a nonprofit organization assisting persons
with developmental disabilities
in the community

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Dear Governor Kat Brown; Senate President Peter Courtney, Senate Majority Leader Rob Wagner, Senate Republican Leader Fred Girod; House Speaker Tina Kotek, House Majority Leader Barbara Smith Warner, and House Republican Leader Christine Drazan; members of the Joint Interim Committee on the First Special Session,

I am the Executive Director of Community Access Services, and I am writing this letter to urge you to introduce and pass LC 52. The need for this legislation is NOW. I have provided one of our stories to demonstrate the DIRE NEED for this bill, along with The Arc Oregon, in another written testimony that we hope to share together verbally during the 6/22 hearing. So I won't reiterate that particular example in this testimony. I'll instead share two additional stories here to further exemplify the urgency of bill passage.

Community Access Services (CAS) is a nonprofit provider agency that serves individuals who experience IDD (Intellectual and Developmental Disability) living in Columbia, Washington, Clackamas and Multnomah Counties. One of our areas of specialty is serving individuals with IDD who also experience medical complication. Given this specialty, and given that we have been around for a little over 30 years, we have found ourselves frequently battling for full and equal access to all medical intervention/treatment options. Thankfully, we have many long time employees, such as our Associate Director who has been with CAS for 30 years, and who is adept at medical advocacy. We also have five RN Medical Managers in our employ, who work closely with those we support residentially, armed with their medical expertise juxtaposed with passion for the mission.

Scenario One:
Last month, in the middle of the night, a resident we serve was admitted to a hospital ER. I was notified by our Associate Director that they were not allowing our DSPs to attend to them, with the excuse being their being tested for COVID. We assumed this was as a precaution, as our CAS RN Manager supporting this individual indicated that they presented as having UTI symptoms.

After texting ODDS leaders and the DD Council's Policy Director for verification that the OHA guidance had indeed been changed to ensure DSPs were allowed as an accommodation even when someone was being tested for or had been diagnosed with COVID-19, and not hearing back immediately (as they were all asleep – although they answered swiftly in the morning), I searched through my emails and online, and found the OHA revised guidance on this accommodation, and the DRO – Know Your Rights document that also reinforced right to DSP accommodation in the hospital.

Despite my forwarding these docs to my Associate Director and the Program Supervisor, who were reading through these and pointing out over the phone that there was revised OHA guidance that clearly states the right to this DSP accommodation during COVID, they continued to refuse to let staff accompany this individual in the COVID unit while awaiting results, saying we were wrong, and that they knew what the OHA guidance truly indicated. They also said that if she tested negative they planned to transition them to the ICU where they would not allow DSPs to accompany them either.

This was very scary to us, given all that we did not know that occurred in the previous scenario described, the risks involved due to pre-existing medical conditions, the fact that this individual was unable to communicate to them without us there to support, the fact that we have a Program Supervisor and an Associate Director who have known them for over 20 years and a trusted RN Manager who has been in our employ for over 15 years

who know their baseline and history and should be communicating readily with their medical team during the hospitalization. We feared we were going to be cut off and/or evaded once again.

So, once we learned, hours later, that they still had refused the accommodation, after talking through it with the ODDS Director, and after hearing the reminder from the DD Council Policy Director that the guidance did not exclude support in ICU, I went to this hospital myself, met by my HR Director as back up support and witness, and the DSP (who has worked with the individual for around 5 years and knows her well) who was ready to attend to their accommodation needs.

We asked to speak to an Administrator, who we found to be congenial. He tried to explain their not allowing us in because of the COVID test. I showed him in the OHA document itself where it said patients have a right to the DSP accommodation even if being tested for COVID, and even had they been deemed COVID positive. I also showed him the "Know Your Rights" guidance document from DRO. The Administrator explained that, given that their COVID test came back negative, this individual was about to transfer to the ICU, where they could allow their DSP to accompany them. He then said that he did not want our staff trying to do their job for them – said when this individual was basically non responsive that had determined that we were not needed there. I explained that our staff was needed to ensure they had support in communication to them when more alert, and to communicate information about their care needs and preferences generally, as well as serving as a liaison to any of us who would have info needed that would help inform next steps. The Administrator, after my pressing, and providing him with the revised OHA guidance and DRO docs in hard copy form, said the DSP accommodation would be allowed in the ICU as they were in the process of transferring them there, while we were meeting.

Regrettably, once our DSP was in, the nurse attending to this individual tried to drive him out, and tried to disallow the next staff from coming in at shift exchange. The DSP articulated that he was allowed there as an accommodation, as a communication support and as someone who could help liaise with those from CAS with individual-specific info if needed. He stayed with them, and the next DSP coming on shift was able to get in, and remained, as did subsequent DSPs. Perhaps it took some time for the Administrator to inform them of his decision to allow the DSP accommodation.

FYI, I also talked with Emily from DRO on the phone that afternoon (last Saturday), and updated her on this new situation. She informed me that she had just received a call from the hospital's lawyer about it.

Although the hospital Administrator cautioned that they might not make it, even after verifying they had a UTI, they DID survive! Their DSPs talked with them throughout their hospital stay, reassured them, facilitated video chats with one of their most long time, and favored DSPs from the group home. They are resting now, recovering in the comfort of home. What a tremendous relief. Senate and House Leadership, I thank you for your interest in this critical problem. The fight for equal/full access to medical care is not a new one to Community Access Services, but no one should not have to fight for accommodation and equal access to all medical treatment options; many don't know how to fight for it; and the problem seems to have been exacerbated during the COVID crisis. During this time of limited visitor access, even when DSPs are allowed as an accommodation, we are far more reliant now on phone and video communication from the hospital staff to guardians, provider administrators and provider medical managers – we simply cannot send in our typical complement of expert/experienced agency advisors during this time, so this also needs to somehow be remedied.

<u>Scenario Two</u>:
This situation was with someone we support recently (earlier this month) going into the ER, at another hospital, for severe vomiting. They initially allowed the DSP to accompany them, but when she explained another DSP

was going to come in and relieve her, the hospital staff told her they would not allow more than one visitor in a day. When the staff tried to explain that the individual needs their staff support in order to communicate and be safe (he has communication, behavioral, and dementia support needs), they said their policy would not allow for this.

While I was on the phone trying to get a hold of an administrator to talk with, the Doctor reinforced with the staff that this was not allowable per hospital policy, to have another DSP come in on the same day, and directed them to talk with the hospital Social Worker about it. In the meantime, initially I was told by hospital admin support staff trying to get me through to a Hospital Administrator, that it was up to the attending physician to decide who was allowed in, and that much depended upon where this individual was being transferred to. I explained that, in fact, they had a right to the DSP accommodation regardless of what their doctor preferred, and regardless of which unit they were being transferred to, per the ADA and per the OHA guidance.

They then got me through to the ER's Assistant Manager. I referenced the most recently revised OHA doc, and the individual's need for and right to DSP accommodation. She said she was working on getting authorization "from above" to approve it, and put me on hold for a few minutes. When she returned she said it was authorized, and was no problem to have the DSPs come support them as long as the DSPs passed the COVID screening process. I told her I was relieved to hear this, and that I recently had to go in person to another hospital to review the OHA guidance with the Administrator (scenario one), and that I had followed up with Disability Rights Oregon about it as well. She reiterated that it "shouldn't be a problem" and that I didn't have to go there in person.

Now, again, although the resident was eventually allowed the accommodation, initially they were refused it, and I had to contact them myself and reference the OHA doc, emphasizing, strongly, that this was his right, and was an accommodation referenced in their OHA guidance. I am glad they then allowed for the DSP support, but getting this accommodation should not require an Executive Director having to be aware of and to push to get the accommodation. And once again, it seemed clear that the hospital staff, including the Doctor, were not aware of this section of OHA's guidance document (Oregon Health Authority's "COVID-19 Guidance on Screening and Visitation at Acute Health Care Facilities," revisions dated April 23, 2020 and June 8, 2020). I am happy to report that in this situation the individual has been discharged and feeling much better. But that is not always how situations like this end. Please see the example I share along with The Arc Oregon, for Sara's story, in our shared testimony, also submitted for this hearing. Hers did not end so well, as she passed away.

I am hopeful that our legislature can address these inequities and rights violations in a way that will not only change things during COVID, but will also support healthcare equity into the future. **These stories demonstrate the real need NOW for this legislation. Lives are literally, particularly at stake in our current environment**. Thank you for your interest and your leadership on these vital Civil Rights issues. I am happy to provide more information if needed.

Most Sincerely,

A. Keenan-Mudrick

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