



June 22, 2020

Dear Governor Kate 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,

The Arc Oregon and Community Access Services are providing this testimony to reinforce the DIRE need for SB 1606 to become law, during this Special Session. It explains what one individual we supported experienced in her hospitalization. It involves challenges to the OHA visitor/accommodations guidance, pressure to change POLST status to DNR and DNI, and discrimination in access to medical care.

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. CAS is the provider of Sarah, the woman whose story we are sharing today.

For more than 65 years The Arc Oregon, along with its affiliated network of chapters and members, has been a leader in creating positive change for Oregonians with intellectual and developmental disabilities (I/DD) and their families. This work has included the closing of Oregon institutions and helping people successfully transition from those institutions into community living. One of the ongoing, vital programs of The Arc Oregon is the Guardianship and Advocacy Planning Service (GAPS). The Arc Oregon has been Sara's Guardian for 19-1/2 years, and is a key partner in the telling of this story.

SARAH'S STORY

We'll lead by saying that in the situation we are about to describe, regrettably, Sarah ended up passing away. Emily Cooper, Disability Rights Oregon's (DRO's) Legal Director, is investigating the circumstances leading up to Sarah's death. This specific example was also discussed by Jake Cornett, DRO's Executive Director, in recent testimony to the Senate Health and Human Services, Committee.

Pressure to Change POLST

On April 21, 2020, Sarah was brought to the hospital for a spiked temperature, and was diagnosed with pneumonia. Very early on in the process, the hospital staff tried to compel her support team (Sarah, The Arc Oregon Guardian, CAS, County Case Manager) to change her Full Code to a DNR order. In these conversations it was clear the hospital staff did not believe she could live a quality life, even given her baseline, long term medical conditions. Sara had been very active in her community-based day supports

program, had gone on many trips 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 she had a full, robust life, the lead doctor on her case said things like "so you mean she can typically walk and talk?" He was also clearly shocked to hear, when discussing possible need for a tracheotomy or ventilator if things were to progress medically, that her provider, CAS, serves four individuals in a community-based home, friends of Sarah's, who have a tracheotomy and use a ventilator, and who 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.

Initial Denial of DSP as ADA Accommodation, & Failure to Provide Needed Medical Care

Also occurring at the onset of this hospitalization, was the hospital's refusal to allow our Direct Support Professionals (DSPs) to accompany and support her. They explained that they would not allow this because 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 had been allowed to send in no more than two 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 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 was Sarah's nurse and who knew her 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 The Arc Oregon guardian. Guardian updates are critical, but even The Arc Oregon agreed that our nurse be the 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 the point person for all things medical. But it did not.

Lack of Communication to Explain Progression to End of Life Situation; Further Indication of Discrimination

Shortly after having this meeting, we heard Sara's health was improving and we started planning for discharge. But then her 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 to either the CAS nurse or The Arc Oregon guardian. By the time they informed us of the constant aspiration issues occurring, things were not looking good for Sarah at all. There was another medical care meeting held with the Guardian and CAS' 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 Sarah 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 Sarah present, "this girl?" The hospital staff bias was once again rather evident. So, although at that point it was clear to Community Access Services' RN, to The Arc 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 testimony 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.

Why This Legislation is Needed Urgently

The problems highlighted in Sarah's story - the initial denial of access to ADA accommodation of her support staff, pressure to change POLST status to DNR, and discrimination in access to treatment - are problems that The Arc Oregon and CAS have seen in numerous cases over the years, but both entities have seen these problems significantly INTENSIFIED and INCREASED IN FREQUENCY during this COVID pandemic.

SB 1606 would enforce ADA access to support people in hospital settings, (also called for in recent OHA and US Health and Human Services guidelines), ensure that Crisis Care Guidance does not allow for discrimination in who gets care and who does not based on disability, ensure there is no further pressuring to make end of life decisions based on disability or as a condition of receiving care, and ensuring those for whom end of life care is being discussed have support from people they choose before making decisions (i.e. in changes to POLSTs).

Sarah's story, and those of so many more Oregonians with Intellectual and Developmental Disabilities, clearly demonstrates why the passage of this bill is so incredibly URGENT. Further, the existing guidance from OHA regarding hospital visitation, and related accommodation, are not being followed in *many* cases, and need enforcement.

SB 1606's protections listed above must become law immediately. Before more rights are violated, before more are not given full and equal access to medical care which is so often life altering, and before more lives are unjustly lost.

Most Sincerely,



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Executive Director
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Paula Boga
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