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Hospitalized Patients & Designated Support Staff Policy Statement Committee on Public Policy and Advocacy // April 2020

SUBJECT: Providing hospitalized patients with Intellectual and Developmental Disabilities (IDD) with Designated Support Staff During the COVID19 Pandemic: Rationale for Revised Visitor's Policy

The COVID-19 pandemic is causing a crisis globally which is leading many infected persons to seek high levels of healthcare and support services. The need for immediate, safe, humane, and equitable care of individuals infected by COVID-19 in hospitals is clear. Due to the spread of the coronavirus, the risk to hospital personnel, patients, and visitors of becoming infected, and the unavailability of personal protective equipment (PPE), has led hospitals across the nation to enact policies prohibiting visitors. While this policy is epidemiologically sound, it presents hardships to a vulnerable population -- people with intellectual and developmental disabilities (such as autism, Down syndrome, cerebral palsy, Fragile X, and related complex disabilities with cognitive impairments).

Many individuals with intellectual and developmental disabilities have certain limitations or behaviors that may impact clinical care for both the patient and the provider. These limitations may include having limited verbal communication skills, difficulties with understanding consent, care plans, and treatment, situational trauma with unfamiliar settings, low stress thresholds, and anxiety due to separation from known family members, friends, or staff. These limitations are exacerbated with the loss of personal support from their agency's Direct Support Professional (caregiver) or family member who has been prohibited in providing "in-hospital" support.

Regrettably, the "No Visitors" policies may result in deleterious and sub-optimal clinical outcomes because vital bio-psycho-social information is not available to medical staff. Agency personnel and family caregivers who have this type of information can provide it stat when on site in the patient's room or floor. Such persons also may serve as the patient's medical proxy when legally eligible. Such designated support personnel are not passive "visitors," they can provide vital information that can impact clinical decisions and outcomes. Such information may include previous hospitalization information, preferences for therapeutics, sensory accommodations, fall prevention, swallowing and feeding techniques, positive behavioral tactics, and other personal care information not readily available from hospital intake notes. They may also provide communication support between the patient and hospital staff or implement specialized support strategies to aid the patient to comply with clinical treatments.

"It is recommended that hospitals provide reasonable accommodations... in their visitor policies for persons who need support from known and acknowledged support persons (family... or other designated caregivers)."

Therefore, it is recommended that hospitals provide reasonable accommodations in accord with the Americans with Disabilities Act in their visitor policies for persons who need support from known and acknowledged support persons (such as family, designated support personnel -- such as direct support professionals, or other designated caregivers). Accommodations in the policies are needed to ensure that a caregiver is permitted to be with the patient starting with admission and through to the care/treatment process. Such policies should permit a caregiver to be present to the greatest extent possible. It is further recommended that hospitals have a protocol in place for providing infection control briefings and providing appropriate PPEs to support persons.



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Designated support personnel should be advised to comply with all hospital infection control procedures and act as facilitators for and support of medical personnel. The state of New York was first to recognize the unique issues and concerns of those with ID/DD, and their Department of Health adopted a model COVID-19 hospital visitation policy addressing the needs of persons with ID/DD admitted to hospitals for whatever reason.

https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf

In order to ensure that visitation guidelines provide for safety for the patient, medical personnel, and the designated caregivers, it is recommended that the following are in place:

1. Agency/family should provide a short summary of the patient's abilities and cautions with respect to behavior
2. Agency/family should provide written information on the patient's decision-making abilities (e.g. supported decision-making, power of attorney, guardianship, etc.) and wishes re DNR orders, feeding support, etc.
3. Agency/family should provide information on any dietary restrictions and list of medications taken including drug allergies
4. Accompanying persons should be advised on any special hospital/unit protocols in place and how to abide by them
5. Accompanying persons should wear a name/agency/family tag identifying them as being cleared by the hospital to accompany the patient
6. Accompanying persons should be cleared as to what level of medical information they are entitled to (as next of kin, medical advocate, health proxy, etc.) which is noted on the identification tag.

In addition, a general disability hospital visitation statement would serve the needs of many who share the same concerns and issues with those with ID/DD (such as patients with dementia, chronic health conditions, etc.). Here is an example of a policy taken from Rush University Medical Center in Chicago:

"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."

The noted physician Dr. Martin Fischer taught that "Knowledge is a process of piling up facts; wisdom lies in their simplification."

Astute caregivers to individuals with intellectual and developmental disabilities can provide indispensable "knowledge" and "wisdom" to hospital clinicians and support staff. To provide both, first they need "to be there."

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