

# How Nurses can Support Self-Determination for People with Developmental Disability

# Today's objectives

- To identify current events that challenge nurses' decision making about care for people with developmental disability.
  - Coronavirus
  - Transplants
  - Behavior modification
- Describe how nurses implement health policies that affect people with developmental disabilities.
  - Informed consent
  - Supported decision-making
  - Mandatory reporting to child/adult protective services



# PollEverywhere

Text LaurenClark430 to 37607

[PollEv.com/laurencclark430](http://PollEv.com/laurencclark430)



# Are you happy with your life?

Yes

Most of  
the time

Once in  
a while

No

# What is the QOL of people with Down syndrome?

Are you happy with your life?

Do you like who you are?

Do you like how you look?

284 people 12 y.o. and older with DS

More than 95%

85%

65%

45%

25%

5%

# Are you happy with your life? Yes or Most of the Time

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# Do you like how you look?

>95%

85%

65%

45%

25%

5%

# Quality of Life: Transplant Policy

May 5 2020 *Pediatrics*

## Children With Intellectual and Developmental Disabilities as Organ Transplantation Recipients

Mindy B. Statter, MD, MBE,<sup>a</sup> Garey Noritz, MD,<sup>b</sup> COMMITTEE ON BIOETHICS, COUNCIL ON CHILDREN WITH DISABILITIES

The demand for transplantable solid organs far exceeds the supply of deceased donor organs. Patient selection criteria are determined by individual transplant programs; given the scarcity of solid organs for transplant, allocation to those most likely to benefit takes into consideration both medical and psychosocial factors. Children with intellectual and developmental disabilities have historically been excluded as potential recipients of organ transplants. When a transplant is likely to provide significant health benefits, denying a transplant to otherwise eligible children with disabilities may constitute illegal and unjustified discrimination. Children with intellectual and developmental disabilities should not be excluded from the potential pool of recipients and should be referred for evaluation as recipients of solid organ transplants.

POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

American Academy  
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®



# Quality of Life: Coronavirus

- Complaints to Health and Human Services Office of Civil Rights : treatment rationing plans that discriminate against people with disabilities.
- Those plans violate federal disability rights laws.
- HHS swiftly issued a bulletin advising states and hospitals of their civil rights obligations in providing medical care during this pandemic.



**Quality-Adjusted  
Life Years and the  
Devaluation of Life  
with Disability**

Part of the Bioethics and  
Disability Series



**National Council on Disability**

November 6, 2019

# Personhood



Ariel Henley, Rooted in Rights <https://youtu.be/-tcxPWu3lZc>



## Beatings, Burns and Betrayal: The Willowbrook Scandal's Legacy

Children with developmental disabilities were held under brutal conditions at a notorious New York facility. Decades later, they still face abuse and neglect.

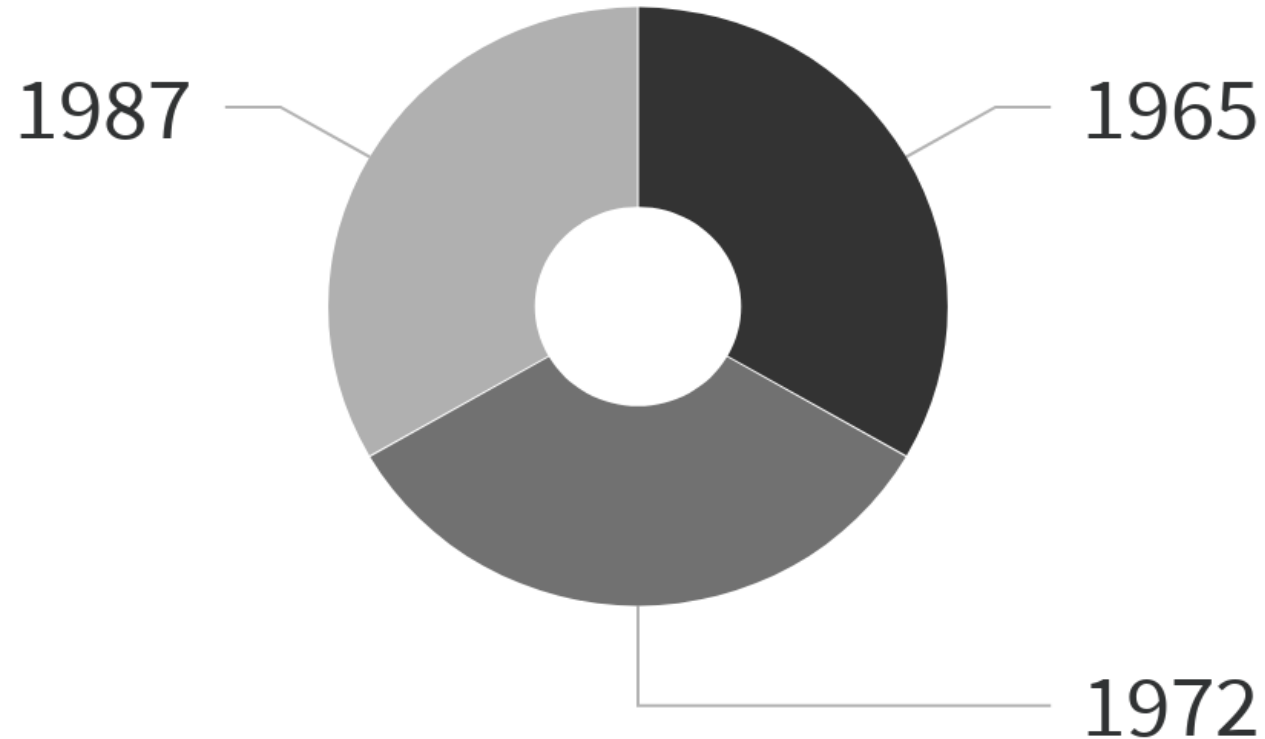
# Willowbrook: Established 1947 to house 4000 residents.

- It housed 6000
- When did the last residents leave Willowbrook?

- 1965
- 1972
- 1987

# In what year did the last resident leave Willowbrook?

1965 A 1972 B 1987 C



# In the news: electrical stimulation devices (ESDs) used for behavioral management



“the available evidence has not established a durable long-term conditioning effect or an overall-favorable benefit-risk profile for the devices. The medical literature shows that ESDs present physical risks (burns, tissue damage, pain) and a number of psychological harms (depression, posttraumatic stress disorder (PTSD), anxiety, fear, panic, substitution of other negative behaviors, worsening of underlying symptoms, and learned helplessness).”



# FDA Ruling



○ <https://www.youtube.com/watch?v=XV5D2ZL0icM>



## FEDERAL REGISTER

The Daily Journal of the United States Government



Rule

## Banned Devices; Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior

A Rule by the Food and Drug Administration on 03/06/2020

### PUBLISHED DOCUMENT

Start Printed Page 13312

#### AGENCY:

Food and Drug Administration, HHS.

#### ACTION:

Final rule.

#### SUMMARY:

The Food and Drug Administration (FDA, the Agency, or we) is finalizing a ban on electrical stimulation devices (ESDs) for self-injurious or aggressive behavior. FDA has determined that these devices present an unreasonable and substantial risk of illness or injury that cannot be corrected or eliminated by labeling. This ban includes both new devices and devices already in distribution and use; however, this ban provides transition time for those individuals currently subject to ESDs for the identified intended use to transition off ESDs under the

### DOCUMENT DETAILS

#### Printed version:

[PDF](#)

#### Publication Date:

03/06/2020

#### Agencies:

[Food and Drug Administration](#)

#### Dates:

This rule is effective April 6, 2020. However, compliance for devices currently in use and subject to a physician-directed transition plan is required on September 2, 2020. Compliance for all other devices is required on April 6, 2020.

#### Effective Date:

04/06/2020

#### Document Type:

Rule

<https://www.federalregister.gov/documents/2020/03/06/2020-04328/banned-devices-electrical-stimulation-devices-for-self-injurious-or-aggressive-behavior>





March 10, 2020

# In the News 3/10/2020

## FDA Bans **Electrical** Stimulation Devices for Self-Injurious or Aggressive Behavior

The U.S. Food and Drug Administration last week published a [final rule](#) to ban **electrical** stimulation devices (ESDs) used for self-injurious or aggressive behavior because they present an unreasonable and substantial risk of illness or injury that cannot be corrected or eliminated through new or updated device labeling.

ESDs administer **electrical** shocks through electrodes attached to the skin of individuals to immediately interrupt self-injurious or aggressive behavior or attempt to condition the individuals to stop engaging in such behavior. Evidence indicates a number of significant psychological and physical risks are associated with the use of these devices, including worsening of underlying symptoms, depression, anxiety, posttraumatic stress disorder, pain, burns, and tissue damage. In addition, many people who are exposed to these devices have intellectual or developmental disabilities that make it difficult to communicate their pain. Evidence of the device's effectiveness is weak and evidence supporting the benefit-risk profiles of alternatives is strong.

The act of banning a device is rare and the circumstances under which the agency can take this action is stringent, but the FDA has the authority to take this action when necessary to protect the health of the public. The FDA has only [banned](#) two other medical devices since gaining the authority to do so.

[Read the FDA's news release announcing this final rule.](#)

ACL participated in discussions with the FDA about ESDs and the importance of humane treatments for people with disabilities.

## AMA Code of Medical Ethics

**Informed:** Patients have the right to receive information and ask questions about recommended treatments so that

they can make **well-considered decisions** about care.

Process of communication in the patient-provider relationship fosters trust and supports shared decision making.

# Informed Consent

# Let's look at UCLA health system policy

Who can give consent?

# Who gives consent?

1. An older adult with dementia who lives in a nursing home is solicited to participate in a study of off-label use of hydroxychloroquine to treat confirmed COVID-19
  - a. Child/Adult Protective Services
  - b. Legally authorized representative
  - c. Family member
  - d. Physician or nurse
  - e. Patient
2. An 18 y.o. with a moderate intellectual disability is brought by parents for surgical sterilization
3. A two-year old is checked in for an outpatient tonsillectomy by her parents. You notice both parents have intellectual disability.

# Who gives consent?

child/adult  
protective services

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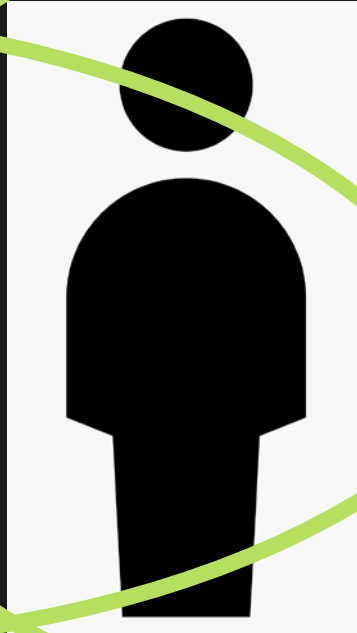
physician or nurse

patient

# Supported Decision-Making

# What is supported decision-making?

- Shared decision-making
- Supported decision-making





Gabby's story about eye surgery <https://www.youtube.com/watch?v=duyJJkZ2mIQ>

# How does SDM work?

- It starts at home.
- PWD choose their own trusted advisors and supporters.
- Supporters agree
  - Clarify values, understand information, communicate **their** decisions
- Use tools and decision-aids
  - Plain language materials
  - Extra time to discuss choices
  - Create pro/con lists
  - Role play
  - Attend meetings or appointments to aid question recall or clarify
- May involve signing formal document (like a HIPAA waiver) to go on file

Where can I learn more about supported decision-making?

- ACLU Disability Rights Program, [www.aclu.org/disability](http://www.aclu.org/disability)
- National Resource Center for Supported Decision-Making, [supporteddecisionmaking.org](http://supporteddecisionmaking.org)
- Quality Trust for Individuals with Disabilities, [dcqualitytrust.org](http://dcqualitytrust.org)

# How is it related to informed consent?

- SDM does **NOT** insert a substitute decision-maker or durable power of attorney
- SDM **slows** the informed consent process
- SDM seeks to **ensure** a more informed, more voluntary consent

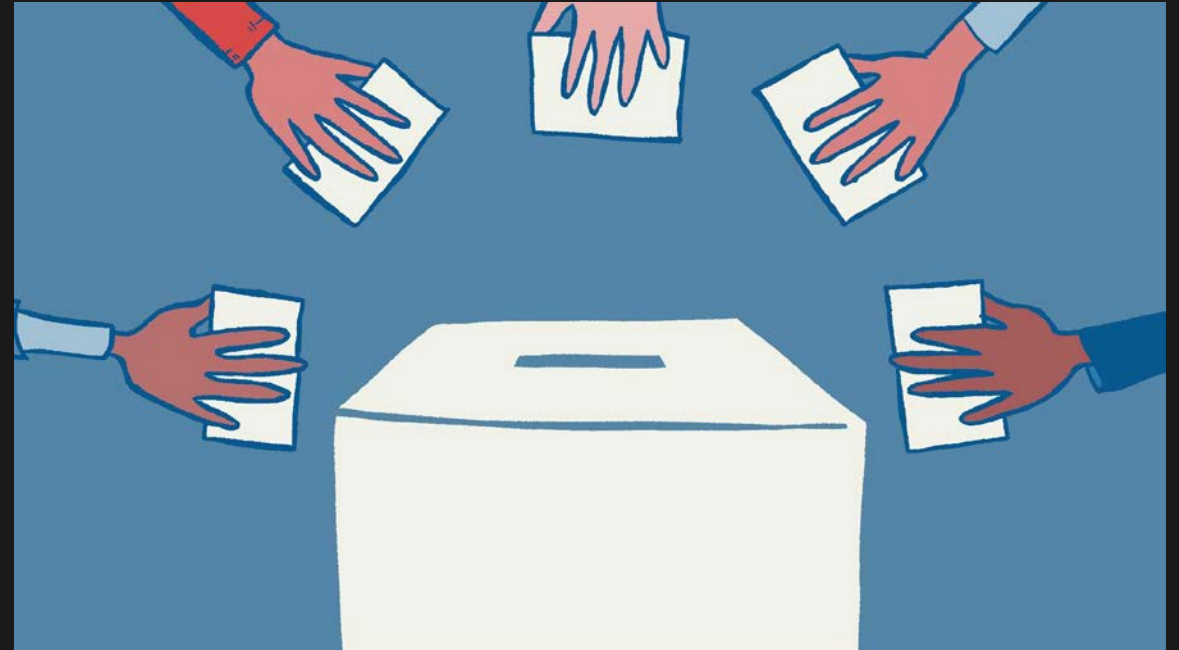




# Compared to standard consent, what benefits might be possible from SDM?

Consider the stakeholders....

- Person with a disability
- Supported decision-making team
- Nurse and care team
- Healthcare system
- Society



When poll is active, respond at **Pollev.com/laurenclark430**

Text **LAURENCLARK430** to **37607** once to join

# Benefits of Supported Decision-Making

# Mandated Reporting of Abuse

# History of Mandated Reporter Laws

- Battered Child Syndrome (1962 by Henry K. Kempe)
- California and Idaho first states to enact mandatory reporting
- By 1967, 49 states had adopted mandated reporting of suspected child abuse (physical abuse to be reported by physicians)
- 1974 US Congress enacted Child Abuse Prevention and Treatment Act to standardize reporting
- Expanded mandated reporting: more professionals (some states “universal”), more kinds of abuse or suspected abuse or neglect

# Policy

- National Child Abuse and Neglect Data System (NCANDS)
- Universal reporting: increase in reports by ~25%
- “additional reports will be made but not necessarily more maltreated children found, especially seriously abused children”

Palusci, Vandervort, 2014, p. 25

# Mandated Reporting

- California Board of Registered Nursing
- Reporting requirements



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### Abuse Reporting Requirements

#### Website:

<http://leginfo.ca.gov/calaw.html>

#### Article 2 Report of Injuries

#### Article 2.5 Child Abuse and Neglect Reporting Act

<http://leginfo.ca.gov/calaw.html>

#### § 15610.37 "Health Practitioner"

<http://leginfo.ca.gov/calaw.html>

#### Article 3 Mandatory and Nonmandatory Reports of Abuse §15630 Welfare and Institutions Code

This information is available in the published California Nursing Practice Act 2010 Edition. This book can be ordered from <http://www.lexisnexis.com/bookstore>

Registered nurses are among the health practitioners who must report known or observed instances of abuse to the appropriate authorities. This mandate applies to those situations that occur in the RN's professional capacity or within the scope of employment. Registered nurses must also be aware that failure to report as required is also considered unprofessional conduct and can result in disciplinary actions against the RN's license by the BRN.



# Mandated Reporter Requirements

- California Penal Code
- [https://leginfo.legislature.ca.gov/faces/codes\\_displayText.xhtml?lawCode=PEN&division=&title=1.&part=4.&chapter=2.&article=2.5](https://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml?lawCode=PEN&division=&title=1.&part=4.&chapter=2.&article=2.5)
- Report as soon as possible (<36 hrs)
- To California Dept of Social Services
- <https://www.cdss.ca.gov/reporting/report-abuse>
- Failure to report: \$1000 fine & misdemeanor

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Reporting | Report Abuse



## Report Abuse

- [How do I report suspected child abuse?](#)
- [I need to report human trafficking.](#)
- [Where can I report financial crimes against the elderly?](#)
- [How do I contact Adult Protective Services?](#)

# Disability & Nurse Mandated Reporters Case Study

- 2013: Ms. Gordon (age 19), who has a developmental disability, gave birth in Massachusetts, and a nurse called Child Protective Services at day 2 post-partum

Mudrick, N. R., & Smith, C. J. (2017). Mandatory reporting for child protection in health settings and the rights of parents with disabilities. *Disability and health journal*, 10(2), 165-168.





# Alternative Endings

Marie



"Medical professionals, have this assumption that we [parents with IDD] can't take care of our kids.

CPS sometimes does take babies away from families. And that's something I want to change. I want to make sure that parents can get supports they need."

*Ivanova*

Photo <https://disabilityhorizons.com/2014/07/disability-and-parenting-how-possible-is-it/>

Text from Ivanova, mother with IDD, [Parenting without Pity](#) p. 185



