DISABILITY RIGHTS CONNECTICUT
Justice. Community. Inclusion.

Disability Rights Connecticut
"Connecticut's protection and advocacy system"

846 Wethersfield Avenue
Hartford, CT 06114

Sent Via Electronic Mail & U.S. Mail

May 4, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

RE: **Illegal Disability Discrimination Concerning Hospital COVID-19 Visitation Policies**

Dear Mr. Severino:

Please accept this letter as a complaint against the State of Connecticut for failing to ensure that persons with disabilities who are hospitalized receive reasonable accommodations from hospitals during the COVID-19 public health emergency. Specifically, persons with disabilities are not being permitted necessary exceptions to strict "no visitor" policies adopted by hospitals due to the pandemic. The State of Connecticut's guidance is unenforceable and unreasonably narrow, thereby allowing hospitals to ignore requests for reasonable accommodations and to fail to ensure persons with disabilities have equal access to medical care and treatment from hospitals in Connecticut.

As a result of Connecticut's policy, individuals with disabilities are being 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.

People with disabilities are already at significantly higher risk of contracting COVID-19 and experiencing life-threatening complications from the virus.[1] Many others with disabilities may need to be admitted to the hospital for other reasons. It is critical that, in any event, they be able to effectively communicate with medical personnel during this pandemic. We urge you to immediately investigate and take swift action to resolve these allegations of disability discrimination.

[1] Centers for Disease Control and Prevention, People with Disabilities, https://www.cdc.gov/coronavirus/2019-ncov/need-extraprecautions/people-with-disabilities.html.

This complaint is filed by Disability Rights Connecticut (DRCT)[2] along with the advocacy organizations listed below, on behalf of their constituents, people with disabilities in Connecticut, who like the individuals described below, are being denied their right to equal access to proper medical care and treatment. As Connecticut's Protection & Advocacy system, DRCT is authorized to pursue legal, administrative, and other appropriate remedies to ensure the protection of, and advocacy for, the rights of individuals with disabilities. 42 U.S.C. § 15043(a) (2)(A). This action is brought under the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA).

Background

In early March 2020, hospitals across the state of Connecticut began implementing new policies restricting visitor access to their premises in order to contain the spread of the COVID-19 pandemic. According to information published on hospital websites, this action was based on COVID-19 guidance from the Centers for Disease Control and Prevention (CDC) and the Connecticut Department of Public Health (DPH). As of this writing, every hospital in Connecticut, maintains a strict "no visitor" policy.[3] Similarly, every "no visitor" policy contains exceptions. These exceptions usually allow one visitor into the hospital for the following reasons: end-of-life; pediatric care; labor/delivery; and outpatient surgery/procedures. With the exception of three hospitals operated by Nuvance Health, not a single Connecticut hospital makes an exception for persons with disabilities.[4]

On March 27, 2020, the State of Connecticut Department of Developmental Services (DDS) issued a template for providers of residential and day programs for persons with disabilities to use when an individual requires a support staff person to accompany them in the hospital or emergency department. This fill-in-the blank form was issued after providers reported to DDS the challenges they confronted when taking persons with Intellectual/Developmental Disabilities (I/DD) to hospitals. The form was to be used for persons served by DDS who receive residential and/or staff supports from an agency (Exhibit A). The form provides notice to the hospital that the individual with I/DD requires a support staff person to accompany him/her while at the hospital. The form is signed by the Director of Health & Clinical Services at DDS.

In response to the State's action, disability advocates contacted Governor Ned Lamont, the Commissioner of DPH, Renee Coleman-Mitchell, and the Commissioner of DDS, Jordan Scheff, raising significant concerns. Specifically, advocates pointed out that the State's guidance is discriminatorily too narrow and by its very terms excludes large classes of individuals, most obviously, persons with disabilities who do not have I/DD and those who are not served by DDS, and are entitled to accommodations to the no-visitor policies under federal law. DRCT, The Arc Connecticut, and a group of seventeen State Senators from

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[2] DRCT is the Protection & Advocacy system ("P&A"), as that term is defined under the Developmental Disabilities Assistance and Bill of Rights Act ("DD Act"), 42 U.S.C. § 15041 *et seq*., the Protection and Advocacy for Individuals with Mental Illness Act of 1986 ("PAIMI Act"), 42 U.S.C. § 10801 *et seq*., and the Protection and Advocacy of Individual Rights Act ("PAIR Act"), 29 U.S.C. § 794e *et seq*.

[3] *See for example:* **Yale New Haven Health** Covid 19: Patient and Visitor Information: https://www.ynhhs.org/patient-care/covid-19/patient-care/patient-and-visitor-information.aspx and Covid-19 Pregnancy Patient and Visitor Information: https://www.ynhhs.org/patient-care/covid-19/patient-care/pregnancy-and-covid19-faq.aspx and **Trinity Health of New England** Visitor Policy Change: https://www.trinityhealthofne.org/body.cfm?id=4329&iirf_redirect=1 and **Hartford HealthCare** Visitor Restrictions: https://hartfordhealthcare.org/health-wellness/coronavirus/visitor-restrictions and **UCONN Health Center**: https://health.uconn.edu/coronavirus/patient-visitor-information/.

[4] Nuvance Health hospitals, by contrast, identify extenuating circumstances allowing for two visitors (one at a time) to serve as support persons when determined to be essential to the care of the patient, for example, "patients with intellectual and/or developmental disabilities, or patients with cognitive impairments including dementia." Nuvance Health Temporary Visitation Guidelines*:* https://patients.healthquest.org/temporary-visitation-guidelines/.

Connecticut's General Assembly wrote to the Governor *urgently* requesting that he direct the Department of Public Health to issue one uniform patient support policy for people with disabilities (Exhibits B, C, D). In our communications with the Governor, advocates provided examples from other states (such as New York) where public health departments had issued guidance for making exceptions for persons with disabilities to "no visitor" hospital policies.

On Tuesday, April 28, the DDS Commissioner issued revised guidance concerning patient support for persons with disabilities. The guidance notifies families that Connecticut hospitals should allow all people with I/DD who are served by DDS to bring a support person with them to the hospital if they need help with matters related to their disability (Exhibit E). The guidance states that it was developed with the Connecticut Hospital Association (CHA) and the DPH. The guidance states that the CHA "will *strongly recommend* and *work with* hospitals to allow one support person to accompany an individual served by DDS" to a hospital. (Emphasis added)

Once again, Governor Lamont's guidance unlawfully limits protections to only those individuals with I/DD who are served by DDS. The letter excludes people with disabilities in Connecticut not served by DDS, as well as those who do not have I/DD but have equally critical needs for, and the legal right to, a support person to accompany them to the hospital. Equally disturbing, Governor Lamont's "guidance" guarantees no real protection because neither DDS nor CHA have authority over hospitals in Connecticut. By issuing policy that cannot be enforced the Governor is in effect sanctioning the hospital's illegal behavior. Thus, as seen below, facially and as applied, Connecticut's policy violates the rights of all individuals with disabilities - a group that is already at heightened risk of contracting and experiencing life-threatening complications from the virus and for whom effective communication with medical personnel is critical to their survival.

Individual Constituents:

Patient G.S.[5]

1. Patient G.S. is a 73 year old woman who experienced a frontal lobe aneurysm eleven years ago followed by several small strokes. As a result, she is aphasic, has severe short term memory loss and is mostly non-verbal. In addition to her brain injury, G.S. has polycystic kidney disease which results in frequent kidney infections. Since July 2020, she has been admitted to a hospital approximately six times for treatment of sepsis or infections. She does not have I/DD, nor does she receive services from DDS.

2. During past hospital admissions, family members (primarily G.S.'s husband and three daughters) would remain at the hospital around the clock with G.S. and facilitate communication between G.S. and the staff. Over the years, family members have developed sophisticated individualized means of communicating with G.S. including modeling words, simplifying and chunking information, making direct eye contact and recognizing when G.S. is experiencing fever, fatigue, pain, and discomfort through various non-verbal cues. Through these communication techniques, G.S. has been able to

[5] Patient G.S. is using fictitious initials in order to protect her privacy and avoid retaliation. She remains inpatient at a hospital in Connecticut at the time of this writing and is fearful that public attention to the allegations raised herein will result in negative repercussions to herself and family members. Personally identifiable information concerning the patient and hospital can be provided under seal if required.

understand the treatment being offered to her and been provided with the opportunity to make informed decisions concerning her care.

3. On April 19, 2020, G.S. was transported to a Connecticut hospital by ambulance for treatment of a kidney infection. Family members were instructed by emergency room personnel that they would not be permitted to accompany G.S. to the hospital this time due to COVID-19 visitor restrictions. A written document was prepared listing G.S.'s medications, diagnoses, and communication limitations and was given to the ambulance attendants.

4. Upon arrival at the hospital G.S. was tested for COVID-19 and found to be positive. Family members were informed of this via telephone and told that G.S. would be placed in a unit designated for COVID-19 treatment. The family immediately began to worry that G.S.'s kidney infection may not be addressed adequately and sought to provide information to the hospital staff concerning cues to look for that signify worsening kidney infection and sepsis.

5. For the next 48 hours G.S.'s family had limited communication with staff from the hospital and no direct communication with G.S. Family members sought help from an advocacy organization, CommunicationFIRST, to obtain access to the patient to facilitate communication between G.S. and the treating professionals. After numerous communications between CommunicationFIRST's Legal Director and the hospital's nursing staff and patients' rights employee, the hospital continued to deny access to family members who could provide G.S.'s necessary communication supports and other disability-related needs, but agreed to provide a "sitter" in the room 24/7 and two video calls per day using an iPad.

6. During the first video call on the iPad, the family was able to see G.S.'s condition had declined and immediately relayed their concerns that she was developing sepsis. During that first video call the family instructed the staff regarding how to communicate with G.S. and the family spoke directly to G.S. explaining to her what was happening, who the people were in the room, and the types of treatment she was receiving.

7. Over the next three days G.S.'s health fluctuated between stable and improving. The family continued to utilize the iPad and continued to instruct new staff on different shifts as well as the different "sitters" regarding how to interpret G.S.'s non-verbal cues. G.S. remained on the same unit and the family felt rapport was being established between them, the staff, and G.S.

8. On April 25, G.S.'s oxygen levels decreased and she was moved to a step down unit of the Intensive Care Unit. On behalf of the patient, DRCT requested that a family member be permitted entrance to the hospital as an exception to the no visitor policy. An exception was sought in order to provide communication for G.S. whose physical health status had declined and decreased her ability to communicate even further.

9. The hospital granted access to one of G.S.'s daughters. The daughter complied with the hospital's requirements to be screened and agreed to the use of Personal Protective Equipment (PPE) at all times while in the hospital. The daughter was instructed that only one person from the family would be designated as a support person for G.S. and the

person must remain in the patient's room at all times. If the support person left the hospital, she would not be allowed back in.

10. Once admitted to G.S.'s room, the daughter noticed immediately that her mother's stomach had become distended. She noticed that G.S. was using shallow stomach breathing which the daughter knew to be a sign of pain. The daughter sought the help of a nurse who evaluated G.S. and confirmed she was experiencing great pain likely due to lower lobe collapse in both lungs. The daughter also communicated G.S.'s discomfort related to the abdominal swelling and sought additional assessment to determine the cause.

11. For the next twenty-four hours, the daughter remained in the room with G.S. except for a brief reprieve when she was permitted to step into a nearby empty room in order to eat a tray of food provided by the hospital. The daughter was allowed to eat in the empty room after discussions with staff concerning whether it would be safe for her to remain in the patient's room and remove her mask in order to eat and drink. The daughter understood from these discussions that it would not be safe to do so, which is why she was permitted access to the empty room. Subsequently, hospital staff was instructed not to allow the daughter to leave the room again. Having no way to eat or drink safely in the patient's room, the daughter felt she had no choice but to leave the hospital. A sitter was put back in place upon the daughter's exit.

12. DRCT requested permission for a second family member to be allowed entrance to the hospital after the first daughter left. DRCT asked the hospital to allow a second support person due to the fact the patient was expected to have a prolonged stay at the hospital (she had already been inpatient for 8 days) and one person could not stay in the room with G.S. without food or water indefinitely. The hospital's policy makes no provision for a second designated support person for patients experiencing prolonged stays and the request was denied.

13. Over the next four days, G.S.'s health continued to fluctuate but evidenced a gradual decline. As her health declined, G.S. became increasingly confused, fearful and agitated. On different occasions, she attempted to remove her oxygen mask, refused medications, and tried to bite a nurse after a painful procedure involving testing her blood gases. After that incident, G.S. was sedated and placed in restraints.

14. In the many years since G.S. experienced her aneurysm and throughout her numerous admissions to the hospital she has never been physically aggressive. Nor has she ever had to be restrained. Similarly over time, the family has learned that when given sedatives G.S.'s damaged brain and metabolic system struggles to clear the medication which causes her to be groggy, confused and in a fog for long periods of time.

15. After the use of restraints and sedation, during the next regularly scheduled video call, the family could see G.S. was terrified and confused. They had to explain all over again who the masked people were in her room, what they were doing to her body and why she was in so much pain. After the call, G.S. was able to settle and the staff remarked how calm she was after speaking with family. The family requested to participate via iPad during the next blood gas test and was able to keep G.S. calm throughout the procedure using words and a tapping technique they have used in the past.

16. Due to G.S.'s escalating anxiety and changing health status, DRCT requested again that an accommodation be made to the hospital policy and asked that two family members be designated as support persons for G.S. to stay with her (one at a time) for manageable periods of time so that eating and drinking in the patient's room could be avoided altogether. Until such an arrangement could be secured, DRCT also requested that iPad video calls be permitted at two-hour intervals or as needed, in order for family members to explain to G.S. what was happening in an effort to decrease behaviors and avoid the use of restraints and sedation. The hospital did not respond to DRCT's second request for an accommodation.

17. On Thursday April 30, G.S. was moved to the hospital's Intensive Care Unit (ICU) and intubated. Upon arrival at the ICU, G.S. was finally assessed for a bowel obstruction as her abdomen was still distended and according to hospital records no bowel movement had been recorded for seven days. DRCT requested for a third time that a family member be permitted access to G.S. this time under the "compassionate care" exception to the visitor policy. The hospital refused to grant the accommodation stating that the ICU is a different level of care and due to COVID-19, visits by family to say goodbye cannot be allowed.

Maria Dadario

18. Maria Dadario is a 27 year old woman who is hard of hearing and has limited vision. She identifies as a deaf-blind person and utilizes a licensed sign language interpreter as her preferred method of communication. Due to limited vision, Maria does not communicate effectively through lip reading, writing, or the use of Video Relay Interpreting (VRI). She does not have I/DD, nor does she receive services from DDS.

19. On April 2, 2020, Maria went to a New Haven hospital Emergency Department (ED) to receive medical care for mental health symptoms she was experiencing. Maria traveled by Uber and arrived alone at the ED. She produced a pre-printed Emergency Information Card which identifies her disabilities and states she requires a sign language interpreter.

20. When Maria arrived at the ED the staff knew she was hard of hearing and asked if she wanted a sign language interpreter. Maria said yes and the staff called for an interpreter who is employed on-site at the hospital. When told the interpreter was not on-site, Maria was presented with VRI equipment. Maria could not see the interpreter on the VRI screen clearly and the equipment began malfunctioning by freezing repeatedly.

21. Maria handed the hospital staff a card issued by the National Association of the Deaf (NAD) which describes why VRI may not be effective. The hospital staff looked at the card and just handed it back. Through limited use of the VRI, Maria learned that no sign language interpreters were being allowed on-site at the hospital due to the COVID-19 restricted visitor policy. Only VRI was available.

22. While at the ED a psychiatrist came to see Maria. She wore a mask so Maria could not read her expressions or see her mouth. The psychiatrist attempted to communicate with Maria using VRI. But because the VRI was not working well Maria felt there were many miscommunications.

Additionally, when Maria is upset and emotional she tends to sign very fast. The VRI was not able to see Maria signing clearly and had trouble understanding her. Maria knows from experience that when she is upset she needs a live sign language interpreter who can slow her down and clarify her communications in order to be effective.

23. After three hours of little to no effective communication Maria left the ED with discharge instructions to follow-up with her mental health provider. DRCT later contacted the patient relations officer at the ED to discuss the incident and received confirmation that outside sign language interpreters are not being allowed on site due to the hospital's COVID-19 visitor restrictions.

Shane Sessa

24. Shane Sessa is a 48 year old man who has intellectual disability and cerebral palsy. Shane has challenges communicating and is not independently mobile. In order to communicate Shane uses one or two word phrases, sounds, and gestures. To aid in his communication Shane uses pictures on a tray and pictures on his iPad. Because articulation is difficult for him, a limited number of people, consisting mostly of his mother and one or two staff members, can understand his speech. Shane resides at a group home for persons with intellectual disability.

25. On April 5, 2020, Shane was transferred by ambulance to a Middletown hospital because he was experiencing a high fever, symptoms of pneumonia, and abdomen pain. A staff member followed the ambulance to the hospital and stayed with Shane in the Emergency Department (ED) for several hours. While Shane was in the ED a nasogastric tube (NG tube) was inserted to help alleviate pain from a suspected bowel obstruction. Shane's mother and legal guardian, Penny Barsch, called the ED and requested permission to switch with the staff member so he could go home. Ms. Barsch was informed that under COVID-19 visitor restrictions she would not be allowed in the hospital. The only exceptions being made were for patients receiving end-of-life care or for patients who were minor children.

26. Shane was admitted to the hospital at approximately 4:00 a.m. and placed on a unit designated for patients suspected of having COVID-19. The group home provider agency made the decision not to provide staff to accompany Shane to the COVID-19 unit. The staff member who had accompanied Shane to the ED left the hospital and Shane was alone. Throughout his life, Shane has always been accompanied to medical appointments by his mother or a staff person. He had never been alone in a hospital before.

27. Ms. Barsch attempted regular communications on an iPad with her son but no consistent schedule was developed. Typically, Ms. Barsch would call the nurses' desk several times a day and ask if someone was available to facilitate a video call with Shane. Usually Ms. Barsch was able to speak with Shane a couple of times per day, though on one day staff was unavailable to assist Shane for the entire day. Frequently, during video calls the connection was poor and Ms. Barsch and Shane would become disconnected.

28. Shane was evaluated in the Coronavirus unit for four days and, after testing negative for COVID-19, was transferred to another floor where it was determined Shane required

emergency intestinal surgery. Ms. Barsch requested again to be permitted access to support Shane before and after the surgery but she was denied.

29. Ms. Barsch reports it was the worst time in her life. When Shane was told he had to go to surgery and people were rushing around him, he became hysterical. The hospital staff called Ms. Barsch and set the iPad on Shane's stomach while they transported him to surgery. Ms. Barsch could see he was terrified and he began screaming for her. Shane used words referring to his grandfather who had passed away which Ms. Barsch understood to mean Shane thought he was going to die and be with his grandfather.

30. After surgery, when Shane was waking from the anesthesia he became upset again. The hospital staff called Ms. Barsch with the iPad. She saw him crying and knew he was in pain. Ms. Barsch tried to calm Shane and assure him he was going to be okay. Later when Shane returned to his room, Ms. Barsch was called again and observed Shane yelling and becoming almost combative. At that time, hospital staff asked Ms. Barsch for verbal permission to apply restraints. Prior to that day, Shane had not pulled at his NG tube and no restraints had been necessary.

31. Ms. Barsch's presence would not only have been a comfort to her recovering son, but would likely have provided assistance in managing his fear and confusion through recovery. Without such comfort and assistance, Ms. Barsch was forced to consent to the use of restraints to prevent Shane from tampering with the NG tube.

32. Finally, after three weeks, without visitation from his mother or support staff, Shane returned to his group home. Shane is still upset and shaken from the experience, and his mother reports, he is not over it yet. Shane periodically makes the sound of an ambulance siren to communicate his concern of being taken to the hospital and to receive assurances that he is not going back.

Legal Standards

Title II of the ADA prohibits public entities (such as state and local governments) from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Unlawful discrimination under Title II includes, *inter alia*: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8).

Moreover, the United States Department of Justice has explicitly instructed that Title II of the ADA applies to emergency preparedness efforts of state and local governments, writing:

> One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments

must comply with Title II of the ADA in the emergency and disaster-related programs, services, and activities they provide.[6]

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Connecticut's state agencies and most hospitals and health care providers. 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA including failing to make reasonable modifications in policies, practices or procedures when necessary to avoid discrimination. *See, Southeastern Community College v. Davis*, 442 U.S. 397 (1979); *Henrietta D. v. Bloomberg*, 331 F.3d 261, 273-76 (2d Cir. 2003).

Section 1557 of the ACA provides that no health program or activity that receives federal funds may exclude from participation, deny the benefits of their programs, services or activities, or otherwise discriminate against a person protected under Section 504 of the Rehabilitation Act, 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a) and 92.101(b)(2)(i). This includes an obligation to make reasonable modifications in policies, practices, and procedures necessary to avoid discrimination. 45 C.F.R. § 92.205.

The Office for Civil Right's March 28, 2020 Bulletin specifically discusses the obligations of entities covered under federal disability laws to ensure equal access to medical treatment and "effectively address[ ] the needs of at-risk populations."[7] This includes providing effective communication, meaningful access to information, and making reasonable modifications to address the needs of individuals with disabilities. [8]

Connecticut's policy is wholly at odds with the non-discrimination standards cited above. Instead of ensuring that all individuals with disabilities are afforded reasonable accommodations when hospitalized, Connecticut is excluding tens of thousands of people from equal access to the benefit of hospital services. Connecticut's policy enumerating exceptions to no-visitor policies inexplicably excludes certain people based on their disability diagnosis and whether or not they receive services from the state. As such the policy contains illegal eligibility criteria that screens out individuals with disabilities from accessing services. Compounding its illegal actions further, Connecticut issued a policy that is unenforceable, thereby perpetuating the ongoing discriminatory conduct by the hospitals.

Finally, there is no legally justifiable reason for excluding certain people with disabilities from being provided accommodations to hospital visitor policies. Neither Connecticut nor the individual hospitals could in good faith even allege that the requested modifications are a fundamental alteration or undue burden. Connecticut's statewide policy allows for modifications of the no-visitor policies, albeit for a narrower group than those entitled to the modification. For purposes of the feasibility and safety of the modification, there is no difference between individuals with I/DD receiving state services and people with other disabilities or people with I/DD who do not receive state services.

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[6] DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at 1 (July 26, 2007), available at https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm. *See also,* Department of Health and Human Services (HHS)Office for Civil Rights, Bulletin:Civil Rights, HIPAA,and the Coronavirus Disease (COVID-19), 1-3 (Mar. 28, 2020)(available at: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog) (hereinafter "OCR Bulletin").

[7] OCR Bulletin at 2.

[8] *Id.*

Moreover, individual hospitals' policies evidence that DRCT's requested modification would not be a fundamental alteration or undue burden. Though restricting the spread of the virus is critical, Connecticut hospitals already recognize that in limited circumstances, it is both possible and necessary to allow patients to be accompanied by a support person. In light of the accommodations hospitals are already making for classes of patients such as minors, people in labor, and people at the end of life, making limited exceptions for individuals with disabilities is a reasonable modification. There is no reason for Connecticut to limit its policy to only those persons with I/DD who receive services through DDS. Lastly, the fact that numerous other states have issued statewide policies allowing for reasonable modifications to no-visitor policies for all people with disabilities who are legally entitled shows that this would not be a fundamental alteration.[9]

It is critical that all reasonable steps be taken to ensure support persons such as guardians, family members, and health care agents are afforded an equal opportunity to communicate with the disabled individual and their treating clinicians. Communication supports may include accommodations such as access to interpreters and specialized assistive technology, including telephonic or video technology; they may also include the presence of a family member, personal care assistant, or trained disability service provider if that is what the patient with a disability requires. Support persons not only assist with communication but can also provide critically important physical and emotional support necessary for the patient to receive equal access to the medical treatment the hospital provides to others without disabilities.

Based on guidance issued in New York,[10] New Jersey,[11] Oregon,[12] Illinois,[13] and California,[14] DRCT proposes Connecticut adopt and disseminate the following statewide policy upon which hospitals can make individualized determinations and allow access in accordance with proper precautions to contain the spread of infection:

> **Patients 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, that may include (but not be limited to) altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns.**
>
> **If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, to physically or emotionally assist them or to ensure effective communication during their hospitalization, this must be allowed with proper precautions to contain the spread of infection.**

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[9] See infra at n. 9-14.
[10] New York Department of Public Health: https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf .
[11] New Jersey Department of Health: https://njcdd.org/wp-content/uploads/Visitor-Policy.pdf#%5D.+?)%5B'%22%5D)&link_id=45079976764548&source_id=45079984840849&source_type=Contact
[12] Oregon Health Authority: https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf
[13] Illinois Department of Public Health: https://coronavirus.illinois.gov/sfc/servlet.shepherd/document/download/069t000000AiOFZAA3?operationContext=S1
[14] California Department of Public Health : https://www.cdph.ca.gov/Programs/CHCQ/LCP/Pages/AFL-20-38.aspx.

For hospitalized patients, the patient or family/caregiver may designate two support people; but only one support person may be present at a time. This restriction must be explained to the patient and support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patients fully understand this restriction, allowing them to decide who they wish to identify as their support person.

Accordingly, DRCT requests that the Office for Civil Rights immediately investigate and issue findings that the actions taken by Governor Lamont and his administration unlawfully discriminate against persons with disabilities in the State of Connecticut. We further request that OCR advise Connecticut that it must eliminate its discriminatory guidance and instead develop revised, mandatory, uniform, standards for allowing patient support providers within hospital settings during this public health emergency. People with disabilities face significantly heightened risks during this pandemic and it is essential that their right to effective communication in receiving medical care is enforced.

We greatly appreciate your prompt consideration of this urgent matter. We can be contacted at the numbers/emails below concerning any questions or responses to this Complaint.

Respectfully,

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Together With:

CommunicationFIRST

CommunicationFIRST is the only national, nonprofit, 501(c)(3) organization dedicated to protecting and advancing the civil rights of the more than five million people of all ages in the

United States who, due to disability or other condition, are unable to rely on speech alone to communicate. Run by and for people with expressive communication disabilities, CommunicationFIRST advances its mission by educating and engaging the public, advocating for policy and practice reform, and engaging the justice system to ensure access to effective communication, to end prejudice and discrimination, and to promote equity, justice, inclusion, and opportunity for our historically marginalized community. https://CommunicationFIRST.org/

The Arc of Connecticut, Inc.

The Arc Connecticut is our state's oldest and largest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families. We were founded more than 65 years ago by parents who believed that their loved ones with I/DD should have the supports they needed to live, work, and fully participate in the life of their communities. We are a chapter of The Arc of The United States. The National Arc is the nation's largest organization of and for people with I/DD. In Connecticut, our 13 Arc local chapters deliver over $100 million in jobs, supports and services to thousands of people in 162 communities. Together, Arcs are the largest provider of supports and services for people with I/DD and their families in Connecticut.

Independence Northwest: Center for Independent Living of Northwest CT, Inc.

IN: Center for Independent Living of Northwest CT, Inc., a federally and state recognized Center for Independent Living, is filing this Complaint on behalf of the people with significant disabilities the organization serves. 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. IN offers peer support, individual advocacy, independent living skills instruction, information and referral, youth transition and transition from nursing facilities to people with all types of disabilities and of all ages.

EXHIBIT
A

From: DDS.Alert@ct.gov <noreply@everbridge.net>
Sent: Friday, March 27, 2020 1:20 PM
To: sjacovino thearcct.org <sjacovino@thearcct.org>
Subject: Provider Updates

Please click here to acknowledge receipt of this message

Dear Providers,

Attached please find the following documents:

• A DDS memo providing updated guidance for Day and Employment Programs

• A template for providers to utilize when an individual requires a support staff person accompany them to the hospital or emergency department. The Department understand that some providers have run into challenges with this process, and DDS asks that this template be used to help mitigate these situations.

Please email any questions to DDS.COVID19@ct.gov

Thank you!

State of Connecticut
Department of Developmental Services

Ned Lamont
Governor

Peter Mason
Deputy Commissioner

Jordan A. Scheff
Commissioner

Cres Secchiaroli
Regional Director
Public Operations

COVID-19 Pandemic
Hospital Admissions and Emergency Department Notice

Date:_____

Individual's Name:_____

Date of Birth:_____

_____is served by the Connecticut
(individual's name)

Department of Developmental Services (DDS) and receives residential and/or staff supports through

_____
(agency's name, contact person and phone number)

The needs of the individual noted above requires a support staff person to accompany him/her while at the hospital or during his/her evaluation in the emergency department.

The support staff person _____
(name of support staff person)

will provide copies of the individual's current medication list, diagnoses, name of the primary care provider and the contact information for the individual's legal guardian.

Thank you.

Valencia Bagby-Young, EdD Psychology, FNP-BC, MSN, MA, RN
Director of Health & Clinical Services
Department of Developmental Services
460 Capitol Avenue, Hartford CT 06106

EXHIBIT
B

Justice. Community. Inclusion.

Disability Rights Connecticut

"Connecticut's protection and advocacy system"

846 Wethersfield Avenue
Hartford, CT 06114

Sent Via Electronic Mail and U.S. Mail

April 14, 2020

Renée D. Coleman-Mitchell, MPH
Commissioner, Department of Public Health
410 Capitol Avenue
Hartford, CT 06134

Re: **Hospital Visitation Policies for Individuals with Disabilities**

Dear Commissioner Coleman-Mitchell:

I write on behalf of Disability Rights Connecticut (DRCT), the state's designated protection and advocacy system. I am urging you to take swift action and provide statewide guidance to hospitals and health care facilities concerning visitors during the COVID-19 emergency. It is imperative that exceptions be made to the restricted visitor policies in order to allow individuals with disabilities the ability to have with them a support person.

DRCT became aware of a situation involving an individual who is deaf-blind who went to an emergency department in New Haven on Thursday, April 2, and was informed the only interpreting service that could be provided was VRI (Video Relay Interpreting). The individual cannot communicate through VRI due to the person's blindness. No other interpreter was provided or allowed by the hospital due to restrictions regarding PPE, social distancing, and visitors.

Individuals with disabilities who need communication or behavioral supports in hospital situations retain their rights to reasonable accommodations under federal law, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA), even in a pandemic.

To assist the Department, DRCT reviewed several polices from other states and hospitals.[1] We propose the Department of Public Health immediately issue a directive stating that hospital visitation policies restricting visitors must include an exception with language similar to the following:

[1] / *See*: **Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation**; New York Department of Health (4/10/2020);

Patients with disabilities who need assistance due to the specifics of their disability may have one designated support person with them. This could include specific needs due to altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection.

For hospitalized patients, especially with prolonged hospitalizations, the patient or family/caregiver may designate two support people; but only one support person may be present at a time. This restriction must be explained to the patient and support person in plain terms, upon arrival or, ideally, prior to arriving at the hospital. Hospital staff should ensure that patients fully understand this restriction, allowing them to decide who they wish to identify as their support person.

Your tireless work on behalf of individuals with disabilities and all of us in Connecticut is sincerely appreciated. Please do not hesitate to contact me at 503-502-1967 or bob.joondeph@disrightsct.org if you have questions or would like additional information. Thank you in advance for your consideration of this matter.

Sincerely,

Bob Joondeph
Interim Executive Director

cc: Governor Ned Lamont
Attorney General William Tong
Barbara Cass, RN Chief, Healthcare Quality & Safety Branch
Donna Ortelle, Section Chief, Facilities Licensing and Investigations Section (FLIS)

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https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf ; **REVISED COVID-19 Guidance for Entry into Acute Health Care Facilities**: **April 11, 2020**, Oregon Health Authority; https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf ; Rush University Medical Center, Chicago, IL https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates

EXHIBIT
C

The Arc Connecticut

Please join us in asking Governor Lamont to issue uniform guidance that will permit the loved ones or caregivers of adults and children with intellectual and developmental disabilities (I/DD), including autism and behavioral disorders, to accompany that person in the event of hospitalization during the current COVID-19 crisis.

The hospitalization of a person with I/DD - even in less trying times- can create problems that quickly spiral out of control, leading to sedation and restraint. This is difficult for everyone involved and it imposes huge burdens on hospital staff that, in the current crisis, is already stretched to the breaking point. Permitting a trusted person to accompany a person with I/DD will make treatment far easier and more efficient, while at the same time being more compassionate for the person needing treatment.

Connecticut currently has a compassionate exception in place, but it is only for paid staff to accompany people with I/DD who reside in group homes (CLAs) or other residential facilities supported by the DDS. On the other hand, the State of New York, with which Connecticut has closely allied itself throughout this crisis, has developed clear Guidance on Hospital Visitation Policies that require hospitals to permit a patient-support person for people with I/DD regardless of where they reside or who supports them. People with I/DD in CT deserve those same protections.

We fully appreciate the strain that state officials, and all people on the frontline of this crisis are under, but we can so easily foresee the needless suffering that will occur if people with I/DD- most of whom have never faced a challenge like hospitalization on their own- are left to fend for themselves during the middle of an unprecedented health crisis. Please contact Governor Lamont today.

Click the link below to log in and send your message:
https://www.votervoice.net/BroadcastLinks/PQbQC466IxPrQCEIXBsr7A

EXHIBIT
D

Connecticut General Assembly
SENATE DEMOCRATS

Legislative Office Building, Room 3300
Hartford, Connecticut 06106-1591

April 22, 2020

Dear Governor Ned Lamont:

Thank you for your tireless work on behalf of the people of Connecticut during this time of unprecedented challenge and crisis. We are gratified that your initiatives to deal with the COVID pandemic have always included those of our fellow citizens for whom the crisis poses the greatest challenges, including the poor and the powerless. The undersigned Senate Democrats and House Democrat write to ask that you consider an important form of support for one group of our fellow citizens for whom COVID poses an especially grave threat, is people with intellectual and developmental disabilities (I/DD), including autism and behavioral disorders.

On their behalf, and on behalf of their fearful families, we are writing to urgently request that the State of Connecticut issue a uniform policy that would permit their loved ones or caregivers to accompany them in the event of their hospitalization during the current COVID-19 crisis. This compassionate policy has already been implemented in New York.

The hospitalization of many people with IDD- even in less trying times- can create problems that quickly spiral out of control, leading to the sedation and restraint of that person with I/DD. This is difficult for everyone involved as it imposes huge burdens on hospital staff that, in the current crisis, are already stretched to the breaking point. Permitting someone to accompany the person with I/DD will make treatment far easier and more efficient, while at the same time being more compassionate for the person needing treatment.

We understand that on March 27, 2020, the Department of Developmental Services (DDS) sent a letter to hospitals that would create this sort of compassionate exception for some persons with I/DD, *and we applaud that effort.* However, it did not go far enough, because it only addressed a small percentage of people with I/DD, namely those residing in group homes (CLAs) or other residential facilities supported by DDS.

All the challenges, behaviors, and types of disability that exist in DDS-funded facilities, also exist in Connecticut family homes and other community settings. We believe that any policy, no matter how well-intended, that results in such illogically disparate treatment of the larger I/DD population demands modification.

Moreover, DDS lacks the authority to direct any hospital to change its policies. Accordingly, we respectfully request that you direct the Department of Public Health to implement one consistent patient support policy for all people with I/DD who might require hospitalization during this crisis.

On April 11, 2020, the State of New York, with which Connecticut has closely and productively allied itself throughout this crisis, issued an Updated DOH Guidance on Hospital Visitation Policies, (https://www.gnyha.org/news/updated-doh-guidance-on-hospital-visitation-policies/). The policy requires hospitals to permit a patient-support person at the patient bedside for several populations, including those for whom "a support person has been determined to be essential to the care of the patient (medically necessary) *including patients with intellectual and/or developmental disabilities…"* (Emphasis supplied.) The guidance also includes recommendations for PPE, and screening of visitors.

The NY guidance is clear, straightforward and does not treat people with I/DD differently based on where or with whom they reside. While Connecticut has aligned its response with New York in so many regards, it has thus far failed to do so when it comes to this vulnerable group of Connecticut citizens.

We fully appreciate the strain that you, and all people on the frontline of this crisis, are under. However, it is our understanding that this is something that has been discussed by DPH, CHA and DDS over the course of the past two weeks without resolution or action.

We are reaching out to you because the surge in COVID-19 is projected to occur over the next several weeks and we can so easily foresee the needless suffering that will occur if people with I/DD- most of whom have never faced a challenge like hospitalization on their own- are left to fend for themselves during the middle of an unprecedented health crisis.

There is so much suffering in Connecticut, and throughout our country, that is beyond our power to avoid or mitigate. The terror of a person with I/DD hospitalized alone, and the almost unimaginable angst of their loved ones, is something that we can avoid.

We stand ready to assist you in any way you request to help fashion a policy that both lessens the trauma for people with I/DD and lessens the imposition on hospital staff during the current crisis.

Sincerely,

Martin Looney

Senate President Pro Tempore Martin M. Looney
11th Senate District

Senate Majority Leader Bob Duff
25th Senate District

Senator Derek Slap
5th Senate District

Julie Kushner

Senator Julie Kushner
24th Senate District

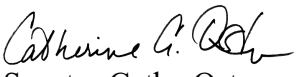
Senator John Fonfara
1st Senate District

Senator Saud Anwar
3rd Senate District

Senator Steve Cassano
4th Senate District

Senator Alex Kasser
36th Senate District

Senator Gary Winfield
10th Senate District

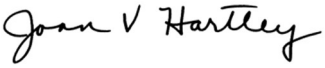


Senator Cathy Osten
19th Senate District

Representative Jonathan Steinberg
136th Assembly District

Senator Mary Abrams
13th Senate District

Senator Matt Lesser
9th Senate District



Senator Joan Hartley
15th Senate District

Senator Will Haskell
26th Senate District

Senator Carlo Leone
27th Senate District

Senator Doug McCrory
7th Senate District

EXHIBIT
E

State of Connecticut
Department of Developmental Services

Ned Lamont
Governor

Jordan A. Scheff
Commissioner

Peter Mason
Deputy Commissioner

April 28, 2020

Re: Hospital and Emergency Department Visits

Dear Families and Guardians,

This letter is to provide communication on family members and guardians accompanying a loved one to a hospital admission or emergency department visit during the duration of the coronavirus (COVID-19) pandemic.

DDS has been working in collaboration with the Department of Public Health (DPH) and the Connecticut Hospital Association (CHA) to create a process that meets the needs of the individuals we support while providing the hospitals with the safeguards necessary to maintain the health and safety of their frontline staff and all the patients within the hospital. CHA's membership includes every acute care hospital.

With these important factors in mind DDS, DPH and CHA are issuing the following guidance specific to individuals supported by DDS living in their own home or in their family home:

- CHA has agreed that it will provide this information to its member hospitals and will strongly recommend and work with hospitals to allow one support person to accompany an individual served by DDS to a hospital admission or emergency department visit, when the physical presence to assist the individual through the hospital or ED visit is necessary.
    - The necessity of the support person will be determined by the individual, their support person and the hospital.
    - The role of the support person will be to provide care and mitigate stressors for the individual throughout the duration of their stay in the hospital or ED.

- When arriving to the hospital or ED the support person must have the DDS Support Person- Hospital Admissions Emergency Department Notice (please see attached) completed and must present such form to the hospital staff.

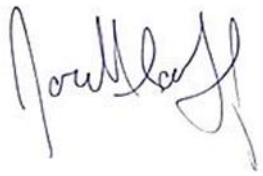
- The hospital will provide an appropriate mask for the support person to wear, as instructed by the hospital, for the duration of the visit.
    - The hospitals will be provided with an allocation of masks from the statewide supply chain for this specific usage.

Phone: 860 418-6000 ◆ TDD 860 418-6079 ◆ Fax: 860 418-6001
460 Capitol Avenue ◆ Hartford, Connecticut 06106
www.ct.gov/dds ◆ e-mail: ddsct.co@ct.gov

It is important to note that any support person in a hospital setting is bound to the guidelines and policies of that hospital and must follow such instructions to continue their presence in such setting.

For individuals that may not need a physical presence with them at a visit, the hospitals have made virtual communication options available for the family and loved ones of all hospital patients. This option should be utilized when the physical presence of a support person is not necessary for the care of an individual. We ask that families think through when a support person is truly a necessity and how virtual communication options may be a suitable alternative.

Thank you.



Jordan A. Scheff
Commissioner
Department of Developmental Services

State of Connecticut
Department of Developmental Services

Ned Lamont
Governor

Peter Mason
Deputy Commissioner

Jordan A. Scheff
Commissioner

Cres Secchiaroli
Regional Director
Public Operations

COVID-19 Pandemic- Hospital Admissions and Emergency Department Notice
For Individuals Served by DDS Living in Own Home or Family Home

Date:_____

Individual's Name:_____

Date of Birth:_____

_____is served by the Connecticut
(individual's name)

Department of Developmental Services (DDS).

The needs of the individual noted above requires a support person to accompany him/her while at the hospital or during his/her evaluation in the emergency department.

The support person _____
(name of support person & relationship to individual)

will provide information regarding the individual's current medications, allergies, diagnoses and the name of the primary care provider.

The support person, as noted above, shall follow all hospital guidelines and instructions as applicable.

Thank you.

Valencia Bagby-Young, EdD Psychology, FNP-BC, MSN, MA, RN
Director of Health & Clinical Services

Phone: 860 418-6000 ◆ TDD 860 418-6079 ◆ Fax: 860 418-6001
460 Capitol Avenue ◆ Hartford, Connecticut 06106
www.ct.gov/dds ◆ e-mail: ddsct.co@ct.gov