

Oregon Health Policy Board September 1, 2020 meeting

Presentation by three members of the Oregon disabilities communities: West Livaudais, Krystal King, Christine Getman

Note from West Livaudais:

The disabilities communities is experiencing a disruption in services and resources due to COVID. For example, services have been disrupted due to staff cuts at community-based organizations due to funding shortages, or services have been disrupted because personal care attendants can not commit to entering a medical bubble with a single vulnerable client because they don't receive a livable wage from DHS. PPE supplies are limited and people with disabilities are reusing gloves or they are not using gloves to perform daily procedures that help keep their health stable in order to not acquire an infection. Additionally, low income people with disabilities living in some congregant independent living settings are required to supply gloves for staff who enter their apartments. They are using their limited financial resources to purchase PPE that they wouldn't need to outside COVID.

People with disabilities also experience stigma and discrimination as they access healthcare in hospital and clinical settings, which SB1606 has helped to buttress during COVID. This includes assumptions about a disabled client's quality of life, mental capacity, or ability to represent themselves independently by a provider, among other things. Additionally, a dearth of culturally responsive health care providers with lived experience of a disability persists in hospitals and clinics. It is our experience that living with a disability is a culture unto itself. Lastly, widespread environmental barriers and untrained health care professionals exacerbate these stigmas and attitudinal barriers to care.

People with disabilities also experience systemic barriers that prevent workers with disabilities and their families from getting access to care, including personal care attendants not earning a living wage during a pandemic, and the Medicaid eligibility asset and income restrictions for workers with disabilities that prevent them from earning more for themselves and their families merely because they live with a disability and need long-term supports and services.

There are significant technology barriers among people with disabilities that live in poverty. In Oregon, a person with a disability is 2x as likely to be under- or unemployed, and 4x as likely to live in a household that earns less than \$15k/year as the general population (BRFSS 2017).

### **Notes from Krystal**

#### Testimony

Hello, my name is Krystal King and I am here representing the PDX Disability Justice Collective. I am autistic, I am the founder of a group called Autistics and Allies for Ethical ABA, and I work

in both Behavioral Therapy and Home Health with children with physical and/or cognitive disabilities. I'm grateful for the opportunity to be here to shed some light on what has been happening within my community. (0:24) (0:24)

I have one home health client. She is sweet, she's intelligent, she's expressive, she's creative, and she's incredibly aware of what's going on around her. She is also medically complex with significant cognitive support needs. She has a number of medications to balance throughout the day, and at any given time she is enrolled in speech therapy, physical therapy, and behavioral therapy. She has an extensive care team that includes all of her therapists, her primary, her neurologist, her endocrinologist, her psychiatrist, the specialist for her condition, and her Home Care Aide, which was me prior to the pandemic. She is fully nonverbal, which means not only does she not speak but she doesn't use any formal communication systems. (1:08) (1:10)

And this is why it's so important that she has **her** care team. I know from the way she touches my arm in the car whether she wants a snack, or the radio turned up, or is just done being in her car seat. I know all the subtle cues that come before a seizure, and I know how to care for her through them and keep her safe; her seizures can be violent and dangerous. I know how to balance her various medications to give her the best quality of life. This child cannot just go to anyone. It takes us weeks to train a new person to communicate with her and to provide the level of support that she needs. (1:46) (1:49)

And it's not just her that needs support. This child is being raised by her incredibly dedicated Grandma, who is also taking care of Grandpa. It's very physical work, this child is not small and she's not that young. She regularly goes multiple nights without any sleep. And she cannot be left unsupervised, so Grandma also goes multiple nights without sleep. This is a family very much in need of home care services. (2:11) (2:14)

When we began to see community spread of Covid-19 back in March, the family and I had no choice but to pause home care services because their entire household is considered medically fragile. I spent time running errands and gathering supplies and medications for them, but I could not help with the rough days or the sleepless nights. We tried to find out if there was any support for a healthcare bubble or access to rapid testing for healthcare workers, but there was no existing infrastructure. I have not seen this family since the beginning of the pandemic. Which is good because we actually did contract Covid in my house; my husband tested positive for 7 weeks straight while I tested negative and showed no symptoms. (2:42) (2:45)

Our story is far from unique. Because of my advocacy work, I spend a lot of time talking with families with young children. The process of finding quality caregivers is extremely discouraging in our current system. Compensation for this work is below a living wage, and as such it is a near-impossible task to attract people who are educated and experienced enough for these positions. Many families either go without care, or are forced to pay out of pocket for services that are supposed to be provided by the state.

It can be difficult for caregivers and home health workers to be able to afford to do this work alone. Many of us have to supplement our income with other jobs; this is why I only have one home health client, I am incredibly passionate and well-qualified for this work but unfortunately I can't afford to take on more. I believe that if we had already put in place a strong healthcare network with living wages and affordable benefits, I would have been in a better position to go into a healthcare bubble and continue to provide services. Instead, families across the entire country are going without care because exposure risk is too great when their home health workers all have additional jobs. (3:52) (3:54)

Families in the disability community need support. Their home health workers need support. We need living wages that will allow us to fully devote ourselves to this work as a legitimate career rather than being treated and compensated like glorified babysitters. We need to start treating Home Health as a legitimate branch of healthcare so that we can adequately serve our communities, because under the current system, they are not being served. They are being left behind. (4:18) (4:19)

#### Original Email

Hello, my name is Krystal and I am an autistic/ADHD resident of Portland, Oregon. I was given this email address with the understanding that you are looking for participants to give testimony to the Oregon Health Policy Board on the impact of Covid-19 on disability services. My family has been heavily impacted, as I have been struggling through telehealth therapy and psychiatric appointments while quarantined; my husband tested positive for Covid-19 for 7 weeks straight. Several months ago I had requested a neuropsych evaluation to update my diagnosis, and I eventually had to lodge a formal complaint with my healthcare network to be taken seriously because telehealth was not a sufficient medium for them to see my difficulties and they would not take my self-reports seriously.

I work in behavioral therapy, and services have been significantly interrupted. I am considered medically vulnerable because of a history of respiratory illness, so I have been waiting over a month to be assigned a telehealth client so that I can provide therapy from home.

I also work in children's disability home health, and I have not been able to see my home health client since March because her entire family is medically fragile. The child has significant needs and does not have many people bonded to her in her life, so this separation has been hard.

I hope I can be of service, as I'm an avid Disability Advocate; I founded and am currently operating an online forum of 1400+ members regarding the ethical treatment of autistic children in ABA therapy services.

I'm a strong speaker with excellent written and verbal communication skills, and I'm extremely comfortable speaking in front of an audience. I would be willing to either speak on my own

personal experiences, or to provide testimony on the experiences of people far more heavily impacted than myself. Thank you for your time and consideration.

#### OHPB TESTIMONY

##### **Introduction**

- My name is Christine Getman. I'm the executive director of a nonprofit called Magic wheelchair, which promotes inclusion and self-expression for children with disabilities. --- WTW = durable medical equipment and services denied by insurance
- I have a disability called spinal muscular atrophy type 2 - which is a degenerative neuromuscular disease affecting my mobility... I can feel everything but I can only move one finger on my right hand. I use a wheelchair and have a tracheostomy and ventilator for speaking.
- I'm able to live, work, etc because I've trained a team of caregivers who know the nuances of my disability. My situation is not unique.

##### **Connect to Krystal –**

Krystal illustrated how people with disabilities are being left behind with Home and Community-Based Services. I'd like to echo that we are being forced to come up with solutions to impossible problems..

- From incentivizing caregivers to live cautiously without proper funding, convincing workers reducing # clients
- Assistive technology
- Shortage in medical supplies and accessing disinfectants
- providing PPE and testing to workers
- the onus is on us to stay safe, stay healthy, and stay out of the hospital

Our nonprofit pivoted to virtual mentoring and making PPE. After being hospitalized and experiencing the direct effects of the Visitation Guidance for Acute Care Facilities, I focused my free time on advocacy within hospitals.

##### **Theoretical headlines in hotspots**

We saw the headlines about critical care triage, ventilator rationing... But in Oregon there was an innocent assumption that those things wouldn't happen here because our in-patient numbers weren't that high... There is also an assumption that the ADA would somehow fix these discriminations and violations of basic human rights.

##### **Hospitals turned to policy, and they took it literally**

In communities, reducing movement and slowing spread made absolute sense, but in the hospital setting it actually removed basic human rights of people with disabilities and increased their potential exposure. In early April the alarms began to sound, all over Oregon, reports rolled in about COVID policy harming people with disabilities.

##### **This led to our work on SB1606**

The legislation was requested by Disability Rights Oregon, the Oregon Council on Developmental Disabilities, and the Developmental Disabilities Coalition. And championed by senator Sarah Gelser.

1. In Oregon, people with disabilities can have at least one support person/caregiver with them at all times in the hospital.
2. They must be allowed to have someone of their choosing with them for end of life care discussions and they cannot be required to sign a DNR or DNI in order to access care. This bill also applies to patients with dementia.

**That was a huge win.** I've received messages from hospital healthcare workers thanking me because some of their patients needed the constant hands on care of their own support person.

**I hope** this law means that Oregonians with disabilities can have the peace of mind that they won't become another tragic story or headline in the news, over the consequences of simply seeking medical care... COVID or not.

**But can we be sure?**

During the rapid creation/passing of **SB1606 FEDERAL RIGHTS SECTION PULLED**

**crisis standards of care document** -- People with disabilities shouldn't have to give an elevator pitch with photos convincing doctors, nurses, and even the state about why their life is worth saving. I have had to this.

- What can we do to **support you in future decision making and policy making?**
- How will you **elevate** the lives and the voices of people with disabilities as we continue to navigate this pandemic?
- How will you prepare for and implement policy and exemptions that ensure human rights and the ADA?

This summer was the 30<sup>th</sup> Anniversary of the ADA, paired with COVID its evident that we need to push for another revolution the ensure inclusion of people with disabilities.

I hope you see this as an opportunity to make history in the way Oregon protects, supports, and includes people with disabilities.

Unanswered questions and goals?

**LAW**

The Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services (HHS) enforces the federal law (Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act), which prohibit discrimination on the basis of disability in federally funded services. These laws, like other civil rights laws, remain in full effect. This means that persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. Medical decisions should be based on an individualized assessment of the patient based on the best available objective medical evidence.