Disability Rights Oregon

TO: Chair Powers, Vice Chair Wallan, & Members of the House Committee on Civil Law
FROM: Disability Rights Oregon
DATE: February 24, 2021
RE: Testimony Opposing HB 2638

Dear Chair Powers, Vice Chair Wallan, and Members of the Committee:

Disability Rights Oregon submits this testimony opposing HB 2638. This legislation would cut off access to justice for many people with disabilities, especially when a state or local government has endangered our lives through ill-conceived COVID-19 guidance.

Since 1977 Disability Rights Oregon has been the State's Protection and Advocacy System. See ORS 192.517. We are authorized by Congress to protect, advocate, and enforce the rights of people with disabilities under the U.S. Constitution and Federal and State laws, investigate abuse and neglect of people with disabilities, and "pursue administrative, legal, and other appropriate remedies".[1] We are also mandated to "educate policymakers" on matters related to people with disabilities.[2]

HB 2638 would shield any "individual, corporation, association, firm, partnership, limited liability company, joint stock company or public body" for any acts or omissions related to COVID-19 so long as the entity is in "reasonable compliance with guidance". Guidance includes executive orders, federal guidelines, state rules, local rules and state informational materials. These guidance materials need not have been intended to provide immunity if followed, gone through the formal rulemaking process, or be binding. Even in cases of unlawful discrimination against a person with a disability, the corporation or covered entity would be immune from liability for the harm it caused so long as it could point to a single State or County guidance document.

STATE GUIDANCE DOCUMENTS HAVE CONFLICTED WITH STATE LAW

Under ORS 659A.142(4) it is unlawful for a person or business to discriminate on the basis of disability; and, businesses are required to make reasonable modifications in policies, practices, or procedures to ensure equal access to services provided for people with disabilities. However, during the COVID-19 Emergency Period, Disability Rights Oregon has received numerous complaints from consumers about hospitals and other businesses refusing to make reasonable modifications in policies, practices, or procedures. These hospitals and businesses have specifically cited guidance documents issued by the Oregon Health Authority, including guidance documents on mask wearing, rationing of healthcare, and infection control guidance.

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[1] See 42 U.S.C. § 15041 et seq; 42 U.S.C. § 10801 et seq.

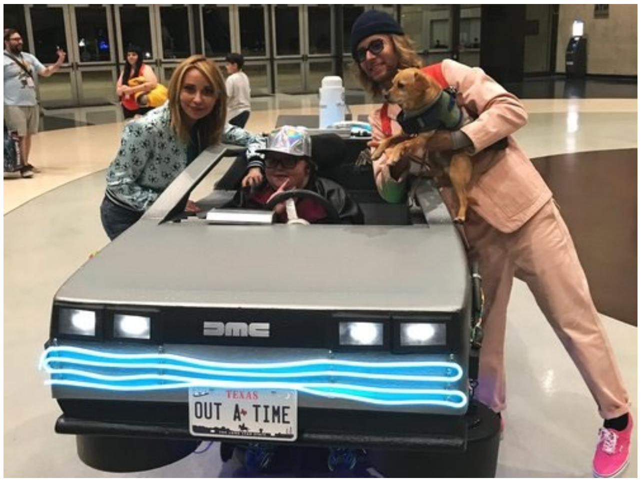
[2] See 42 U.S. Code § 15043(a)(2)(L).

To put it plainly, the guidance issued by Oregon has led to unlawful discrimination prohibited in Oregon law. This legislation would provide law-breakers immunity from any meaningful repercussions and deny justice to people with disabilities who have been harmed or discriminated against.

EXAMPLE: CHRISTINE GETMAN'S CARE AT OREGON HEALTH AND SCIENCES UNIVERSITY

During the COVID-19 emergency period, Disability Rights Oregon received a complaint from Christine Getman about her treatment at the Oregon Health and Sciences University (OHSU). Christine sought treatment for bacterial meningitis.

Christine runs Magic Wheelchair, a national nonprofit based out of Oregon that creates custom costumes for children in wheelchairs.[3] Christine also has Type 2 Spinal Muscular Atrophy, a rare neurological disorder that weakens a person's muscles over time. She uses a wheelchair, can only move one finger on one hand, and has a tracheostomy tube for breathing. Christine requires assistance from her caregivers to eat, reposition her body, or use the bathroom.



During her treatment at OHSU, the hospital's no-visitor policy during the first several months of the pandemic meant Christine had to navigate her stay in the hospital alone, did not have access to her communication devices, and was without the supports she needed. OHSU relied on state guidance restricting access to healthcare facilities when denying Christine the supports she needed, in violation of nondiscrimination law. See the enclosed article published in the *Oregonian* on June 15, 2020, for more of Christine's harrowing story.

Hospitals must be held accountable when they violate non-discrimination law by failing to modify policies, even if they have relied on state COVID guidance. HB 2638 would foreclose accountability for harms to Christine through Oregon's liability laws.

PREVENTION: WHY LIABILITY LAWS MATTER TO PEOPLE WITH DISABILITIES

Liability laws play a powerful role in making sure companies take seriously their obligation to maintain a safe place of business and treat customers and employees fairly. Liabilities laws create an incentive to prevent harm to customers, employees, and patients. HB 2638 undermines the basic concept of liability in Oregon and rebalances incentives in favor of

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[3] See https://www.magicwheelchair.org/

businesses who are negligent, at the cost of consumers. For people with disabilities, these laws are especially important in medical and long-term care settings.

Under current and well established medical liability law, physicians, health maintenance organizations, and hospitals that harm Oregonians through their negligence can be found responsible for this harm. This results in the physicians, health maintenance organizations, or hospitals being ordered by the court to make a consumer whole. These cases are already difficult to win because a patient must prove the medical provider did not deliver the same care that an ordinarily careful physician would have provided to another patient in similar circumstances. Moreover, while physicians, health maintenance organizations, hospitals, and their insurance carriers have substantial resources to fight these claims in court, most patients do not—making access to justice even more difficult.[4]

Notwithstanding these challenges, liability laws play a powerful role in making sure health care companies take seriously their responsibility for providing quality care to all patients, including people with disabilities. The liability framework in current law balances personal responsibility of businesses with the right of patients. HB 2638 upends that balance in favor of corporations, which will deny justice to patients.

Ultimately, medical liability provides a powerful disincentive for medical providers to deviate from the standard practice of care for patients. In other types of business settings, these laws provide a powerful disincentive to endangering consumers through neglectful actions.

DEVIATION FROM THE STANDARD PRACTICE OF HEALTHCARE IS ALREADY HAPPENING DURING THIS PANDEMIC WHILE THERE IS NO SHORTAGES OF SUPPLIES OR EQUIPMENT

Disability Rights Oregon has investigated complaints and identified a series of serious deviations from established standards of care. These complaints have been widespread, coming from every corner of the State and from nearly every hospital system. This included substandard care provided to people with disabilities who were diagnosed with COVID-19 during the COVID-19 emergency period and people who were seeking care for other illnesses during the emergency period. See the enclosed report from the National Public Radio's (NPR's) Investigation Unit, which has also investigated dozens of complaints in Oregon.[5]

For all of these reasons, Disability Rights Oregon urges the Committee to reject HB 2638 and reject any further proposal to limit liability during the COVID-19 emergency period.

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[4] See enclosed Guest Column published in the Oregonian on December 13, 2020.

[5] See enclosed and listen to the NPR article here: https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc ; see also second NPR story here: https://www.npr.org/2020/12/14/946325888/when-hospitals-decide-who-deserves-treatment-npr-investigates-denial-of-care?utm_source=twitter.com&utm_medium=social&utm_campaign=atc&utm_term=nprnews&utm_content=2048

The Oregonian

Access denied: Oregonians with disabilities face extra challenges meeting care needs during pandemic

June 15, 2020

By: Jayati Ramakrishnan | The Oregonian/OregonLive

In early April, Christine Getman had been quarantined for three weeks when she developed a bad headache — the kind she'd only had once before in her life.

"I immediately knew the type of headache it was," she said. "It was bacterial meningitis."

What followed was a hospital stay that shed a light on the strain the coronavirus pandemic has placed on people with chronic illnesses as they try to access care, both during health emergencies and in meeting their daily needs.

But Getman said OHSU's policies posed a host of problems for her that she felt put her in danger.

OHSU's no-visitor policy during the pandemic meant Getman, who has Spinal Muscular Atrophy, had to navigate her stay in the hospital alone, without her fiancé, who is also her full-time caregiver. The issue is one other Oregonians with disabilities have faced since the pandemic started, according to Emily Cooper, a lawyer for Disability Rights Oregon.

"I could inundate you with stories of individuals with disabilities and family members who have been denied access because of visitation policies," Cooper said.

But Cooper said the pandemic has impacted people with long-term disabilities in all kinds of ways — from those with hearing issues who struggle to communicate as mask-wearing becomes commonplace, to people with neuromuscular issues unable to meet with regular medical providers because of stay-at-home orders or the heightened risks they face leaving home.

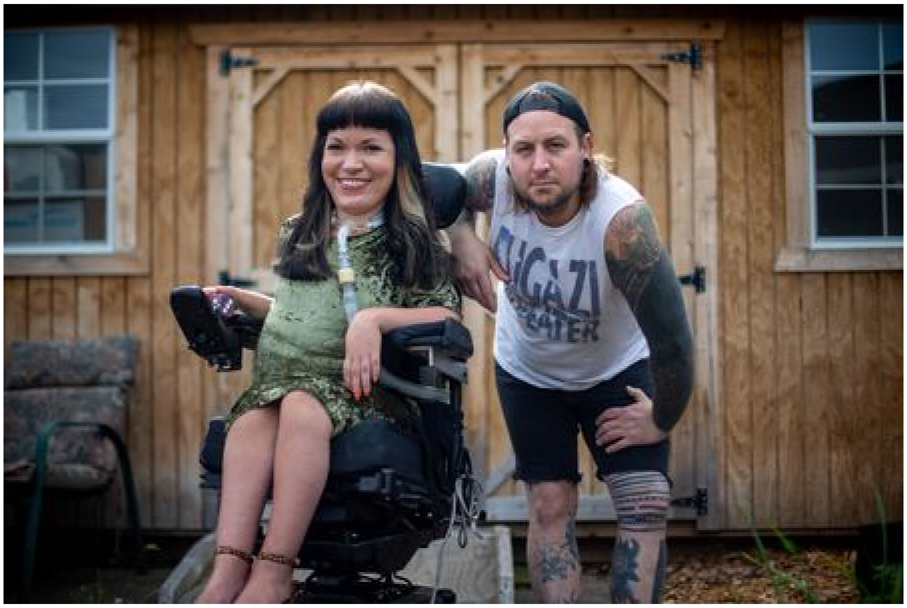
"It's really a test of how our state is going to protect the public," Cooper said. "Lots of us in the disability community are scared we're not going to have the same access to care."

A scary hospital stay

Getman has Type 2 Spinal Muscular Atrophy, a rare neurological disorder that weakens a person's muscles over time. Getman uses a wheelchair, can only move one finger on one hand, and has a tracheostomy tube for breathing. When she first developed bacterial meningitis , she called her doctors, trying to arrange treatment that would allow her to stay home.

Within a few hours, her condition worsened to the point where she needed to go to the emergency room, and was admitted to a room at OHSU Hospital in Portland the next day.

First, she said, doctors tested her for coronavirus and placed her on a floor that housed coronavirus patients, even though she had quarantined for three weeks. She remained there for two days after her results came back negative. Getman's chronic disease puts her in a high-risk category for contracting the virus.



Christine Getman, a woman with Spinal Muscular Atrophy, was subjected to a traumatic hospital stay and denied access to her caregiver, Scottie Foertmeyer, right, because of coronavirus policies. Mark Graves/Staff

Getman's fiancé, who is her full-time caregiver, was also not allowed to be with her in her room — as per hospital policy during the pandemic. Getman needs assistance from a caregiver to eat, reposition her body or use the bathroom. She says the hospital denied several requests from her to allow her fiancé to help and to advocate for her.

"It felt like it made more sense to have one person who knows all my needs and can provide care — I felt like that was very reasonable. Instead I was given lectures about how bad other people have it," she said.

Cooper said issues like visitor limitations during the pandemic raise the issue of patients being able to make informed medical decisions.

She said in many cases, the issue could be resolved after a simple conversation with hospital administrators. But often, the issue is resolved by the time hospitals respond: either the patient gets discharged, passes away, or the visitor has already been allowed in.

In the hospital, Getman said she asked for a compromise to have the hospital assign one nurse or caregiver to her, so she wouldn't be alone in the room. She said the hospital denied the request.

Getman, who has a Master's in Public Health, said the hospital also didn't allow her fiancé to bring her computer — the device she uses to communicate — or other supplies she needs.

After five days in the hospital, Getman said she was allowed to continue treatment at home, where her fiancé administered intravenous antibiotics. She recovered from the meningitis and didn't develop coronavirus, but said the hospital experience was traumatic and impacted her heavily.

"I don't just want some sob story. I want to see change," said Getman, who works as the executive director of Magic Wheelchair, a company that makes costumes for children in wheelchairs. "Specific to COVID, or anything else with visitor restrictions, people with disabilities need to be considered in the fine print. I don't want to see any more headlines of people dying due to improper care or poor policies."

OHSU spokeswoman Franny White said the hospital can't discuss specific patients. But she said the hospital's no-visitors policy only makes exceptions for children, infants, patients in labor or who had just given birth, patients with limited mental capacity, or for patients on end-of-life care.

"We understand hospital-staff provided care is not the same as having the loving companionship of a known caregiver," White said in an email to The Oregonian/OregonLive. "But the unique and pressing circumstances of the pandemic require us to make very difficult decisions to reduce the spread of COVID, preserve protective equipment, and maintain a safe healthcare environment."

Everyday needs

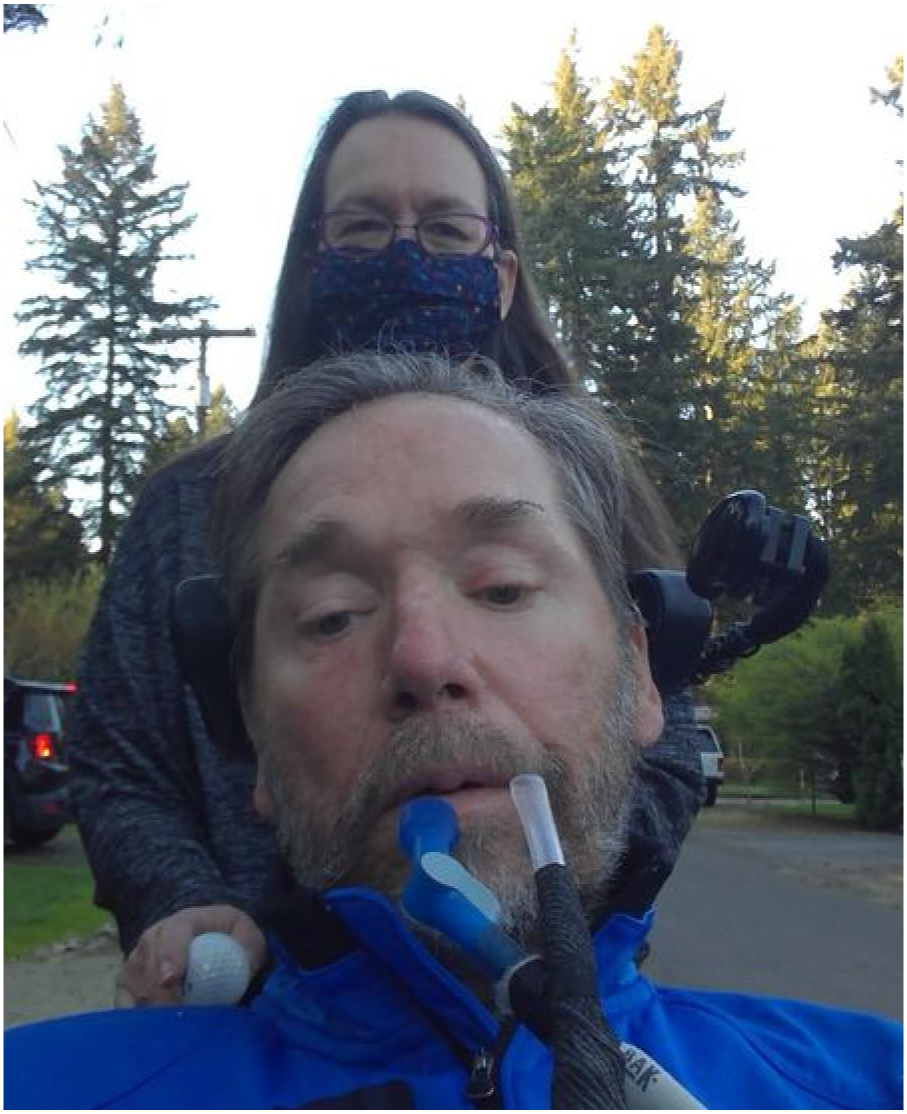
Outside of hospitals, people with long-term disabilities and chronic illnesses have also faced more challenges accessing daily needs.

Donnie Graham, who was diagnosed with Amyotrophic Lateral Sclerosis in late 2014, said life looks a lot different than it did pre-pandemic.

The pandemic has prevented many people who have ALS, or Lou Gehrig's Disease, from leaving the house to attend regular checkups and support groups. ALS is a degenerative neurological disease. Patients lose the ability to use their limbs, swallow, talk and breathe.

Lance Christian, the executive director of the ALS Association in Oregon and Southwest Washington, said patients usually rely on care from a multidisciplinary clinic, where they can see as many as 10 providers during one visit and access doctors for things like pulmonary functions, feeding tube placement and rehab services to help with the disease's paralyzing effects. ALS patients are now receiving most of their care through telehealth services, and mostly through contact with their neurologists, Christian said.

Graham and his wife, Jan Steinbock, are no longer able to attend their support group meetings in-person, and have not visited the ALS clinic since December.



Graham, seated, has ALS. He can't wear a mask because he uses a ventilator to breathe. He takes a sip of air from the straw and it gives him a full puff of air to fill his lungs. He constantly sips water because breathing from the straw dries out his mouth. Jan Steinbock

Graham is losing his ability to swallow and eat. He said the support from medical professionals and family and friends is crucial to managing the fast-progressing disease. But he also knows leaving home poses a huge risk for him, as he is in a high-risk category for contracting the virus.

"We're more than five years past his diagnosis," Steinbock said. "I don't want this to be the thing that cuts him short."

Graham has created some speech-generating devices of his own to help him communicate, but still needs the help of a speech therapist to deliver communication technology.

When they do occasionally let specialists in to help with such equipment, they require people to wear masks and face shields, and only allow them into specific parts of the home.

"In order to get that support, we have to let people into the bubble," Steinbock said.

The pandemic has placed a strain on other activities too — the days of going to the store or anywhere else are gone, for now, and they rely on ordering groceries online or having friends pick them up.

The pandemic has put additional strain on Steinbock, as well. With Graham needing 24/7 care, they can no longer allow family and friends to come and help her with household chores or stay with Graham so that she can rest or have a few hours to herself.

The couple says they're not sure when they'll feel comfortable leaving the house and allowing people to start coming back in — but it will likely coincide with coronavirus testing becoming more widely available.

More barriers

Even efforts meant to slow the spread of the coronavirus, such as mask wearing, can create barriers for people whose disabilities aren't immediately obvious to others.

"You have a demographic of people for whom, if they can't see a person's face, it can be anywhere from just a little bit challenging to absolutely devastating," said Alison Metcalf, an audiologist who runs the practice Audiology Associates in Northwest Portland.

Not only do masks obstruct sound, but they prevent people who are deaf or hard of hearing from reading lip movements, and even make it difficult to decipher the speaker's emotions — all of which can be isolating for people.

Metcalf said there are some masks that have clear panels, which better allow for lip reading. Sunset High School student Eric Kim has been creating such masks for people who are deaf or hard of hearing. But those types of masks aren't widespread.

Accommodating those with disabilities during the pandemic will require ongoing assessment from all places that serve the public, said Cooper, the Disability Rights Oregon lawyer.

"Certain stores require all customers to wear face coverings, which makes sense from a public health perspective," she said. "But if you have a respiratory illness or a tracheostomy, that impacts your ability to breathe."

Such issues require stores to think about potential solutions, Cooper said. For example, businesses could offer clear masks for those who need to read lips or curbside pickup for those who can't wear masks.

Christian said it's important for able-bodied people to remember that the risks of the pandemic will linger for people with disabilities.

"When the world seems like it's going to return to normal for everybody else, for people with ALS and other chronic diseases, it's going to stay locked down for a long time," Christian said.

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The Oregonian

Opinion: Liability protection for health care industry would be an unnecessary barrier to justice

Dec 13, 2020

Jake Cornett and Paula Boga

Cornett is executive director of Disability Rights Oregon. He lives in Portland. Boga is executive director of The Arc of Oregon. She lives in Keizer.

Shortly after 34 people with COVID-19 died at the Healthcare at Foster Creek nursing home last April, the Oregon health care lobby went to Gov. Kate Brown with a request: Would she grant providers limited immunity from civil litigation during the COVID-19 emergency, similar to executive action that New York Gov. Andrew Cuomo took early in the pandemic?

Brown rightly ignored the request. Legislators, too, have so far declined to provide such liability protection. But health care lobbyists have only continued to press for legislation shielding hospitals, doctors and insurers from civil lawsuits over injury or death during COVID-19 except in cases of gross negligence. With the upcoming legislative session, we urge Oregon's elected officials to remain firm in their resolve in rejecting any such proposal, which would deny justice by dramatically rewriting Oregon's liability laws.

Under current medical liability law, physicians, health maintenance organizations, and hospitals that harm Oregonians through their negligence can be found responsible for this harm and ordered by a court to make a consumer whole. These cases are hard to win because in many ways the deck is stacked against patients -who must prove the medical provider did not deliver the same care that an ordinarily careful physicians would have provided to another patient in similar circumstances. However, these laws play a powerful role in making sure health care companies take seriously their responsibility for providing quality care to all patients, including people with disabilities.

But a legislative proposal under consideration would shield businesses from lawsuits for failing to fulfill these responsibilities. Under the proposal, which Disability Rights Oregon was able to review, "gross negligence" must be proven, a nearly impossible standard that requires a high degree of recklessness. Adopting such a high bar for liability would remove an important incentive for businesses to act responsibly.

The early draft also appears to grant hospitals liability protection even for non-COVID-19 cases, so long as the patient saw a doctor or hospital during the COVID-19 emergency period. While it remains to be seen exactly who would be granted such protection and other details of the proposed bill, let us be clear: this concept of mass immunity from lawsuits is not acceptable in any shape or form.

Such legislation would deny justice for harm caused to people like Sarah McSweeney, a 45-year-old Oregon City woman. Sarah loved going out to coffee, getting her hair done and taking trips with friends. She also experienced intellectual and physical disabilities. On April 21, Sarah was admitted to Providence Hospital with a slight fever. Hospital bureaucrats immediately pressed her guardian to sign a Do Not Resuscitate order for Sarah -– as if having a disability should make her less deserving of lifesaving efforts. Sarah’s guardian and care team refused, explaining that Sarah’s life was full and happy. Sarah tragically died on May 10. When Disability Rights Oregon investigated, we found multiple records and statements made about her “quality of life” and remain concerned that the hospital may not have provided Sarah with the medical care she needed because she had a disability.

We believe Sarah’s family and loved ones deserve justice for Sarah. Changing Oregon’s liability laws to shield hospitals from negligence would take that away.

For the 950,000 Oregonians with disabilities who face barriers to accessing the same care as everyone else, eliminating this layer of protection would result in less oversight of their health and safety during a public health crisis, and fewer ways to fix harmful practices.

There’s been no flood of COVID-related medical liability lawsuits since the pandemic started. This proposed legislation is a solution in search of a problem. With the Oregon Legislature convening in weeks, our legislative leaders shouldn’t rubber stamp a New York solution that leaves Oregonians with disabilities, older adults, and people of color—the people most harmed during COVID—paying the price.

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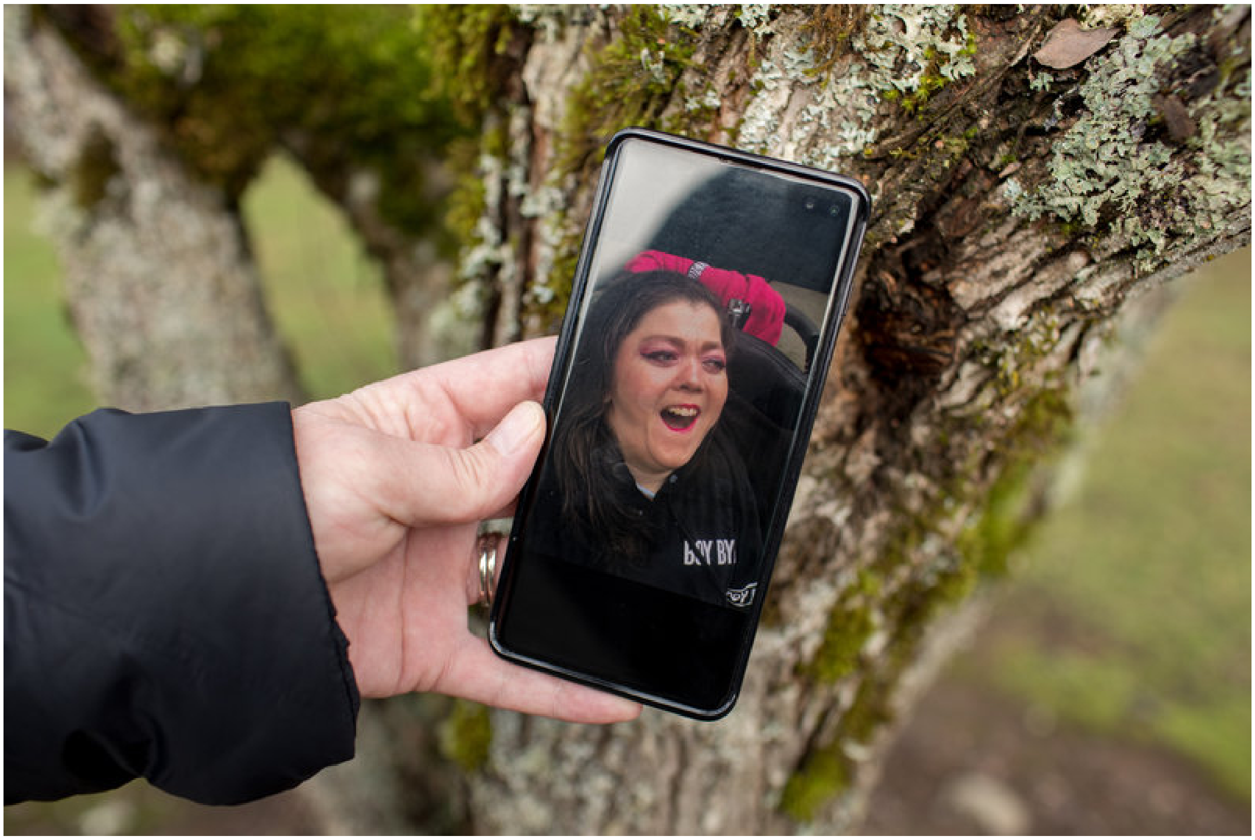
INVESTIGATIONS

As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?

December 14, 20203:47 PM ET
Heard on All Things Considered

JOSEPH SHAPIRO



Kimberly Conger, Sarah McSweeney's nurse at her group home, shows a photo of McSweeney on her phone. She says McSweeney was outgoing and fun: "She absolutely adored going into malls and getting her makeup done and getting her hair done."

Celeste Noche for NPR

On the morning of April 21, Sarah McSweeney woke up with a temperature of 103 degrees — and it kept rising. Staff at her group home worried that the woman with multiple disabilities — she couldn't walk or speak words — had contracted COVID-19. They got her into her bright pink wheelchair and hurried to the hospital, just a block down the street from the group home in Oregon City, Ore.

That afternoon, Heidi Barnett got a phone call from the doctor in the emergency room.

He was puzzled, she says, by a one-page document that McSweeney's caregivers brought with her. It was a legal document that explained what medical care this disabled woman — who couldn't speak for herself — wanted.

"We had her at full code. So all treatment. Because she was young and vibrant and had a great life," says Barnett. "And that was her wishes, that's what we gathered from her. She wanted to be alive."

Barnett works for The Arc Oregon, the agency that was McSweeney's guardian. She had helped McSweeney fill out that document, called a POLST form, for a moment just like this.

It's normal for a doctor to want to understand a patient's wishes. However, Barnett, who kept daily notes on her conversations with medical workers about McSweeney, felt the doctor was challenging the order.

"They wanted it to be a DNR," says Barnett.

A Do Not Resuscitate Order is a medical order to doctors not to treat a patient — like McSweeney — if she stops breathing or her heart stops.

That emergency room doctor would be the first at the hospital to raise a question that would shadow decisions about McSweeney's care over nearly three weeks at the hospital: Why does a woman with significant and complex disabilities have a legal order that requires the hospital to take all measures to save her life?

McSweeney was 45 when she died on May 10. Her death would raise another question, one that people with disabilities and the elderly have worried about since the start of the coronavirus pandemic: Are they denied care when it gets scarce — like drugs or treatment, including ventilators — that might save their lives?

An NPR investigation looked into McSweeney's death and about a dozen reports of discrimination in Oregon: Of doctors and hospitals denying equipment like ventilators; insisting that an elderly or disabled person sign a DNR — maybe when they couldn't understand it and in the middle of a crisis — or even denying a COVID-19 test.

These decisions are made behind closed doors, NPR found, and as a result are little known and little understood. McSweeney's case offers a rare look at how those decisions are made.

When people met Sarah McSweeney they saw different things.

Most saw what she couldn't do. McSweeney had quadriplegia, cerebral palsy and other disabilities.

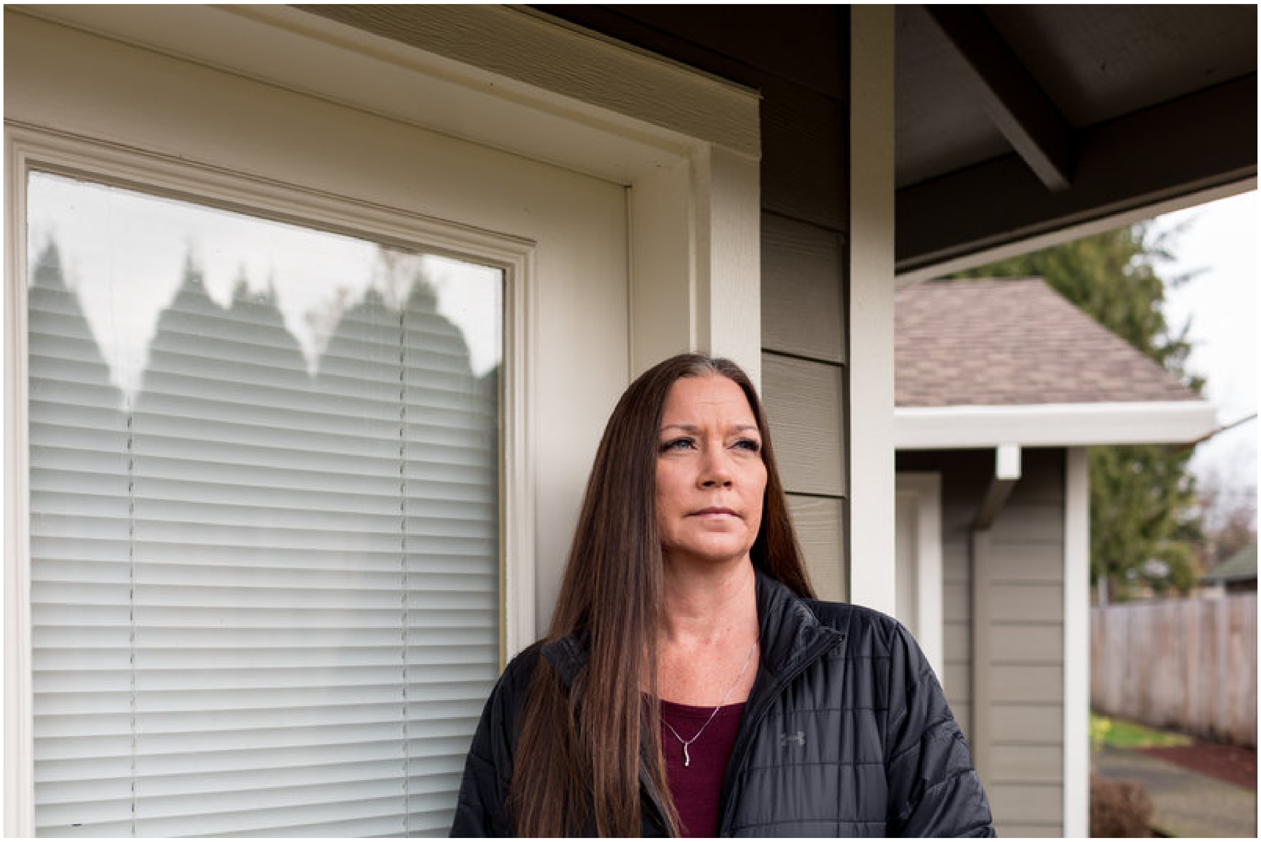
Because she couldn't walk, or even use her hands, someone had to push her in her wheelchair.

Because she couldn't speak words, she communicated by making sounds and gestures.

Because she couldn't eat solid foods, someone fed her a supplement of nutrients through a tube to her stomach.

A smaller number of people, but the ones who knew her best, saw something different. They saw what was possible for McSweeney. They saw the choices she made and the things she did.

"She absolutely adored going into malls and getting her makeup done. And getting her hair done and doing typically girly stuff that girls like to do — get pedicures and manicures," says Kimberly Conger, the nurse manager for Community Access Services, or CAS, the nonprofit agency that provided services and ran the group home where McSweeney lived.



Kimberly Conger, the nurse manager for McSweeney's group home, objected when a doctor said the disabled woman needed to be on a ventilator but then questioned her quality of life: "I feel like they didn't feel like she was worth that."
Celeste Noche for NPR

She loved country music, especially Kenny Chesney, whose poster she had on the wall of her room. She enjoyed when her staff took her to country music concerts — she'd met Tim McGraw twice — and to country bars to watch people in boots and denim do the flips and swing of country dancing.

The people who worked with her enjoyed her vivacious personality. She smiled and laughed and loved to make others smile and laugh. There's a picture of McSweeney sticking out her tongue and laughing at the camera. Her dark hair is dyed a bright red, a color that clashed with her neon-pink wheelchair.

"Her smile would bring a smile to everyone in the room," says Anna Keenan-Mudrick, who runs CAS.

The two views of Sarah McSweeney would collide once she went to the hospital — and during the nearly three weeks she was there.

On April 21, a Tuesday, in the emergency room at Providence Willamette Falls Medical Center, the doctor wrote down his diagnosis: "acute cystitis with hematuria," a urinary tract infection with the presence of blood in the urine.

Hospital medical records indicate the ER doctor was thorough. With his stethoscope, he listened to McSweeney's lungs. "No wheezes, no crackles," he'd write. Those would be signs of pneumonia, a common killer of people with intellectual and developmental disabilities.

But to be sure, he ordered an X-ray. It would show a small pneumonia. It is not unusual for people with swallowing problems to have a chronic build up of saliva in their lungs that they live with every day, sometimes called "silent aspiration."

NPR reviewed hospital records from McSweeney's case file. The information in the records was shared with an NPR reporter by someone with access to them.

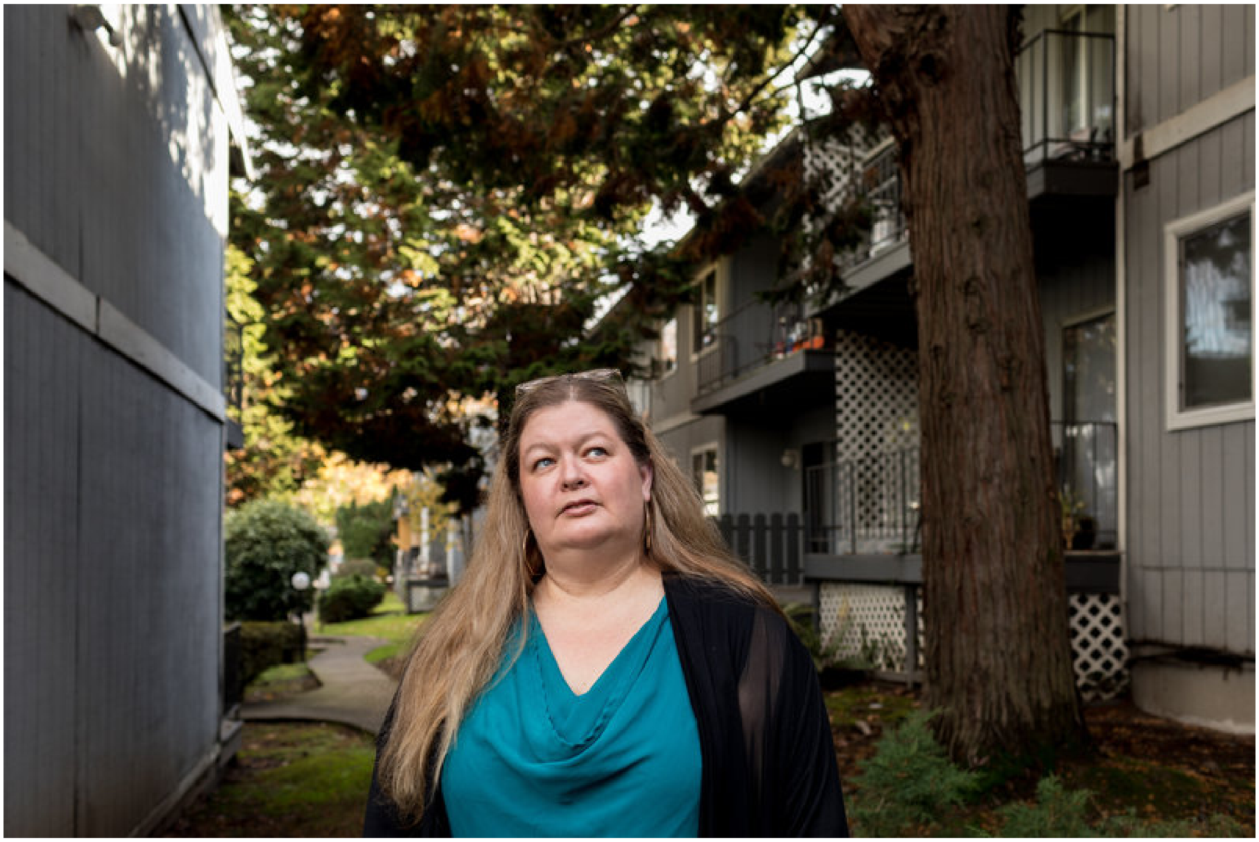
NPR made multiple requests to speak to doctors, staff, and officials at the Providence Willamette Falls Medical Center. "We are not able to comment on the care of a specific patient," a spokesperson for the hospital said. "We do not pressure or force anyone to sign a DNR order, and we are unaware of any evidence to the contrary. We honor decisions by patients and/or their legal representatives. We are not aware of any care needed by any of the patients that was not provided."

As a precaution to prevent the spread of COVID-19, McSweeney was moved to the ICU.

Within a day or two, Barnett says, she got word that the COVID-19 test had come back negative. A second test would return a negative result, too. After the first test, McSweeney was moved from the ICU, back to the general floor of the hospital.

The hospital had a strict limit on visitors because of the pandemic. Barnett and Conger, the nurse manager for McSweeney's group home, spoke every day to doctors, nurses and social workers over the phone and in Zoom calls.

Nearly a week later, on Monday, April 27, another doctor who was leading the care team called Barnett, and said it was "urgent" that she come to the hospital. McSweeney's left lung was "kaput," he told Barnett. She asked what that meant "in medical terms" and he explained that her lung was filled with fluid and not receiving oxygen.



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"She was young and vibrant and had a great life," says Heidi Barnett, who works at The Arc Oregon, of McSweeney. "She wanted to be alive."
Celeste Noche for NPR

Barnett and Conger hurried to the hospital. The doctor showed them the X-ray of McSweeney's lung.

The doctor told them the pneumonia had developed on Friday.

Conger and Barnett told the doctor they should have been notified of the problem then or over the weekend.

This was not the kind of pneumonia associated with COVID-19. Or the small pneumonia, Conger says, that may have shown up on the X-ray on April 21. It was aspiration pneumonia, which occurs when food, saliva or liquids are breathed into the lungs or airways, instead of being swallowed into the esophagus and the stomach, because McSweeney was fed through a gastrostomy tube — or G-tube — directly to her stomach.

Conger says McSweeney did not have a history of that kind of pneumonia at the group home. She had lived there since 2005.

In the hospital that Monday, the doctor said McSweeney, as a result of the aspiration pneumonia, needed to be on a ventilator. It was "critical" that she go, Barnett recalls him saying.

Conger agreed because that's standard treatment. It's what, she felt, a hospital would do for anyone.

"We discussed the possibility of her being intubated and letting that lung rest, giving her time to heal and letting the antibiotics do their magic," Conger recalled.

But then the doctor surprised Conger and Barnett, the women say, when he pushed to rewrite McSweeney's care document. He wanted a new order that would say the disabled woman should not be resuscitated or intubated.

That would be an order to deny McSweeney the ventilator the doctor had just said she needed.

"He said intubating her was a matter of risk versus quality of life," Conger recalls. "I was like, 'But she has quality of life.' And he looked at me and goes, 'Oh, she can walk? And talk?'"

The doctor lifted his index and middle fingers and moved them in a walking motion, like in the old advertisements for the Yellow Pages.
Conger pushed back: "And I said 'Well, no, but there's a lot of people who don't walk who have full quality of life.' And he gets kind of irritated with me and left the room at that point."

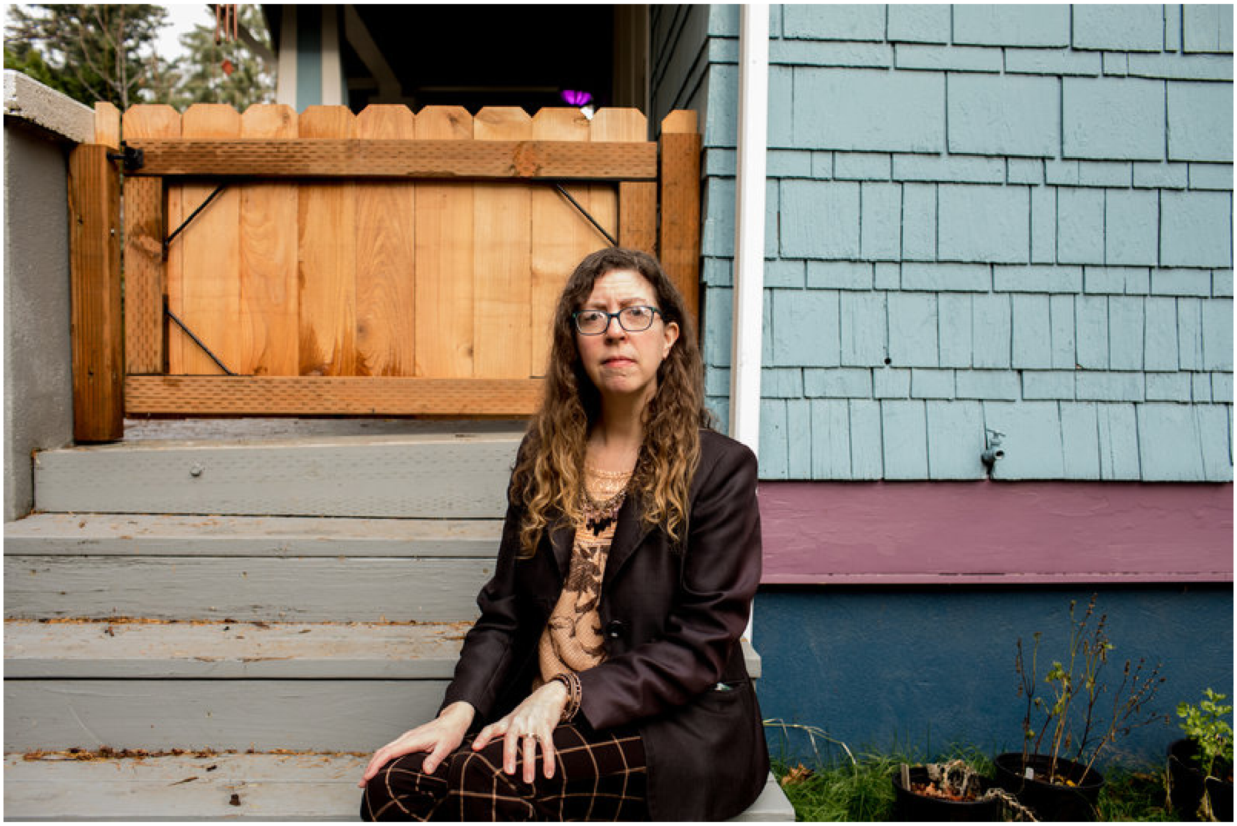
When the doctor walked out, Conger and Barnett understood that they had failed to change the medical team's negative view of McSweeney.

Conger — "she was livid," Barnett says — called her bosses at CAS, the women who were in charge of McSweeney's care. They decided to file a formal complaint with the hospital.

The next day, Tuesday, April 28, Conger filed the complaint, in a phone call with a hospital official. Keenan-Mudrick, the executive director of CAS, would later testify, in the state legislature, about this incident and the doctor's "pressure" to change McSweeney's orders to a DNR.

Conger, in her complaint with the hospital, too, protested the pressure to change McSweeney's stated wishes for health care. She said that staff at the hospital failed to see McSweeney, as she put it, as "a whole person."

At The Arc Oregon, Barnett spoke with her bosses and decided they should try to find another hospital for McSweeney. Barnett notified the hospital. She got a call back from another doctor who told her that insurance would not pay to transfer McSweeney, according to Barnett's notes.



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Anna Keenan-Mudrick, executive director of Community Access Services, told state lawmakers how her staff pushed back when doctors and social workers wanted to override McSweeney's legal document asking for full medical care.

Celeste Noche for NPR

The doctor apologized, too, Barnett says, for the lead doctor's brusque manner and promised she and other advocates for McSweeney would be kept up to date about the woman's condition.

The lead doctor was trying harder, too. Later that day, he called Barnett to say he had called in a specialist, a pulmonologist, to see McSweeney.

On that same day, April 28, Kelly Gauthier, one of McSweeney's direct service professionals — a caregiver from her group home — was allowed to visit. She showed the nurses how to communicate with the disabled woman. She explained how they could ask McSweeney direct questions and she could indicate yes or no.

Gauthier brought a sheet of paper, a one-page introduction to McSweeney. It listed things she liked — country music, getting her hair done, trips to the mall — and things she didn't like. The aide played some Kenny Chesney CDs for McSweeney. In the hospital notes that day, someone writes that McSweeney responded positively to the visit and the music. And that she was breathing "more easily" and at "normal depths."

It's common that doctors often see someone with multiple disabilities, like McSweeney, one way and the person's friends, family and caregivers see her another.

Researchers call this the "disability paradox" — the large gap between how a person with a disability rates the quality of their life and what a doctor would rate it.

A "vast majority" of doctors say people with a significant disability have a worse quality of life, according to a recent poll by Dr. Lisa Iezzoni, a Harvard Medical School professor and physician who studies health care disparities for people with disabilities. Her research will be published in the journal *Health Affairs* in early 2021.
There are, for sure, doctors who take extra steps to understand the lives of their patients with disabilities and who work to help them achieve health and independence.

Still: Doctors save lives. They cure people. They help them get better.

But Iezzoni says, they often hold a bias — often an unconscious bias — about people who won't be cured and as a result "do not make the same effort to restore patients to their baseline health."

McSweeney's advocates at CAS and The Arc Oregon saw their job differently. It was to help the disabled woman live as full a life as possible, according to her wishes.

For example, when McSweeney said she wanted to work--maybe as a greeter in one of those stores in the mall she loved — Susan Gustavson, a veteran advocate at CAS said: OK, let's figure it out.

Gustavson arranged for McSweeney to get trained to use a voice output device called a Tobii Dynavox.

Because McSweeney couldn't move her fingers to type on a keyboard, the Dynavox was set up to track where her eyes gazed. She could look at a letter or a symbol on a computer screen and the device would read and then speak it for her.

Gustavson told the doctors and medical staff about McSweeney's dream to work, and how she was working on the machine when she went to the hospital. And when they asked — why does this disabled woman have medical orders for a full code — she explained something else.

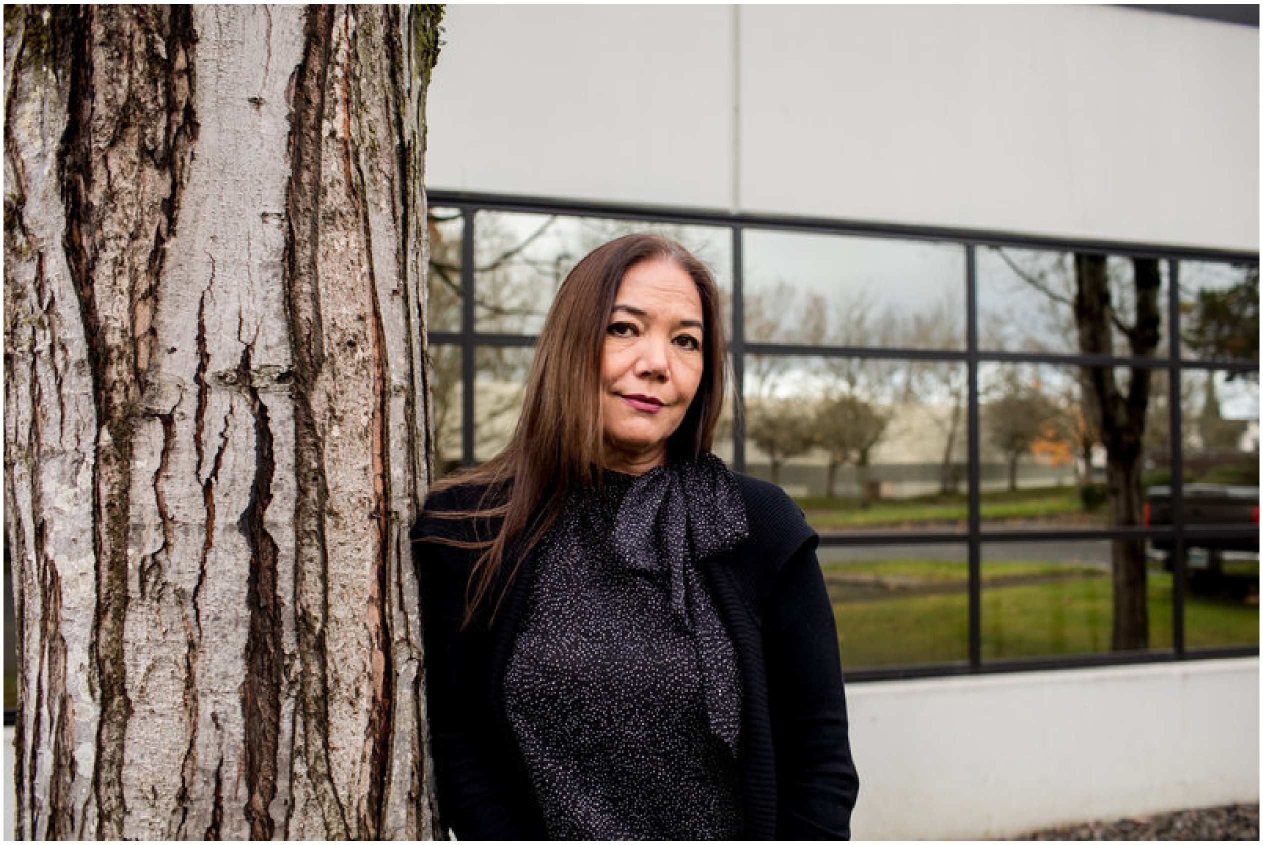
That what was an acceptable part of life for McSweeney was different than what might be acceptable for others.

McSweeney wasn't afraid of being on a ventilator, for example. She'd been ventilated before — in 2017 when she was hospitalized for pneumonia.

But mostly she wasn't afraid because, as Gustavson explained, "Sarah has friends who are vent dependent, 24 hours a day, with traches," a reference to a tracheostomy, a surgical opening in the windpipe to insert a breathing tube.

"These folks were her friends," says Gustavson. "They participate in the same community activities together. They hang out."

They went to the mall and to the movies.



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When McSweeney wanted a job, Susan Gustavson, associate director of Community Access Services, arranged for McSweeney to get trained on a special voice output device.
Celeste Noche for NPR

"That is the norm for Sarah. That is not extraordinary," says Gustavson. "It was definitely received as extraordinary from the hospital staff. They were blown away."

Hospital records say the medical team was debating the best course for McSweeney, who was now dealing with aspiration pneumonia. According to hospital records, on Thursday, April 30, a hospital palliative care team met to discuss whether to put her on a ventilator.

The palliative care nurse argued in favor of keeping McSweeney at full code, to honor her goal to try to get better and go home. But a hospital ethicist argued that intubating McSweeney put her at risk of cardiopulmonary risk and other bad outcomes, according to hospital records. Aggressive treatment, he said, according to the records, could cause "more harm than benefit."

The ethicist, according to the records, said if McSweeney's guardians at The Arc Oregon disagreed, they could seek a second opinion or they could move her to another hospital. But the women in charge of her guardianship say they were never told of this.

Still, hospital staff — after the complaint was filed — started calling with regular updates. Conger, the agency nurse, complained that she, with her medical background, wasn't getting these calls. Her boss, Keenan-Mudrick, would tell state lawmakers that this was "grossly inadequate" communication — and unusual. "We typically do not have this issue of the hospital not directly returning calls to our RNs," she said.

But the hospital was notifying Barnett, McSweeney's certified guardian, and Barnett's boss, Emily Braman, who runs the guardianship program for The Arc Oregon.

Over the course of McSweeney's second week in the hospital, McSweeney's health seemed to be getting better. The pulmonologist called Barnett twice, according to her notes, to say McSweeney's lungs were improving and that she was breathing more easily.

McSweeney's advocates started to plan for her to leave the hospital.

On Thursday, May 7, Barnett looked into possibilities to move her out of the hospital to a group home with nurses who would suction her lungs and provide medical care while she recovered. It would be a temporary stop before she moved back to her group house in Oregon City.

"We were getting notified that it sounded like she was getting better, that things weren't that bad," Braman says.

Then everything changed.

"All of sudden we got a call that it's dire straits," Braman says. On Friday, May 8, a case worker called to say McSweeney's lungs were failing.

There had been added episodes of aspiration pneumonia, on April 29 and May 7 and a clogged feeding tube on May 2 that, according to Braman, Barnett and Conger, had not been disclosed to them.

The next day, on Saturday, Conger and Barnett were summoned to the hospital to talk about McSweeney's worsening condition.

The pair got there early and went to McSweeney's hospital room. "We're standing there in the room waiting for the doctor to be paged and to come into the room," Conger says. "The case manager came up and she really didn't even say hi. She just said, 'So, I'm under the impression that Sarah was going to go for employment and she used to go get her hair done.' I said 'Yeah. She loved to get her hair done and she just finished Discovery for employment.'"

Discovery was the program that was helping McSweeney figure out a way to use that voice computer and find a job.

"And she looked at me and she pointed to Sarah and she's like: 'Her. She used to get her hair done and she was going to be employed?' And I was like: 'Yes.' I mean, it was gross," Conger says.

Barnett could see that Sarah, in her hospital bed, was listening. "She heard it and she understood it." Sarah used her eyes to communicate. And now her eyes followed the case manager — and then her friends — when each spoke.

"She had a very worried look on her face," says Barnett. "And it just broke my heart."

Now Conger could see something had changed. The treatment in the hospital was not working.

"Sarah was desperately trying to communicate something," she recalls. She didn't smile, as she usually did. "It was: Mouth wide open. Arms clinched up. Tears running down her eyes."

And she was in distress.

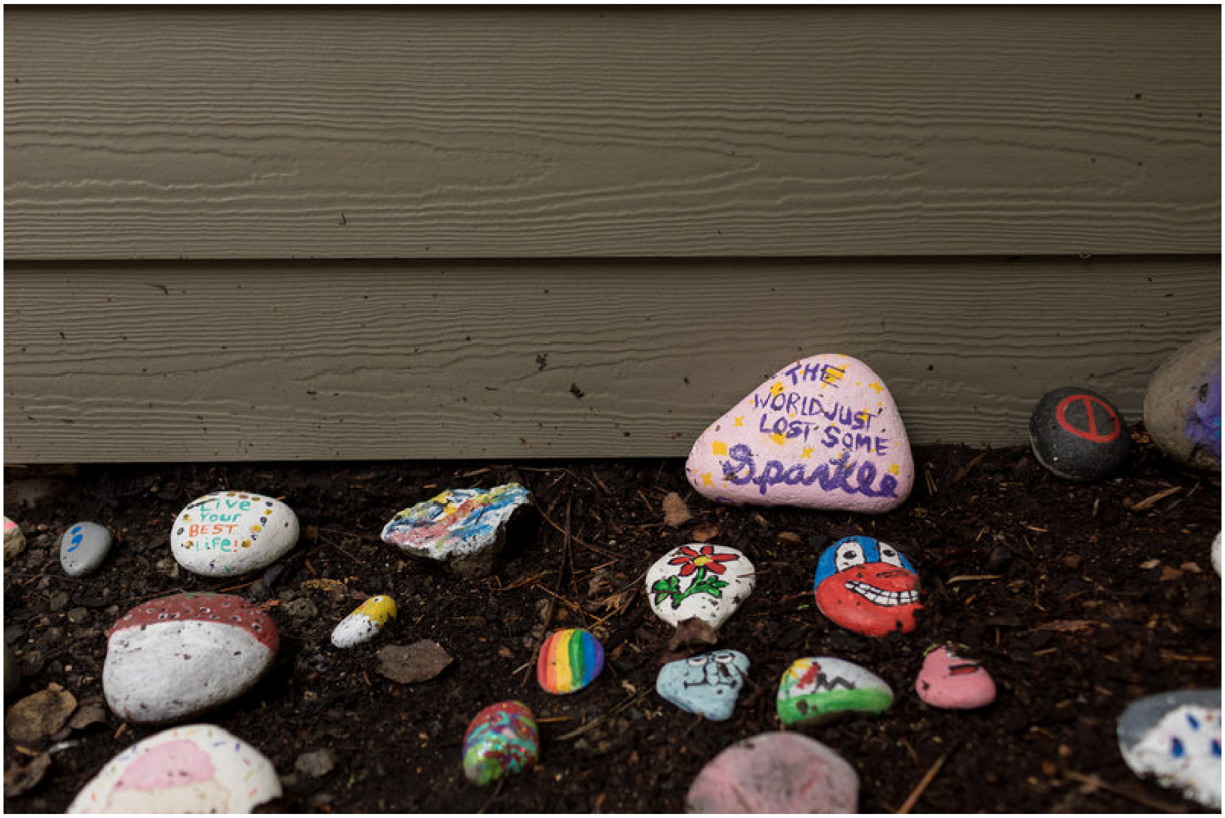
"She was struggling to get air," Conger remembers, "and you could just see the panic and the fear in her eyes. She would rest for a minute, take a nice long breath for a minute, close her eyes, then wake up in absolute fear. She could not take a breath."

Now, Conger and Barnett agreed with the medical staff that it was time to begin palliative, or comfort care for McSweeney.

They said goodbye to McSweeney and left the hospital.

Just hours later, at 3:30 Sunday morning, a phone call woke up Barnett at her home.

It was the charge nurse at the hospital. "I'm sorry to inform you," he said, "that Sarah passed away."



Painted rocks sit outside Sarah McSweeney's group home in Oregon City, Ore., on Nov. 24, 2020. McSweeney's housemates painted a rock to read "The World Just Lost Some Sparkle" in pink and purple after McSweeney's death.
Celeste Noche for NPR

McSweeney didn't die of COVID-19.

She died of severe sepsis due to aspiration pneumonia.

Aspiration pneumonia is a serious medical condition. But, usually, it's treatable.

Conger says doctors could have stopped the feeding tube and instead fed McSweeney through an IV line.

Conger and Barnett said they made repeated suggestions for the IV feedings. Hospital records say a doctor considered it and concluded there was "no evidence" that it would make a difference. But by then it was May 9, when the pneumonia was out of control and McSweeney was just hours from death.

Over more than two and a half weeks, doctors and social workers had questioned why this disabled woman had medical instructions for full care, instead of a Do Not Resuscitate order.

McSweeney's advocates had pushed back.

Says Conger of McSweeney's care at the hospital: "I don't feel like they — and this is my personal opinion — I feel like they didn't feel like she was worth that."

Because of the pandemic, there was no funeral service for McSweeney. Her friends were her housemates and the other disabled people in nearby group homes and the staff that helped her live independently.

In a rock garden outside McSweeney's group home, her housemates placed a stone they'd painted in pink and purple that said: "The World Just Lost Some Sparkle."

"She was so happy and goofy and funny," Barnett says of McSweeney. "I was lucky to know her for the last three years. And I got to know her and how she communicates and what's important to her and how she jokes around. I used to tease her that she was a princess and I was going to buy her a tiara and she'd laugh. And she was so much fun. And even though she had these medical issues, she was vivacious. She just lived her life."

Barnett pauses, and then apologizes for crying. "She was a beautiful person ... I just think she could have gone out better. They owed her more respect than she got."

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