabilities were placed in poor houses or forced into insane asylums. Even after reforms were made to treat these people with respect and dignity they were still stripped of their autonomy with others making decisions for them, which is why as an ally it's imperative that you implement the major qualities of being an ally: Providing affirmation and engaging with informed action.

## OFBEING

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Try and make someone "prove" their disability to you. 4

**DONT** Assume a persons experience just because they look or act a certain way.

 $oxed{1000}$  Judge their needs based on what you think a disability "should" look like.

DONT

Try and label them or shove them into a mold that you understand.

DONT

Try and speak for anyone. Even if it is what you think they need.





Disability advocacy has come a long way since the cruel treatment many suffered in the 1700s but its important to remember that the fight is far from over. So today, I encourage you to go out and, whether through what you've read today or your own research, immerse yourself in the world of invisible disabilities and find creators and even neighbors from whom you can support and learn from.

## ANAILY



**SOURCES** 

Thank you to the following sources for educating me on this topic and I encourage all of my readers to check them out if you'd like to continue learning.

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