



Disability  
Rights  
Oregon



Oregon Council on  
Developmental Disabilities

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## Disability advocates secure legislative victory: Equal access to healthcare during COVID-19

**Oregon Legislature unanimously passed SB 1606, affirms that hospitals cannot cast aside the civil rights of Oregonians with disabilities during an emergency**

Portland, Oregon—Today, the Oregon State Legislature unanimously passed [Senate Bill \(SB\) 1606](#) to ensure that Oregonians with disabilities can see their family and support staff in the hospital to provide disability related supports. SB 1606 also prohibits hospitals from withholding healthcare on the condition that a person with a disability has signed an end-of-life order or POLST. The legislation was requested by Disability Rights Oregon, the Oregon Council on Developmental Disabilities (Council), and Developmental Disabilities Coalition. The legislation was championed in the Legislature by Senator Sara Gelser (Corvallis). SB 1606 will take effect immediately upon signing by the Governor, which could be as soon as next week.

Disability Rights Oregon and the Council have received complaints of healthcare discrimination from every corner of Oregon, involving nearly every hospital system. Disability Rights Oregon requested this legislation and testified in support of the bill numerous times.

“In addition to battling a pandemic like everyone else, people with disabilities are also battling ingrained bias in the healthcare system. While we’ve been told that our lives don’t have as much value as other Oregonians—we refuse to accept this discrimination,” said Jake Cornett, Executive Director of Disability Rights Oregon. “While

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**Disability Rights Oregon is the Protection and Advocacy System for Oregon**

this bill is an important step forward, we've got more work to do in the next session to safeguard the rights of Oregonians. I'm so grateful to the hundreds of Oregonians who wrote in support of this legislation and to Senate President Courtney, Speaker Kotek, Sen. Gelser, Sen. Knopp, and so many others who helped this bill move forward and supported it in the House and Senate."

"I'm encouraged by this legislation recognizing the inequities of people with disabilities and thrilled with the passing of SB 1606. It is powerful to know that people with disabilities can seek medical treatment safely and fairly during this pandemic," said Christine Getman. "The truth is we're only beginning to uncover the needs of the disability community we must continue to raise the bar and welcome their voices when making decisions and setting policy. That is why I'm continuing to call on the Oregon Legislature to revisit this in the next session. I am particularly moved by the dedication and true compassion Senator Gelser showed in not just hearing my story but in understanding the frustration those of us with disabilities experience through the systemic ableism of institutions."

"Today we are grateful for the leadership shown by the Oregon Legislature as they heard the combined power of hundreds of voices of people with disabilities and their families," said Leslie Sutton, the Policy Director for the Oregon Council on Developmental Disabilities. "No longer will people with disabilities be denied the disability support they need from people they trust while in the hospital."

SB 1606 ensures people with disabilities have access to healthcare by:

- Mandating hospitals allow support people to patients as required by the Americans with Disabilities Act, consistent with the order recently released by U.S. Health and Human Services and current Oregon Health Authority guidelines,
- Ensuring that people with disabilities can have support from people they choose if they are discussing lifesaving or end of life care, and
- Ensuring health care providers do not condition providing treatment on a person having a POLST, advance directive or other instruction relating to the administration, withholding or withdrawing of life-sustaining procedures or artificially administered nutrition.

The final bill left out a section on anti-discrimination and a section to require strongly advocated by Disability Rights Oregon. Additional action is needed by the Oregon Legislature to ensure people do not face discrimination in healthcare and that relief is available. Disability Rights Oregon will continue pushing for better protections during future legislative sessions.

On May 8, Disability Rights Oregon filed a federal complaint with the Office for Civil Rights at the U.S. Department of Health and Human Services (OCR), asking OCR to find that Oregon's

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Crisis Care Guidance discriminates against people of color, people with disabilities and seniors in violation of federal law.

## Background

In April, Oregon Health and Sciences University denied a Multnomah County woman with severe physical disabilities her request for the personal support she needed to both communicate and self-care while being in the hospital, due to a new policy regarding coronavirus. Her story was featured by National Public Radio (NPR) ("[Hospital Visitor Bans Under Scrutiny After Disability Groups Raise Concerns Over Care](#)", May 17, 2020).

Christine Getman is unable to use any of her extremities with the exception of one finger. She was denied her request for one-to-one care and access to her personal care attendant (PCA) while being treated for meningitis. Without the support of her PCA while hospitalized, she was put at risk of being exposed to COVID-19 and missed numerous opportunities to communicate with key medical staff during her hospitalization. The lack of interaction left her in the dark about her care and discharge. She lived in fear of receiving improper care.

To prevent other patients with disabilities from facing similar barriers to basic human rights, Disability Rights Oregon (DRO) and Getman called on the Oregon Health Authority (OHA) to reissue its Visitation Guidance for Acute Care Facilities to allow personal care attendant exceptions alongside proper precautions to prevent the spread of COVID-19.

### About Christine Getman's Experience

Getman lives with the neuromuscular disease Spinal Muscular Atrophy, type 2. She serves as the Executive Director of the national non-profit organization Magic Wheelchair, and advocates on several disability organization boards. Though she can feel everything in her extremities, she experiences muscle weakness and require a full assist with daily activities like eating, bathing, using the bathroom, and getting dressed. She can't hold her head up without specific positioning and uses a power wheelchair to get around. She has a trach tube to breath and, if she is moved the wrong way, she can suddenly lose her ability to speak.

Because of COVID-19, staff at the hospital where she received care were minimizing in-room consultation and conducting their daily rounds via phone. Without access to her PCA, Getman was unable to answer the phone as she laid in her hospital bed. She missed calls from critical hospital staff like a patient advocate, caseworker, and home infusion staff. In order to reach the nurse "call" button, Getman was forced to position herself in a way that increased her joint pain.

To speak more clearly, Getman also needs someone to place her hand on her trach so she can breathe out through a hole. She asked the nurses to move her hand to her trach every time a doctor came into her room.

Blocking her access to her PCA also likely increased her exposure to COVID-19 by necessitating that she be in close contact with more hospital staff. She was exposed to roughly eight to twelve different hospital staff members in a shift because of her need for help with eating and assistance in using the bathroom. The patient requested a one-on-one personal care attendant from the hospital, which it denied. Getman even offered in a secondary request that her PCA not leave the room or have in-and-out privileges, until they were both discharged together, assisting in reducing her exposure to COVID-19.

Partner organizations, friends, and nurses from across the country who know Getman joined her and advocated for her by calling the hospital's Patient Advocate office, national hotlines, and DRO.

## Resources

- [Testimony from Jake Cornett, Support of SB1606, to the Joint Interim Committee for the First Special Session of 2020](#) (June 24, 2020)
- [Testimony from Jake Cornett, Responding to Healthcare Industry, to the Joint Committee for the First Special Session of 2020](#) (June 25, 2020; at 56:36 in the recording)
- [Testimony from Emily Cooper, Support of SB 1606, to the Joint Interim Committee for the First Special Session of 2020](#) (June 25, 2020; at 53:16 in the recording)
- [Know Your Rights: Reasonable Accommodations in Hospitals during COVID-19](#)
- [Oregon Health Authority Visitation Guidance for Acute Care Facilities](#) (Revised April 23, 2020)
- [DRO letter to Oregon Health Authority requesting Change in Oregon Health Authority Visitation Guidance for Acute Care Facilities](#) (April 17, 2020)
- [Federal civil rights complaint](#) (May 8, 2020)

## About Disability Rights Oregon

Disability Rights Oregon upholds the civil rights of people with disabilities to live, work, and engage in the community. The nonprofit works to transform systems, policies, and practices to give more people the opportunity to reach their full potential. For more than 40 years, the organization has served as Oregon's Protection & Advocacy system.