



A Self-Advocate's Guide to COVID-19

Part 3: Sample Advocacy Letter About Patients with Intellectual Disabilities Having a Support Person With Them When in the Hospital

This is a letter was written by self-advocates. Many hospitals are not allowing patients to have visitors. This is because of the Coronavirus emergency. Advocates want to change that rule for patients with disabilities. Many people with disabilities need a support person when in the hospital. This letter has examples of what to say to make that change happen.

Sample Advocacy Letter About Patients with Intellectual Disabilities Having a Support Person With Them When in the Hospital

Dear _____,

We are _____, a disability rights organization representing people with intellectual and developmental disabilities (IDD). We have reviewed your hospital policies restricting visitors during Covid-19 emergency. On April 10, the Governor of New York and their Health Department changed their guidance regarding hospital visitation during the COVID-19 outbreak. We are asking you to allow people with intellectual and developmental disabilities to have someone with them when in the hospital. Here are some of the reasons why we are requesting this immediate change:

Communication Issues That Are Of A Medical Necessity:

- Some people use devices to speak, like a letter board or typing on an iPad. Many of us need assistance to use devices to communicate.
- Often people with IDD do not use complete sentences, and it may take us a long time to finish a thought. Some of us might not have the words to describe our symptoms.
- Most of us do not understand what the doctors are saying. We need things constantly explained in smaller and smaller details.

- For some, it may be impossible to explain why a medical procedure must be done. In those situations, we need someone we know and trust with us to tell us that what is about to happen is okay.
- Many people with IDD cannot self-report. To receive the best medical treatment, we need someone who can recognize and interpret our non-verbal communication. Someone who can see that we are in pain and can read those signs.

Other Barriers To Accessing Medical Treatment:

- Without someone there, a person with IDD hospitalized for other reasons, may wander off and be exposed to COVID-19. A person should not be restrained if having someone there would keep them in bed.
- Some autistic people cannot tolerate strong smells, flashing lights, sudden or odd noises. Hospitals cannot very easily limit exposure to those things. We need someone to help us if we experience sensory overload.
- Some people with IDD need support to comply with medical treatment. We need support to not touch any tubes or needles that must go into our bodies.
- Many people with IDD have gone through bad things in life. We are 5 times more likely to experience violence than someone without a disability. Being in a hospital can remind us of the bad things that have happened to us in the past. We might react as if the bad things are still going on.
- If we have panic attacks, we need someone who knows how to help us relax.

- Many autistic people have a hard time in new situations. They say that when you meet one person with autism, you have met only one person with autism. We cannot simply give a list of generic directions to hospital staff on how to interact with an autistic person. We need support from someone who understands our individual needs.
- Finally, parents of a woman with IDD with a serious underlying health condition told us that they will not seek medical treatment for their daughter if it requires her to be in the hospital without support. We worry that other parents will make the same decision.

The New York State policy issued April 10th states that during this pandemic crisis: “Hospitals are required to permit a patient support person at the patient bedside for ... patients with intellectual and/or developmental disabilities....” [tinyurl.com/nys-c19-apr10](https://www.tinyurl.com/nys-c19-apr10). We call for immediately implementing a similar policy in _____.

We know there are many decisions regarding the COVID-19 outbreak demanding your attention. Allowing people with IDD to have someone with them when hospitalized is essential for the person to have the best health outcomes and it also puts less demands on the medical staff.

Thank you for your leadership and support during these uncertain times.

Sincerely,