JAMAICA HOSPITAL MEDICAL CENTER
PALLIATIVE CARE

DENYING THE RIGHT TO DNR
Establishing Goals-Of-Care and Advance Directives in Patients with Developmental Disabilities

Medha Chunduru, MD*; Nandini Vijayakumar, DO; Sally Mathew-Geevarughese, DO; Elizabeth Figuracion, DO; Alan Roth, DO
Jamaica Hospital Medical Center, Jamaica, NY

Background

- Initiating the “goals-of-care” conversation is difficult with most patients, however the difficulty surmounts when discussing goals-of-care of the developmentally disabled.
- In the 1970s, thousands of intellectually disabled children were sent to a state-supported institution named Willowbrook State School. While it was intended to support these children, the population exceeded capacity and they were mostly neglected.
- After the atrocities committed at Willowbrook, the New York State government established an “Office for People With Developmental Disabilities” (OPWDD) to protect the civil rights of the developmentally disabled.

Objectives

- Establishing goals-of-care and advance directives in patients with developmental and intellectual disabilities.
- Identifying ethical, regulatory and legal factors related to hospice and palliative care.
- Identifying family dynamics and involvement in establishing goals-of-care.
- Promoting awareness and early establishment of the role and involvement of the OPWDD.

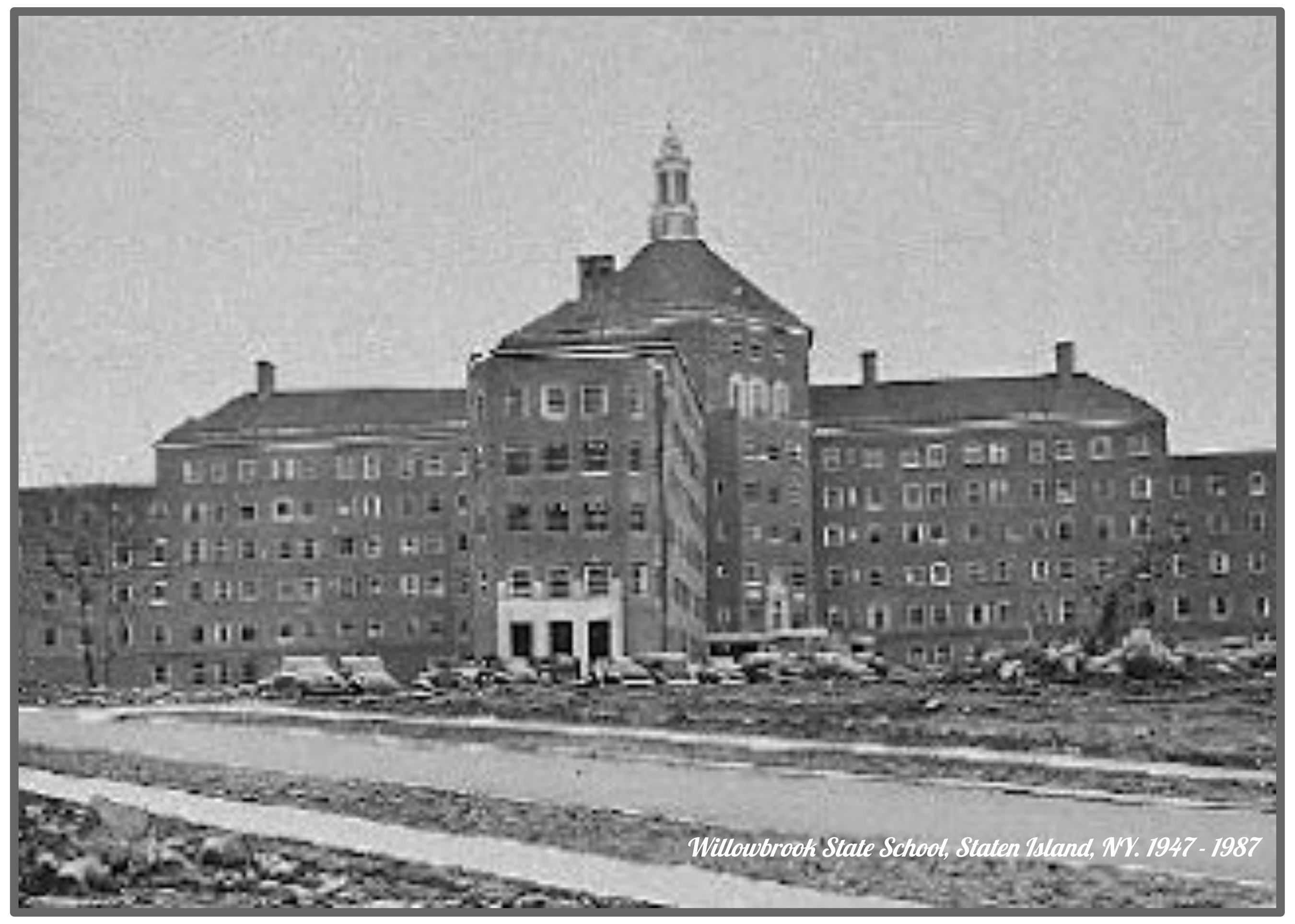
Case Description

35-year-old male with past medical history of Down syndrome, esophageal varices, NASH, and hypertension presented to the ED from his group home after having coffee-ground emesis and dizziness. In the ED, he continued to have episodes of hematemesis and due to hemodynamic instability, he was intubated for airway protection and transferred to MICU.

He stabilized after a few days of medical interventions, including pressors and sedation. However, his hospital course was complicated by multiple failed attempts of weaning off of ventilator support and recurrent episodes of aspiration pneumonia.

Palliative Care was consulted to discuss goals-of-care and advance directives with the family. Upon discussing patient’s overall decline and ventilator dependence, the family requested to de-escalate aggressive medical management, including tracheostomy and PEG tube placement and opted for comfort measures.

However, as he had a known history of cognitive disability due to Down syndrome, approval from the OPWDD was required prior to honoring the family’s wishes for comfort measures. Ultimately, the family’s request for DNR with comfort measures was denied by the OPWDD, as they deemed his multiple respiratory failures and ventilator dependency were due to reversible causes. He eventually received a tracheostomy and PEG tube prior to his discharge to a nursing facility.


Willowbrook State School, Staten Island, NY. 1947 - 1987

- ❖ **M=Medical**
- ❖ **O=Orders for**
- ❖ **L=Life**
- ❖ **S=Sustaining**
- ❖ **T=Treatment**

MOLST Checklist	
Step 1:	Identification of Surrogate
Step 2:	Specification of life sustaining treatment that is requested to be withdrawn or withheld (e.g. intubation)
Step 3:	Confirmation of individual’s lack of capacity to make health care decisions
Step 4:	Determination of Necessary Medical Criteria - individual has a terminal condition - permanent unconsciousness, or - a medical condition other than developmental disability which requires LST, is irreversible, and which will continue indefinitely - <u>AND</u> the LST would impose an extraordinary burden on the individual in light of the person’s medical condition other than DD and the expected outcome of the LST, notwithstanding the person’s DD *If the 1750-b surrogate has requested that artificially provided nutrition or hydration be withdrawn or withheld, one of the following factors must also be met:* - *No reasonable hope of maintaining life* - *The artificially provided nutrition or hydration poses an extraordinary burden*
Step 5:	Notifications (at least 48 hours prior to implementation of decision to withdraw LST): the person with DD, the facility director if the person was transferred from an OPWDD residential facility, or the director of the local DDSO
	All forms must be signed by attending physician and concurring physician.

Case Discussion

Patients with developmental disabilities face ethical challenges when hospitalized for acute illnesses or medical complications. The OPWDD serves as a means of protecting these patients from premature de-escalation of medical management without first weighing the risks and benefits of every decision.

MOLST Checklist:

- A MOLST checklist is a form required for individuals with developmental disabilities who lack capacity to make their own health care decisions and do not have a health care proxy. By completing this form, the medical team ensures the patient has a terminal or other condition that requires life-sustaining treatment and is irreversible. The team is then responsible for fully evaluating the individual’s case prior to making changes in medical management.

American Association of Intellectual and Developmental Disabilities (AAIDD):

- AAIDD encourages people with developmental disabilities to establish their wishes before situations requiring difficult decisions even occur. Their stance is that the “care should always be in the favor of treatment,” except in situations such as when “life-sustaining treatment is ineffective, the person is in an irreversible coma or permanent vegetative state, or the treatment itself would impose excessive pain and suffering.”
- In such cases, “hospice care and adequate pain relief should be available.”

Moral Distress:

- For physicians, the moral distress of these cases lies in the involvement of family members. A family may request de-escalation of medical management to optimize the quality of life of their loved one and reduce suffering. However, the straightforward process of completing a MOLST form and opting for DNR/DNI cannot be applied in these cases. This can sometimes delay withdrawal of care and cause the patient to receive aggressive medical management against the family’s wishes.

Conclusion

There are many aspects of patient care that are taken as default, however, it is crucial to identify the ethical, regulatory, and legal factors to provide appropriate medical management for all patients, especially those with developmental disabilities. The palliative care team helps promote awareness of such complex factors and establish a clear process for identifying goals-of-care and advance directives by ensuring early involvement of the OPWDD in patients with developmental disabilities.

References

1. “Advance Directives and Advance Care Planning for People with Intellectual and Physical Disabilities.” ASPE, 21 Feb. 2017, aspe.hhs.gov/basic-report/advance-directives-and-advance-care-planning-people-intellectual-and-physical-disabilities.
2. Campbell, Leslie Anne, and Steve R Kisely. “Advance Treatment Directives for People with Severe Mental Illness.” Cochrane Database of Systematic Reviews, 2009, doi:10.1002/14651858.cd005963.pub2.
3. Loitman, Jane E., and Gail Gazelle. “Palliative Care for Patients with Down Syndrome #243.” Journal of Palliative Medicine, vol. 14, no. 10, 2011, pp. 1174–1175., doi:10.1089/jpm.2011.9643.
4. “Office for People With Developmental Disabilities.” Welcome to OPWDD | OPWDD, opwdd.ny.gov/.
5. AAIDD.aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life.