

December 2, 2020

The Honorable Gina M. Raimondo
Governor of Rhode Island
State House
82 Smith Street
Providence, RI 02903

Dear Governor Raimondo:

Thank you for your continued leadership during this crisis.

We, the undersigned, write with urgency about critical access to care at hospitals by people with disabilities during the COVID-19 crisis. Our three organizations represent the federally-funded “Developmental Disabilities Network” for the state of Rhode Island: (1) Disability Rights Rhode Island (DRRI), Rhode Island’s federally mandated Protection & Advocacy (P&A) system; (2) Paul V. Sherlock Center for Disabilities at Rhode Island College, Rhode Island’s University Center for Excellence in Developmental Disabilities (UCEDD); and (3) Rhode Island Developmental Disabilities Council (DD Council), mandated by federal law to undertake advocacy, capacity building, and systemic change activities that contribute to consumer-directed care and comprehensive systems of community care for people with disabilities.

At this time, we are requesting that you issue an Executive Order to enforce the RI Department of Health policy (as updated on November 2, 2020) allowing individuals with disabilities to have an essential support person accompany them in the hospital, regardless of COVID restrictions, so that these individuals with disabilities have access to health care. Our rationale for this request is stated herein.

In the early months of the pandemic, DRRI, along with our community partners, strongly advocated for a policy that allows people with disabilities to have the accompaniment of individuals who provide essential supports in order to access hospital care, as has been done in the majority of states. Some states have permitted this access voluntarily while others have required legal action pursuant to civil rights violations of people with disabilities. We were pleased to see, initially, that with our assistance and recommendations, our state was taking steps to voluntarily provide this access at a policy level with the release of a revised policy on May 8, 2020.

We write because this RIDOH policy on access to care, despite our repeated and specific follow-up with state agency personnel, and hospitals, has not been and is not being correctly or adequately implemented, resulting in denied access to care, and in some cases, trauma to individuals with disabilities, as noted in the bulleted section of this letter.

Before turning to specific violations, it is very important to note that this is *not* an issue of “hospital visitation” policy, as it has sometimes erroneously been termed, although the language is unfortunately (albeit understandably) contained within “visitation” policy provisions. We understand the reasons for curtailing typical visitation in hospitals during the pandemic, and fully support such restrictions when they are *not* essential to an individual’s access to care.

That said, many individuals with disabilities *do require* essential support persons to access care, and that is the reason we have strongly advocated for the policy. The language in Rhode Island is defined under the “Special Circumstances” provisions of the updated RIDOH guidance of November 2, 2020. Specifically quoting from that guidance:

“When a support person is essential to the care of a patient with a disability, including patients who have altered mental status, communication barriers, or behavioral concerns (such as patients with intellectual and/or developmental disabilities, dementia, and/or behavioral health needs), accommodations for the patient should be made so that the patient can be accompanied by the support person. The support person can facilitate communication with hospital staff, accessibility, and equal access to treatment and/or the provision of informed consent in accordance with the civil rights of patients with disabilities. A support person may be a family member, guardian, community support provider, peer support specialist, or personal care attendant. In some instances, there may be a need to permit the designation of two support people to ease the burden on any one individual support person.”

Following the issuance of the May 2020 policy, we wrote to Director Nicole Alexander-Scott on June 17, 2020 (copy attached), regarding violations of the policy that had occurred up until that point. We had two conference calls with RIDOH, at the direction of Dr. Alexander-Scott, and were assured by RIDOH staff that a plan for ensuring hospital compliance would be shared and adopted. No such plan has been forthcoming, despite our requests.

Meanwhile, dozens of individuals and families have contacted and continue to contact DRRI, the Sherlock Center, the DD Council and other community organizations about hospitals not permitting access to essential support persons accompanying people with disabilities, citing COVID restrictions. We have advised individuals who call to file complaints with RIDOH and many have followed up with those complaints. We have also assisted individuals in communicating with hospital personnel when the individual permits us to do so and it is feasible. However, the timing of such a last-minute request can make genuine correction impracticable or impossible. There is seldom time for hospital personnel to sign off on a policy with which they appear to be essentially unfamiliar in many cases, in order to avoid the negative consequences of not enforcing the policy, such as denial of access to care, trauma, and other harms.

The bottom line is that violations continue to occur and there does not appear to be any single authority that can be cited quickly and conclusively so that the intended policy can be implemented on the spot, when it is needed most urgently.

While it is understandable, given uncertainties with the pandemic, that hospital staff may have been initially confused, we allowed for time in order for the word to “get out.” Now it has been seven (7) months and the complaints of denial of access to care have only increased. Following is a sampling of the complaints we have received:

- A: October 2020. An elderly woman with dementia, depression, who is legally blind and deaf, sustained a broken hip following a fall and was taken to the hospital via ambulance by the nursing home. Four (4) different hospital staff informed the daughter she could not accompany her mother, citing visitation restrictions. The daughter attempted to remain for four hours but then had to leave as her mother needed testing and she was not permitted to accompany her. She was informed by the doctor that her mother, while unaccompanied, had been “uncooperative” for a medical test and so they administered an anti-psychotic medication. When permitted to see her mother for a 2-hour window, she found her without her hearing aid or glasses and in great distress. This patient required her daughter as an essential support in order to facilitate communication with hospital staff and to provide informed consent.
- B: October 2020. A woman with intellectual disability was taken to a local hospital to have her Percutaneous Endoscopic Gastrostomy (PEG) tube removed, accompanied by her sister. While a nurse was checking the patient in, another nurse removed her for the procedure. The woman informed hospital staff her sister could not receive treatment without accompaniment. Only then was she escorted back to the area her sister had been taken, only to find she had been left alone and had vomited into her mask, receiving no assistance. This patient required her sister as an essential support person in order to facilitate communication with hospital staff and provide informed consent.
- C: November 2020. A woman with intellectual disability, seizure disorder, and a feeding tube, who is both non-verbal and non-ambulatory, was admitted to a local hospital. While her mother was initially permitted to accompany her, the mother was then told she could no longer stay, the hospital citing visitation restrictions. The mother was permitted to enter four days later. She was informed that her stay would be limited to 30 minutes. Upon arrival, she found her daughter in a distressed condition, her feeding tube had not been cleaned and the area appeared irritated and infected. This young woman required her mother as an essential support person in order to facilitate communication with hospital staff.
- D: November 2020. An elderly woman with dementia was admitted to a local hospital with symptoms of possible congestive heart failure. She required the assistance of her daughter, but the hospital would not allow her to enter, citing visitation restrictions. This woman required her daughter as an essential support person to facilitate communication with hospital staff.
- E: November 2020. A young adult with autism, living with his parents, was admitted to a local hospital for emergency surgery due to an infection resulting from a dental procedure. His mother was denied access, the hospital citing visitation restrictions.

After lengthy negotiation with risk management, the mother was permitted to enter. This young man required his mother as an essential support person to facilitate communication with hospital personnel and to provide informed consent. The delay in allowing such access created undue stress and trauma for a young adult with a developmental disability.

- F: November 2020. A woman with Jacobsen Syndrome and a seizure disorder who is non-verbal and non-ambulatory was brought by emergency transport to a local hospital. Her mother accompanied her and was denied entrance, the hospital citing visitation restrictions. The mother removed her daughter the following day, citing the hospital's refusal to let her accompany her daughter. This young woman required her mother as an essential support person for accessibility and to facilitate communication with hospital personnel.
- G: November 2020. A young man with autism who is non-verbal was transported to a local hospital following prolonged and serious illness symptoms. His mother was denied access to the hospital, which cited restricted visitation. She tried to contact him via a communication device which was not feasible given his nonverbal status. She learned from hospital personnel that he had been physically and chemically restrained without prior notice. The hospital continues to deny his mother access, while attending physician reports that her son is presenting in a dramatically compromised manner, with dementia symptoms. This young man required his mother as an essential support person to facilitate communication with hospital personnel and provide informed consent.

We continue to receive calls almost daily and we anticipate it only increasing with the current severity of the pandemic. There is no reason for this denial of care, it is harmful to and traumatizing to people with disabilities, it is a violation of their individual civil rights, and it is a violation of the state's own policy.

Another alarming aspect of these violations is the chilling effect it has upon families seeking hospital care for their loved ones. DRRI Investigators have spoken at length with these families about their terrifying experiences. They remain afraid of their loved ones getting sick, and once again experiencing unnecessary and avoidable trauma that comes with being without the essential support person they require to communicate their needs to hospital staff. Many of these people are saying they are avoiding necessary care out of fear. This is highly traumatic for both individuals with disabilities as well as their caregivers. Again, this should not be happening to our most vulnerable community members. A policy is rightfully in place to prevent it from happening, and it is not being enforced.

At this time, we respectfully request a meeting with you, as soon as possible, to discuss the issuance of an Executive Order to resolve this alarming situation as quickly and conclusively as possible. We have exhausted other channels over the course of several months. We now

request this action from you, as Governor, to achieve clear and consistent enforcement of the existing RI Department of Health policy for people with disabilities to be accompanied in hospitals by essential support persons.

We are available for a virtual meeting at any time. Thank you for your immediate attention to this urgent issue.

Sincerely,

Morna A. Murray
Executive Director
Disability Rights Rhode Island

Amy Grattan
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Paul V Sherlock Center on Disabilities

Kevin Nerney
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cc: Nicole Alexander-Scott, MD, MPH, Director, RI Department of Health
A. Kathryn Power, Director, RI Department of Behavioral Health, Developmental
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