

## Visitation and Support: Enhancing the Care of Individuals with Disabilities During Hospital Stays

Being in the hospital is ordinarily a stressor for all of us. Now, include the factor of a pandemic, with restricted visitation privileges, and that stressor is heightened further. Regardless of the health reasons for inpatient care, visitors may, perhaps, not be allowed. And on top of this, add additional uncertainties for special accommodations for at least some individuals with disabilities...

... like Nancy. Nancy has a disability and limited communication skills but has adopted her own style of body language, hand signs, and drawings that work well with her staff in her group home. Staff are with her virtually all the time, including when she is out in the community interacting with people unknown to her.

Nancy was admitted to the hospital upon exhibiting serious symptoms for pneumonia. Provider staff were instructed she could have no visitors because of the pandemic. Now what? How will healthcare be provided without adequate communication between Nancy and the doctor, nurses, and other hospital staff?

Many individuals with disabilities rely on services that cannot be performed without in-person contact. This may be true for individuals living in their own homes or group homes, but especially if they are hospitalized. Those providing such supports and services, whether paid or volunteer, are essential to many patients with disabilities.

While Nancy's needs are more specific to communication, others may have disability-related issues that require support persons to perform a myriad of tasks and activities. These supporters have in-depth knowledge of the patient's individual needs, including communication methods, positive behavioral practices, and health conditions that hospital staff can't possibly know, especially when patients don't relate or process information in typical ways. Consider someone who may have dementia, or a brain injury, or autism. While supporters can help the patient, they can also make the job easier—and better--for the hospital staff.

So, Nancy's needs aren't limited to what we might traditionally think of as "visitors". She needs ongoing assistance with communication between herself and hospital personnel, not just during "hours for visitors." It is essential for her to share her needs and questions as well as comprehend directions and options in order to make decisions for her care and treatment.

Hospitals, and other medical providers, are encouraged to distinguish between policies for *visitors* from *essential support workers* or *caregivers* in order to be compliant with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. In keeping with established standards of care, supporters should be expected to follow health and hygiene protocols as any other staff or visitors. To learn more see: <a href="https://www.centerforpublicrep.org/wp-content/uploads/Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies">https://www.centerforpublicrep.org/wp-content/uploads/Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies</a> 5-14-20 Final.pdf.

Working together, we can make life better for all of us. Our shared work begins with understanding.

Upcoming topics: Understanding Disability; Decision making: Who is in Charge Here?