



*a nonprofit organization assisting persons
with developmental disabilities
in the community*

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May 21, 2020

Chair Salinas and Members of the House Health Care Committee:

I am submitting this letter that I recently provided to Senator Gelser, as testimony to supplement the letter submitted by Leslie Sutton, on behalf of the DD Coalition.

“Dear Senator Gelser,

Leslie Sutton has invited me to reach out to you with some information about what two of the individuals we support have experienced in their hospitalizations. Both involving challenges to the OHA accommodations guidance, and one of these indicative of discrimination in access to medical care.

As a reminder, Community Access Services (CAS) is a nonprofit provider agency that serves individuals who experience IDD 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

In this first situation, sadly, the individual supported passed away. FYI, Emily Cooper, DRO’s Legal Director, is investigating.

Initially, this individual was brought to the hospital for a spiked temp, and ended up diagnosed with pneumonia. Very early on in the process, the hospital staff tried to compel their support team (individual, The Arc Oregon Guardian, CAS, County Case Manager) to change her Full Code to a DNR order. In these conversations it was clear that the hospital staff did not believe they could live a quality life, even given their baseline, long term medical conditions. This individual had been very active in her community based day supports program, had gone on many a trip with housemates, and was looking forward to seeking employment – she’d recently completed an employment “Discovery” process. They were obviously shocked to hear about all these things she did, and as our team insisted that she had a full, robust life, said things like “so you mean she can typically walk and talk?” This was from the Doctor leading her case. He was also clearly shocked to hear, when discussing possible need for trach or vent if things were to progress medically, that we serve four individuals who use trachs and vents, and they also have robust, quality lives in the community. By the end of this initial meeting, which was called to address their pressure to change to DNR, the support team did not change course, so the Full Code status remained.

Also occurring at the onset of this hospitalization, was their refusal to allow our Direct Support Professionals (DSPs) to accompany and support her, explaining that they would not allow this as they were anticipating needing to send her to the ICU for possible intubation, since the “Full Code” remained. Days later, after great difficulty getting updates and communication from the hospital about her status, we learned that she did not end up being sent to the ICU after all. At the point at which we learned this, we were allowed to send in no more than 2 DSPs per day. The poor communication regarding the individual’s status continued from there, and our concerns about potential discrimination in her care grew. So with the support of The Arc Oregon guardian, we filed a hospital



complaint. This led to a meeting that seemed satisfactory overall in the end, at the time. Post complaint, the hospital staff seemed to have a better attitude about treatment options, and agreed to directly reach out to our RN Manager who is the individual's nurse who knows them incredibly well. Prior to this meeting, the communication between their medical staff and our RN Manager was grossly inadequate. We typically do not have this issue of the hospital not directly returning calls to our RNs. The need to advocate for full access to care is not new to us, but this blatant lack of communication with the CAS Nurse in this situation was a first time experience for us. In the initial stages of this hospitalization, our RN ended up having to get most of their information directly from tracking down floor nurses via phone. The hospital staff kept avoiding our RN, only reaching out with periodic updates to their Arc Oregon Guardian. Guardian updates are critical, but even The Arc Oregon agreed that our Nurse be primary contact person called regarding their medical status and treatment steps. We hoped this would change after this post-complaint medical care meeting, as the hospital staff agreed to contact our RN as point person for all things medical. But it did not.

Shortly after having this meeting, we heard this individual was improving and we started planning for discharge. But then their health suddenly took a turn for the worse, and we still don't understand how it was that this occurred, as the changes in her condition were not immediately communicated. By the time they informed us of the constant aspiration issues occurring, things were not looking good for her at all. There was another medical care meeting held with the Guardian and our RN Manager, who, after talking through her current status, and being walked through the limited medical treatment options, none of which would have effectively addressed this new constant aspiration issue, they were in agreement, at that point, that there was no foreseen medical intervention that was viable. Also during this meeting, the Medical Social Worker commented about her hearing that this individual was looking forward to finding a job, went to salons to get her hair done, went on vacations, et cetera, saying in a surprised/sarcastic manner, with the individual present, "*this girl?*" The hospital staff bias was once again rather evident. So, although, at that point, it was clear to our RN, to the Guardian, and to the full team, that there was no viable intervention, we are still confused to this day about why and how things progressed to that point. How was it that her initial aspiration pneumonia diagnosis, which we have seen many times before with those we serve and it is typically recoverable, then transitioned into a constant aspiration issue of this type – where change in G tube location or trach/vent could not keep them from continuously aspirating.

Also of significance here, is the fact that although this letter provides examples of statements made at one point by the physician, and at another by the social worker, there were four situations in which incredulous reactions like this were expressed by hospital employees involved in her care planning. From the palliative care team, in the first care planning meeting on 4/23, then from the doctor as described above, with palliative care team once again on 5/9, and finally from the Hospital Social Worker, also noted above. With comments and reactions like this, paired with the pressing for DNR early on while with a recoverable condition, juxtaposed with their resistance to communicating with us, we believe there was bias and discrimination in the care provided.

Scenario Two:

Over this past weekend, in the middle of the night, another resident we serve was admitted to a different hospital. 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.

I am happy to report that this story has a far better ending than the first described in this letter. 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.

Senator Gelser, 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.

I am hopeful that our legislature can address these inequities in a way that will not only change things during COVID, but will also aid us into the future. Thank you for your interest and your leadership, Senator!

Most Sincerely,

Anna Keenan-Mudrick, MSW
Executive Director"