

Disability Law Center's Efforts to Advocate for Utahns with Disabilities During COVID-19 Pandemic

The Disability Law Center (DLC) has taken several steps this week to advocate for Utahns with disabilities amid the COVID-19 pandemic. First, the DLC filed a complaint with the Department of Health and Human Services Office for Civil Rights (OCR) regarding the State's Crisis Standards of Care on behalf of the agency and an individual who could be impacted, Jacob Hansen, an individual with cerebral palsy and cystic fibrosis. The guidelines' Patient Prioritization Tool and Adult Triage Guidelines explicitly and implicitly deprioritize people with disabilities for care in violation of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (ACA).

"This policy is facially discriminatory. Through exclusionary criteria and a scoring system, Utah's guidelines make misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living," said DLC attorney, Nate Crippes. "While OCR has put out a statement that care rationing should not be done in a way discriminates against people with disabilities, the guidelines from Utah clearly violate that OCR directive."

"Rationing human life is not only illegal and immoral, it is simply unacceptable. While we recognize that the health care system will be under unprecedented pressure during the next few weeks, no one should face discrimination in accessing life-saving treatment and care," said Executive Director, Adina Zahradnikova.

"It's simply terrifying. Jacob does things like typical people his age. He's graduated high school; he volunteers in the community. There is no reason that his diagnosis should lead to him being treated differently," said Jodi Hansen, mother of Jacob. "It feels unfair that anyone would assume others should be a higher priority," added Jacob.

In addition, the DLC created a plan to monitor long-term care facilities, like nursing homes, during the COVID-19 pandemic. While some facilities took early precautions, reports from other states show facilities facing serious fines for not taking proper steps leading up to and throughout the pandemic, including 6 individuals testing positive at a Salt Lake City facility, according to the Department of Health. For more information on this plan and reporting pandemic related problems in long-term care facilities to the DLC, visit disabilitylawcenter.org/covid-19.

"As we're seeing in other states, and now in Salt Lake City, these facilities are some of the hardest hit by this virus, and many of our constituents live in these types of places. This situation really highlights the problems with states relying too heavily on institutional care. These facilities are crowded, usually with many people per room, and the woefully underpaid staff are

also not kept at high ratios," said Mary Anne Davies, a DLC attorney focused on community integration.

Given the devastating impact the COVID-19 pandemic is having on people with disabilities in a myriad of ways, the DLC also sent a letter to Governor Herbert calling on him to issue a statewide Stay-at-Home Order, and they recommended he take additional steps to make sure all Utahns are safe in this crisis. Several organizations, including the Utah Parent Center and Utah Health Policy Project, and several elected officials, including Rep. Brian King and County Councilwoman Shireen Ghorbani, signed on to this letter.

"People with disabilities rely on home health staff and staff in long-term care facilities. Everything must be done to ensure they can continue to be healthy to provide the support these individuals need. We call on Governor Herbert to take the necessary steps, including a stay-at-home order, to keep all Utahns safe in this crisis," said Laura Henrie, Associate Legal Director of the DLC.

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For more information, interviews, or copies of the abovementioned documents please contact Nate Crippes at (801) 910-5815, or email at ncrippes@disabilitylawcenter.org.