

# HCQU CARES

NURSING EDITION

Nursing Advocacy Story:  
A Case of Diagnostic Overshadowing

## Luke's Story

*"You Make a Difference," the American Nurses Association theme for Nurses Month 2023, is the theme for this issue of the HCQU CARES: Nursing Edition newsletter. A nurse can have an enormous impact on the healthcare provided to individuals with intellectual disability/autism (ID/A). One way to make a positive difference in an individual's life, in the workplace, and in the community is through advocacy. The following articles focus specifically on nurses who support individuals with ID/A.*

## Nursing Advocacy Story: A Case of Diagnostic Overshadowing

Luke is a 56-year-old man diagnosed with severe ID/A who resides in a group home in the local community. Luke enjoys watching television and playing cards with his caregivers. When upset, Luke hits the side of his wheelchair and yells at himself. When nervous or excited, he might flap his hands; if you are close to him, he may accidentally hit you. Today, Luke's appearance and demeanor were different – he was drooling, coughing a little, leaning toward the left, hitting the side of his wheelchair, and yelling at himself. Luke's caregivers were concerned about his change in baseline behavior and contacted the agency's registered nurse. The nurse performed a physical assessment and found Luke to be afebrile. Nevertheless, the nurse was concerned about the changes in Luke's behavior and advised caregivers to schedule an appointment with his doctor.

The doctor examined Luke and concluded that the head to toe assessment results were within normal limits. Caregivers explained that Luke's behavior was highly unusual and could be an indication that something was wrong. The doctor told

them not to worry, because his examination did not reveal any medical concerns and because people with intellectual disability tend to exhibit behaviors that challenge there was no need for concern. The doctor prescribed an expectorant for the cough caregivers had described and acetaminophen for discomfort.

This evening, Luke developed a fever with intense coughing and audible wheezing. He refused to eat or drink and appeared extremely lethargic. Caregivers took Luke to the emergency room, and the nurse met them there. The nurse shared the details of Luke's illness, the visit with his physician, and the quick progression of symptoms. The nurse emphasized the changes observed in Luke's behavior.

The tests and chest x-rays ordered by the emergency room doctor revealed that Luke was positive for COVID-19 and pneumonia. His WBC was 13,000. Based on the clinical data and the rapid progression of symptoms, the doctor was concerned that Luke might have sepsis, as well.





## Diagnostic Overshadowing

Diagnostic overshadowing occurs when healthcare professionals attribute an individual's behavioral and/or physical health symptoms to an existing ID/A diagnosis rather than a probable co-morbid condition. A 2022 "Sentinel Event Alert" publication from the Joint Commission presented concerns related to diagnostic overshadowing for individuals with disabilities, including but not limited to, intellectual disabilities, autism, mobility disabilities, and neurological deficits. The article discussed:

Recognizing clinician's cognitive bias related to diagnosis and reduced ability to consider other alternative diagnoses.

Recognizing individuals with disabilities are at a higher risk of diagnostic overshadowing and health disparities.

Recognizing individuals with a pre-existing diagnosis may face additional barriers to diagnosis and health care due to stigmatization and discrimination.

Recognizing additional factors such as rapid service speed of clinician, lack of training, experience, and skill, may also impact those with disabilities.

(Joint Commission, 2022)

Ultimately, diagnostic overshadowing results in a failure to receive a proper diagnosis and appropriate medical care. According to a recent article by Dr. Craig Escudé (2022), education for healthcare professionals on the following focus areas should be required to increase awareness and decrease occurrences of diagnostic overshadowing:

**Common presentation of medical illness for individuals with ID/A**

Medication management

The Fatal Five

Physical and nutritional support

Effective communication techniques

Healthcare inequities

(Escudé, 2022)

Nurses have a unique position on the frontlines of healthcare in advocacy and prevention of diagnostic overshadowing. In Luke's story above, diagnostic overshadowing was the result of a lack of knowledge, not a lack of willingness to help. Behavioral changes might be the only way a person with ID/A has or knows to communicate serious illness, pain, and discomfort. According to the Joint Commission (2022), some actions suggested to help recognize and subsequently address diagnostic overshadowing include:

Create awareness of diagnostic overshadowing and suggest methods for avoiding it in training and education programs.

Use a person-centered approach to encourage patient engagement and shared decision-making with the patient.

Create alerts or prompts to make clinicians aware of patients with complex diagnoses and/or disabilities.

Identify techniques to assess patients and groups prone to diagnostic overshadowing to overcome bias and look beyond the disability diagnosis.

Consider diagnostic overshadowing when reviewing policies and procedures to ensure they accommodate the needs of all patients, including accessibility and time with clinician.

(Joint Commission, 2022)





## Luke's Story, Continued



## Nursing Advocacy Story: A Case of Diagnostic Overshadowing (continued...)

Once Luke was admitted to the hospital, it was difficult for the nurse to obtain updates from anyone on the hospital floor. After a day with no information from the hospital, the nurse contacted the social worker for a status update. The social worker explained that Luke was restrained after he hit a nurse while flapping his hands. The nurse was shocked about the application of restraints and quickly explained that Luke has autism, that his hand flapping is due to sensory processing issues, and that hand flapping is how Luke communicates feeling overwhelmed. After learning this information, the social worker immediately spoke with the doctors and nurses, and the restraints were removed.

Luke remained in the hospital for two weeks with a severe case of COVID-19 that required supplemental oxygen and intravenous antibiotics. In that time, muscle atrophy set in to the point that Luke could not sit upright in his wheelchair. Luke was discharged to a skilled nursing facility for rehabilitation.

The skilled nursing facility did not understand why Luke was discharged to their facility. They thought his inability to sit up was due to his intellectual disability so he should be able to go home. The nurse from the group home contacted the skilled nursing facility and advised them of Luke's level of ability prior to hospitalization and of his behaviors that challenge. Once the skilled nursing facility had a better understanding of Luke's current condition, they worked steadily with him every day. When discharged one month later, Luke was sitting upright, smiling, and feeling much better.

In this story, the agency nurse advocated for Luke several times through advising his caregivers to seek medical attention and communicating with the ER doctor, the social worker, and the skilled facility. The outcome could have been very different without the nurse's willingness to speak up for Luke to ensure his needs were met.

## The Critical Role of Nurses in the ID/A Service System

In a 2019 blog in Relias, Kathy Aubrey, DNP, RN, CDDN wrote, "Nurses in the field of ID/A provide critical services including consultation, administration, health promotion, assessment, case management, medication administration, advocacy, care and risk plan development, and training of direct support staff." In line with these responsibilities is the critical role of nurses in the ID/A service system to advocate for individuals they support when those individuals are admitted to other health care settings, such as hospitals and skilled nursing homes. This advocacy can be accomplished by:

**Participating in interdisciplinary team meetings and planning meetings in hospitals and skilled nursing facilities.**

**Acting as a liaison between hospitals and nursing homes in discharge planning.**

**Ensuring durable medical equipment ordered by the hospital is received and caregivers receive the necessary training.**

**Ensuring all medication orders are verified and received.**

**Following up with any ordered referrals, such as for home health services.**

Direct support professionals (DSPs) are important members of the individual's healthcare team. Nurses in group homes play a key role in the education of DSPs during transitions from hospitals and skilled nursing homes. This education might involve:

**Understanding discharge instructions**

**Scheduling any follow up appointments**

**Understanding medication changes**

**Changes in any durable medical equipment**

**Changes in diagnosis**







## Conclusion

Nurses have important responsibilities in the ID/A service system. They help prevent diagnostic overshadowing for individuals with ID/A through advocacy, collaboration, and education of other healthcare professionals. They assist and educate direct support professionals in best practice standards to support an individual with ID/A to help maintain health, safety, and welfare. Finally, they advocate for individuals to obtain better outcomes and improved quality of life.

## References

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