

NEWS RELEASE

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Connecticut Agrees to Assure Equal Access to Medical Care for Individuals with Disabilities Hospitalized During Covid-19; Federal Office for Civil Rights Acts on Complaint by Disability Organizations

Disability Rights Connecticut and Coalition of Advocates Had Filed Formal Complaint; State Will Now Ensure Support Person in Hospital for Individuals with Disabilities

In a significant victory for people with disabilities to ensure equal access to medical care and proper treatment during the COVID-19 pandemic, a formal discrimination complaint filed by Disability Rights Connecticut and a coalition of state and national advocacy organizations, has resulted in the State of Connecticut agreeing to end discriminatory practices that jeopardized equal care and treatment for individuals with disabilities.

Under the agreement reached between the Office for Civil Rights (OCR) at the U.S Department of Health and Human Services (HHS) and the State of Connecticut, the state's Department of Public Health is issuing a new statewide policy that supersedes the existing discriminatory guidance that prevented most people with disabilities who are hospitalized from having a support person with them. Many individuals with disabilities require support from family members or staff to effectively communicate with medical personnel or to otherwise receive equal access to medical treatment. Denying such supports under strict no-visitor policies can result in the violation of federal disability rights laws.

Prior to filing the formal complaint last month with OCR/HHS, Disability Rights Connecticut and other advocacy organizations had, since April, asked the state Department of Public Health (DPH) to issue a policy guidance. Its failure to do so led to the complaint.

Resolution of Complaint Sets National Precedent for Hospital Policies

The resolution of the complaint sets a national precedent that hospital visitor policies must comply with federal laws which prohibit discrimination against patients with disabilities. The new policy will ensure that modifications to no-visitor policies are available to people with disabilities who need support due to their disability, including people with altered mental status, intellectual, cognitive, communication, behavioral, or physical disabilities.

"We are grateful that the Office for Civil Rights acted quickly and decisively to ensure that Connecticut protects the rights and safety of people with disabilities. It persuaded our state to do what should have been done from day one – assure that every individual with a disability hospitalized in Connecticut has equal access to care," said Bob Joondeph, Interim Executive Director of Disability Rights Connecticut. "Because the state now has a clear written policy, patients with disabilities can expect to have their rights upheld and not be subjected to discriminatory practices that diminish their quality of care or access to treatment. We expect continued vigilance and an unwavering commitment by DPH, consistent with the letter and spirit of this agreement."

According to the new policy, individuals with disabilities "who need assistance due to the specifics of their disability, may have one designated support person with them to support their disability related needs." The designated support person may be a "family member, personal care assistant, similar

disability service provider, or other individual knowledgeable about the management of their care.” That individual would “physically or emotionally assist them” or “ensure effective communication” during their hospitalization. The order also requires proper precautions be taken to contain the spread of infection.

If the individual with a disability is to be hospitalized for longer than one day, two support people may be designated and allowed to leave and re-enter the facility, although only one support person may be present at a time, according to the new statewide policy in Connecticut.

Complaint Described Denial of Equal Access to Medical Treatment, Effective Communication

According to the formal complaint, filed on May 4, Connecticut’s lack of appropriate policy guidance consistent with federal law had allowed individuals with disabilities to be denied equal access to medical treatment, including by being denied effective communication; being deprived of their right to make informed decisions and provide informed consent; being subjected to the unnecessary use of physical and chemical restraints; being denied adequate and necessary medical treatment and care; and being subjected to substantial and lasting emotional harm.

Disability Rights Connecticut was joined in the formal complaint by the national organizations of the Center for Public Representation, CommunicationFIRST, and The Arc of the United States, and the Connecticut organizations of The Arc of Connecticut and Independence Northwest: Center for Independent Living of Northwest CT. Following receipt of the complaint, OCR/HHS initiated discussions with state officials, which led to the agreement announced today.

“We believe that it’s important to have a uniform policy to enable people with disabilities to be appropriately supported in healthcare facilities,” said Win Evarts, Executive Director, The Arc of Connecticut, Inc. “It’s important for both the patient and the healthcare provider because it improves the quality of and access to care.”

“Joan’s Voice” Is Heard In New State Policy

The detailed 12-page complaint filed with the Office for Civil Rights described circumstances surrounding the hospitalization of three individuals, each in a different Connecticut hospital, where the lack of a statewide policy allowing a patient support person to be present resulted in violations of the equal rights of the individuals with disabilities, in violation of federal law, and jeopardized their quality of care.

OCR/HHS was urged by DRCT and its co-filers to “immediately investigate and take swift action” to uphold the equal rights of individuals with disabilities and advise Connecticut to “eliminate its discriminatory guidance and instead develop revised, mandatory, uniform, standards.” They called on OCR/HHS to “advise Connecticut that it must eliminate its discriminatory guidance and instead develop revised, mandatory, uniform, standards.” The resolution announced today does so.

The individuals included a 27-year-old woman, 48-year-old man and 73-year-old woman, known in the complaint as “G.S.” At the time the complaint was filed, “G.S.” was the only person who remained hospitalized. The family of “G.S.” chose to use fictitious initials to protect her privacy and avoid the possibility of negative repercussions to her and family members.

As “G.S.’s” time in the hospital continued and her health status remained gravely ill, a second complaint was filed with OCR/HHS on her behalf, urging immediate action to remedy ongoing violations of “G.S.’s” right to access her health care. OCR/HHS responded swiftly, assigning staff from its Boston office to facilitate a resolution between “G.S.” and the hospital that is consistent with the new statewide policy. After finally being permitted two alternating support persons (family members) to assist with her medical care, “G.S.’s” condition slowly began to improve, and family members chose to have her return home to continue her recovery from COVID-19 and what

occurred in the hospital, as they were concerned that state policy could compromise the care she would receive in a facility.

“Our experience was terrifying and alarming. We are very relieved that no family will now have to go through the nightmare that we and other families have had to go through,” said Susan Fandacone, a daughter of “G.S.,” whose name is Joan Parsons, identified publicly for the first time because she is now safely back home. “We refer to this new policy as ‘Joan’s Voice,’ because it gives our mom, should she ever need to return to the hospital, and all others with disabilities, the voice they had been denied. This agreement gives individuals with disabilities something quite fundamental – a voice in their own care, and assurance that it will not be compromised or diminished. My father Robert Parsons, my sister Michele McDuell and I are grateful to everyone involved in making ‘Joan’s Voice’ an unquestioned certainty.”

Policy Protects Rights and Safety

The new policy notes that any support person must be asymptomatic for, or not have previously been confirmed positive for, COVID-19, and that hospital staff must screen any support person for symptoms of COVID-19 and conduct a temperature check prior to their entering the clinical area, and every twelve hours thereafter. Any support person suspected of having been exposed to COVID-19 may be denied access where attendant risks of such access cannot be reasonably mitigated. The support person is to wear appropriate Personal Protective Equipment (PPE) as instructed by the Facility for the duration of their stay in the hospital.

“Covid-19 has been a frightening experience for many people with and without disabilities. That fear and anxiety has been compounded by the inability of the medical community to address the needs of some people with disabilities to have a person with them during their treatment and to have access to communication,” said Eileen Healy, Executive Director of Independence Northwest: Center for Independent Living of Northwest CT, Inc. “The resolution of the Office for Civil Rights’ complaint will ensure that people with disabilities are not discriminated against and will set a standard of care for Connecticut and beyond.”

Disability Rights Connecticut, a statewide non-profit organization, advocates for the human, civil, and legal rights of people with disabilities in Connecticut. DRCT replaced the state Office of Protection & Advocacy for Persons with Disabilities in 2017, and is the Protection & Advocacy System for Connecticut. DRCT (www.disrightsct.org) has been a leading advocate throughout the coronavirus pandemic, as have Protection & Advocacy Systems nationwide, along with the organizations that collaborated with DRCT in the filing the May 4 complaint with HHS-OCR.

The Arc Connecticut is our state’s oldest and largest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families. The Arc Connecticut (www.thearcct.org) is a chapter of The Arc of The United States. In Connecticut, our 13 Arc local chapters deliver over \$100 million in jobs, supports and services to thousands of people in 162 communities.

Independence Northwest: Center for Independent Living of Northwest CT, Inc., (www.independencenorthwest.org) is a federally and state recognized Center for Independent Living. IN is responsive to our communities and provides systems advocacy to ensure that people with disabilities aren’t discriminated against by lack of architectural or attitudinal accessibility and public policy.

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Media Contact: Catherine Cushman, Legal Director, DRCT 860.469.4461, catherine.cushman@disrightsct.org