

# Hospitalized People with IDD Need their Caregivers: They Aren't Visitors

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# Learning objectives

- Supply an overview of hospital visitation policies for people with IDD
- Discuss the best practice policies that advocate for the rights of people with IDD to have a caregiver with them while hospitalized
- Delineate strategies that support healing for people with IDD if caregivers cannot be present in a hospital

# Overview

- *Covid 19 impact*
- *Infections rates higher than general population*
- *Death rates and complications also higher*

*(Turk, et al., 2020; Landes, et al., 2020)*

# Unfortunately not new

- Headline from Boston Globe –April 9, 2020

“Just like the coronavirus, the 1918 flu pandemic ravaged group living facilities”

<https://www.bostonglobe.com/2020/04/10/opinion/just-like-coronavirus-1918-flu-pandemic-ravaged-group-living-facilities/>

# What happens when hospitalized

- In New Jersey – A headline from the Daily Mail  
“Man with Down syndrome died from coronavirus on his 30th birthday a week after disease killed his mother and quarantine rules prevented family from being with him in hospital”

# WHY?!!!

- Many persons with IDD have
  - Limited verbal communication skills
  - Difficulties understanding what is happening and any treatments
  - Already have trauma with unfamiliar settings
  - Already have anxiety due to separation from family, friends, or staff

# Complete Visitor Restrictions

- Violate Human Rights
- Civil Rights
  - We just celebrated 30 years of ADA Act

# Not only that

- Detrimental to health outcomes
  - Vital information may not available
  - Trauma and anxiety complicate care



# Best Practice Policies

## **Rush University April 2-3**

“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.

# New York Department Public Health

**April 9**

**Hospitals are required to permit a patient support person at the patient bedside for:**

- Patients for whom a support person has been determined to be essential (medically necessary) including patients with intellectual and/or developmental disabilities and patients with cognitive impairments including dementia

# AADMD Campaign Visitation Policy

- AADMD (American Academy of Developmental Medicine and Dentistry) campaign on visitation policies began in April
- By June 9th, the Change.org petition had about 47,000 signatures and gained support from 57 organizations

# Office of Civil Rights (OCR)

- June 9th, 2020, OCR and the U.S. Department of Health & Human Services issue resolution:
  - Federal law requires hospitals and state agencies overseeing them to modify “no-visitor” policies
  - Patients with disabilities can access the in-person supports needed to benefit from care during the COVID-19 pandemic

# Strategies to support Persons with IDD when hospitalized

- Rush University has ADA Task Force since 1991
- Committee to address needs during healthcare –particularly Emergency Department visits and hospitalizations- since 2007
- Documentary on this work can be viewed at <https://vimeo.com/415331167>

# Important strategies

- Portable health records  
<http://www.betterhealthcare.info/health-resume-form/>
- Education for staff
- Standards of care
- Training of security department
- Proper charting



# Build culture of respect and inclusion

- Partner with community
- Hire people with disabilities
- Build culture where comfortable to self identify

# Better cost outcomes

- And there are better cost outcomes with tailored programs

<https://www.ajmc.com/journals/issue/2020/2020-vol26-n3/patient-outcomes-associated-with-tailored-hospital-programs-for-intellectual-disabilities>

“Patients with intellectual disabilities who were cared for in hospitals without programs tailored to intellectual disabilities had 6% higher costs, and those with extreme admission severity had 42% higher costs.”



# Questions?

Here is my contact

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