

June 22, 2020



To Whom It May Concern,

I am writing to you to inform you about why I think Legislative Concept 52 is vital to the rights of those who experience disability. I am a professional guardian solely supporting people who experience intellectual/development disabilities as well as a parent of a teenager who experiences intellectual disability. Since this pandemic has started, I have experienced multiple situations where people were subject to discrimination and based upon their disability diagnosis.

We had one young woman in her 40's who experiences intellectual / developmental disability who upon arrival at the Emergency Department had a fever of unknown origin. On her second day in the hospital and after she had transferred out of the ICU the care team had a meeting with us as guardian and her residential care providers. At the time of this meeting she was improving and getting better however we as guardian and her residential care team were asked to change her POLST to require a lesser level of care and treatment. We declined to make this decision as it was not the right decision for her. She was an active lady who was pursuing employment, enjoyed getting her hair done at the salon, and had a dark sense of humor. In the end due to multiple discriminatory factors this young woman ended up passing away from what had originally been a treatable diagnosis. Anna Keenan-Mudrick will be sharing more about this woman's experience through verbal testimony today.

We had another elderly lady with Down Syndrome who went to the Emergency Department and when she was admitted her support staff was told she could not have any visitors. This elderly woman is non-verbal and uses gestures and a couple signs to communicate. She was left at the hospital for two days before we were able to convince the hospital that she could have a visitor and by then she was being discharged. Without a support person there was no one there who knew her who could relay to the nurses and doctors if she was in pain, hungry, or uncomfortable. She did not have anyone available to help her understand her care options nor communicate with her care providers. Additionally, due to her disability she is not able to call for or request help, order her meals, nor consent to any treatment.

I share this story with permission from a friend of mine. Her adult son experiences disability and was to have a CAT scan at a local hospital. He brought his mom with him to assist as a reasonable accommodation due to his disability as an email from the hospital had stated was available. At Admissions he told them he had a disability and needed his mom as an accommodation for the procedure. Admissions eventually let his mom accompany him to the waiting area but then again refused him the accommodation from that point on. The way he had to fight to have her accompany him to the waiting area and then no further resulted in increased stress and agitation and a difficult hospital experience.

It is vitally important that people with disabilities have access to their ADA afforded right of reasonable accommodations within the health care system especially in times of crisis. The ability to access a support person assures they are able to communicate their needs during their stay. If, due to disability, the person is unable to relay, pain, hunger, discomfort and/or fear having that support person is imperative to assure quality of care and understanding of care.

Thank you,



Emily A Braman
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The Arc Oregon