

Invited testimony for HCR 14

March 05, 2020

Annette Alfonsi

Hello! Can you hear me?

Thank you for letting me speak with you today. My name is Annette Alfonsi. Before 2012, I worked for the 1%, had a college degree, was in great health, and was looking at grad school. After I was a passenger in a rollover car accident with a reckless driver, my primary provider gave me one day off of work to rest. I had multiple internal injuries and persistent concussion symptoms over time, and was told different things by doctors. Some didn't believe me or assumed my symptoms were only behavioral and not physical, and some said my healing would not improve and I would live my life with my current symptoms and would never work again, or that I should be a housewife. None of them supported treatments for healing. I was laid off one business day before I would have qualified for medical leave, was denied disability, and was told at the municipal and state level that I am not in a category people care to help. I no longer have a retirement. I am statistically likely to get reinjured, experience homelessness, have lower lifetime outcomes, and have greater risk for comorbid health conditions that most health providers don't currently know they should be screening for. Multidisciplinary treatment, working with a brain injury specialist physician and leaving Alaska for treatment is what helped me. Leaving was less expensive and more effective than what I paid for and experienced here.

When the brain injury doctor I was seeing left Alaska in 2015, I planned a TBI conference while recovering from back surgery, so her knowledge could stay in Alaska. Over 100 people attended. By request, this led to our annual conferences with different host organizations. I've been told I cannot attend educational events because I am a patient, so the events I plan allow everyone to learn the same thing and facilitates advocacy with knowledge.

This year, I am planning another TBI conference hosted by Hope Community Resources on Friday, March 27 and Saturday, March 28. We have continuing education credits approved in 8 professional fields, and we're offering distance education, so you are all invited to attend for free. I plan this with volunteers that want standards of excellence in multidisciplinary and intercultural health care around brain injury in Alaska. Go to AlaskaBrainInjuryEducation.com for more info.

In 2017 I became the Alaska Coordinator for Unmasking Brain Injury, an internationally known brain injury awareness project, in which people with any kind of traumatic or acquired brain injury and their loved ones can make a mask, with an explanation of their art, to share what it feels like to live with a brain injury. We work with groups to host mask making events, and to host mask exhibits. Visit unmaskingbraininjury.org for more info.

But I am still not employable, because this type of work with my level of education is only available full time and I can't work 40 hours a week.

The past two years I've hosted community conversations with groups that tend to have a higher number of clients that have experienced brain injury. This includes organizations in fields like domestic violence, homelessness, reentry, suicide prevention, substance misuse, child abuse, and senior citizens. Directors and project managers know their folks have brain injuries, their client's brain injuries affect every part of life, and they are often the first point of contact for clients. But they don't understand their client's symptoms through the lens of brain injury. I am tired of these groups asking you for more money when they are ignoring an undercurrent that is the biggest issue for their clients.

There aren't social service programs around brain injury compared to mental illness, so if someone has a brain injury and a mental illness, and must choose one diagnosis, they may disclose the mental illness to qualify for programs.

So I'd like to suggest two concrete ideas to this body:

Number One Idea: Make state funding for any group that is known or suspected to have more than 50% of their clients experiencing a brain injury be tied to education, in other words, state funds would not be disbursed unless the staff get brain injury education, and the funding should not be used for that education. Unlike medical professionals that tend to focus on diagnosis, these groups focus on function and need to understand the client symptoms they are witnessing. I know program directors in social service groups that love this idea.

Number Two Idea: create or support a housing unit specifically for brain injury, the way other housing units are for people with specific diagnoses and health issues. This would allow tailored environmental modifications, and could be excellent for group therapies, peer support, and individualized treatment opportunities. I know directors that love this idea also.

Damage to the brain can be healed but the amount of that healing is dependent on a number of concurrent factors not being maximized in Alaska. We need to get away from the idea that someone is good enough, or looks fine, when inside they are suffering. We can do better, and it starts with awareness. Please pass this resolution to raise that awareness. Thank you for your time.