

Health Disparities-

A look through a lens called my life

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A patient

Out of My Control- Medical Biases

- As a person with disabilities, I noticed that I have been treated in a wide variety of ways.
- Multiple different factors contribute to why I am treated differently some of which are written below:
 - Being a woman
 - Being African American
 - Having invisible disabilities
 - Being visibly disabled
 - Having mental health diagnosis
 - Being educated

My Background

- In middle school, I began to have noticeable health issues in which multiple providers considered a case of anxiety, depression, or even a lack of social skills.
- This is when my fear of medical providers started, and my medical files began to receive life altering notes that make finding reputable doctors for my care difficult.
- I dealt with on and off issues which resulted in getting many different health diagnosis almost 8 years later. This was the start to a very long and hard medical journey.
- All it takes is one note for someone like me, a disabled ethnic woman to receive subpar medical care for the rest of my life.

Medical Bias and Discrepancies

- In December of 2020 I contracted Aseptic Meningitis from a treatment one of my most trusted providers suggested via home health. The nurse I had at the time decided to disregard my doctor's instructions on the orders and I received this medication in less than half the time my doctor wanted.
- This led to almost two weeks hospitalized. The first five or six days I received amazing care. I was sent home prematurely which resulted in me going back and getting readmitted.
- During this admission I had the doctor on my floor refuse multiple daily medication and pain medications although he could see visible pain.
- When I asked him why he said, “ People like you don't have pain from diseases like this”

Medical Bias and Discrepancies

- In July of 2022 I had back pain which caused significant trouble for several months. I finally saw a Physicians Assistant who informed me I could trust him, and he would help me find answers. After one or two different test I received the following message while out of town. He gave up on me.

9:55 AM

Really sure what else we can do, as on not sure of the source of your pain. I think when you get back to Virginia work on half to seen due to a pain management specialist as I believe your problems are above my pay grade.

Stories Like These

- Stories like these are all too common. Having information in your chart that treats you like you are noncompliant, incompetent, lying, or exaggerating will cause you to deal with many adversities.
- Stories like these make applying for any type of assistance extremely difficult including SSI or SSDI.
- This is why it is important to focus on specific definitions of terms used within different health records and program requirements.

The Definition of Disability According to the Social Security Code of Federal Regulation

- **§ 404.1505. Basic definition of disability.**

(a) The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months.

What does this mean

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- This definition sounds simple and unbiased but a quick look at the definition and social security administration website you will see areas of the application that fall short of being inclusive.
 - To receive a final decision on the qualifications of disability determination for SSI/SSDI, you are required to provide extensive documentation.
 - The level of documentation can be troubling for anyone. In order to go receive help you have to have established records and diagnosis.
 - Medical records are not easy to obtain due to the discrepancies or lack of notes. Medical care does not have a one size fits all approach due to medial bias.

No Documentation? No Approval

- The documentation that needs to be acquired to complete the application have no room for errors or gaps if you want your case accepted.
- They require the need for a chronologically well put together medical records and documentations to be submitted.
- To obtain these medical records, I have personally called previous doctors offices where the hospital system claim my records are destroyed or do not exist.

No Documentation? No Approval

- As a minority disabled woman, I often believe that sometimes I am better off avoiding doctors and medical offices due to the amount of medical bias, discrepancies, and ablism I endured.
- I have personally significantly struggled in obtaining documentation to the extent required for approval, I decided that for my physical and mental wellbeing I would retract my SSDI/SSI application in which I started.
- Due to the tedious requirements, I quit before I even turned it in.
- Giving up seemed to be the best option and this is truly unacceptable.

My Why

- When it was time for someone to get a new wheelchair, they reach out to the Durable Medical Equipment (DME) company and this company tells the person they need a Primary Care Physician to provide a referral / script. Once this is done the DME company informs the patient that they need to get an evaluation by a Physical or Occupational Therapist. All of the companies must work together to provide the best care in order for the patient to receive the medically necessary equipment. If one of the company's skip a step all the other companies must wait thus causing the patient to wait months and sometimes over a year for something that could have been completed sooner if the companies communicated to one another. As an Advocate I work as an ombudsman to bridge the gaps, see where the patients progressed stopped and advocate to move them along to the next step.

The Need For Change

- SSI/ SSDI are designed to help people with disabilities. The process is so tedious that people like myself either start the application and do not complete it or they attempt to complete the application, receive a denial, and they do not try again.
- The policies surrounding SSDI/ SSI and the definition of disability need to be reassessed in order to focus on the entire population being served.
- This is a process designed to help people but instead it results in people with disabilities dealing with consistent stress of approval.

As An Advocate

- When receiving medical care, I found a gap within the intercommunication between different medical companies, hospitals, and pharmacies
- People were waiting months for an item due to the lack of communication.
- As an advocate I use my voice to speak for people with disabilities who are unable to receive the items they need in order to receive the best care.
- This is why I started to advocate. My passion is to Amplify Disabled Voices