

Student Manual



Nursing in OPWDD

Registered Nursing Responsibilities in Facilities
Operated/Certified by the NYS Office for People
With Developmental Disabilities



October 25, 2012



Nursing in OPWDD Table of Contents

Part I: Nursing Functions

- 1. Introduction.....1-2
- 2. Overview of Nurse’s Role.....2-4
- 3. History: Nurse Practice Act Exemption.....4-5
- 4. Supervision.....6-8
- 5. Plan of Nursing Service (PONS).....8-10
- 6. Nursing Procedures.....10-11
- 7. Training.....11-12
- 8. Clinical Evaluations.....13
- 9. Staffing Ratios.....13-14

Part II: Laws Rules and Regulations

- 1. Background.....15-17
- 2. Reportable Incidents.....17-21
 - a. Overview.....17-18
 - b. Serious Reportable Incidents.....18
 - c. Reportable Injury.....19
 - d. Missing Persons.....19
 - e. Death.....19
 - f. Restraint.....20
 - g. Medication Error.....20
 - h. Possible Criminal Act.....20
 - i. Sensitive Situations.....21
 - j. Abuse.....21
- 3. Protection of Individuals Receiving Services.....22-37
 - a. Rights of a Person Receiving Services.....22-23
 - b. Applicant Backgrounds.....23
 - c. Supervisory Requirements.....24
 - d. Conduct of Staff and Volunteers.....24
 - e. Staff Training.....24



- f. Allegation of Abuse.....25
- g. Care and Treatment.....25-26
- h. Objection to Services Process.....26
- i. Tuberculosis.....27-28
- j. Medication.....29
- k. Electronic Rx’s.....29
- l. Over-the-Counter Medication.....29
- m. Medication Administration.....30-32
- n. Medication Regime Review.....32
- o. Medication Storage.....33
- p. DNRs.....34
- q. HIV.....34-37

Part III: Health Care Decisions

- 1. Medical Immobilization and Protective Stabilization (MIPS).....37-39
- 2. Informed Consent.....39-42
- 3. Who Can Decide.....43-50
- 4. Surrogate Decision Making Committee (SDMC).....50-52
- 5. Consumer Advisory Board (CAB).....52-53
- 6. Consent Committee.....53
- 7. Health Care Decisions Act.....54-58
- 8. Medical Orders for Life-Sustaining Treatment.....59-64

NYS Office For People With Developmental Disabilities
Putting People First

Nursing in OPWDD



Registered Nursing Responsibilities in Facilities Operated/Certified by the NYS Office for People With Developmental Disabilities

NYS Office For People With Developmental Disabilities
Putting People First



Acknowledgements

Victoria Schultz RN, MS, ANP-C
 Kathleen Keating RN, MSN, CPNP-PC, CNS/DD
 Linda Guy BSN
 Lauren Lange BA

NYS Office For People With Developmental Disabilities
Putting People First

Objectives

At the conclusion of this training, you will be able to:



- Describe the role of the Registered Professional Nurse in facilities operated and/or certified by OPWDD
- Define the difference between laws, regulations, alerts and guidelines
- Identify laws and regulations pertinent to the practice of nursing in facilities operated and/or certified by OPWDD

Putting People First

OPWDD Website




www.opwdd.ny.gov

- The OPWDD website contains much of the information being presented here today
- To access the "Health Services" section, click on the "Resources" tab on the home page; then click on the "Information for Clinicians" link

Putting People First

Links and Information

Information for Clinicians (Formerly "Health Services")

- http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians

Nursing Services

- Click on the "Nursing Services" tabs on the left side of the "Information for Clinicians" webpage

Department of Health (DOH) Regulations

- <http://www.health.ny.gov/regulations/>

Surrogate Decision Making Committee (SDMC) Forms

- <http://cqc.ny.gov/advocacy/surrogate-decision-making/sdmcdecs>

Healthcare Choices Booklet

- <http://www.opwdd.ny.gov/node/70>

Putting People First

How is Nursing in OPWDD Different?



- In general, registered nurses in OPWDD provide little direct "hands on" care
- The RN's role is to provide:
 - Oversight of individual's health
 - Advocacy with health care providers and others
 - Supervision of direct care staff

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Oversight of Individual's Health

- Coordinate and monitor medical, nursing and clinical services
- Monitor individuals for signs and symptoms:
 - Acute illness
 - Complications/exacerbations of chronic illness



7

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Oversight of Individual's Health



- Review of:
 - Medication regime
 - Laboratory results
 - Consults/doctor's appointments
- Ensure follow-through on all doctor orders
- Monitor care when an individual is admitted to the hospital, and participate in discharge planning

Ready to Go Form
http://www.opwdd.ny.gov/opwdd_resources/opwdd_forms/ready_to_go

8

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Advocacy



- With medical providers to ensure that the individual receives appropriate care in a timely manner
- With other clinicians to ensure that clinical services are provided as needed
- With administrators as needed to ensure proper care

9

Putting People First

Supervision of Direct Care Staff

Direct care staff provide the majority of care in OPWDD certified facilities, such as:

- Medication administration
- Diabetic care (in some cases insulin administration)
- Colostomy care (in some cases)
- Wound care
- Tube feedings (in some cases)



Order form for Medication Administration Curriculum:
<http://www.opwdd.ny.gov/node/179>

10

Putting People First

History: The Nurse Practice Act Exemption



11

Putting People First

History: The Nurse Practice Act Exemption

§ 6908 of Education Law

"This article shall not be construed... b. As including services given by attendants in institutions under the jurisdiction of or subject to the visitation of the state department of mental hygiene if adequate medical and nursing supervision is provided."



- Written in 1938
- Individuals were all in developmental centers
- There were RNs and MDs on site so supervision was not an issue

12

Putting People First

History: How Did We Get Here?

- As individuals moved into the community it became unclear as to where the exemption applied and what constituted "adequate supervision"
- Meetings began between OMRDD (now OPWDD) and the New York State Education Department (SED) to determine the adequacy of supervision of direct care staff in community residential settings



13

Putting People First

The Process

- OMRDD (now OPWDD) and SED had several meetings to discuss the development of a mutually agreed upon administrative directive (ADM) outlining nursing supervision of unlicensed staff
- Preliminary agreement on the ADM reached in July of 2002
- Final agreement reached January 2003
- ADM # 2003-01 <http://www.opwdd.ny.gov/node/1040>



14

Putting People First

Applicability



- The ADM only applies to the supervision of direct care staff
- All certified community-based residences (ICFs, CRs, and IRA's) where two or more individuals receive services
- This directive, and the provisions of § 6908(1)(b) do not apply to non-certified residential settings

15

Putting People First

Definition of Supervision

An RN shall be responsible for the supervision of direct care staff in the performance of nursing tasks and activities:

- Initial training of the task or activity by an RN
- Periodic inspection by an RN of the actual act of accomplishing the task or activity



16

Putting People First

Definition of Supervision



Amount of supervision required is to be determined by the RN and will depend on:

- The complexity of the task;
- The skill, experience and training of the staff; and
- The health conditions and health status of the individual

LPN Scope of Practice
<http://www.op.nysed.gov/prof/nurse/nursepracticeissues.htm>

17

Putting People First

Frequency of Visits

- At least once a week
- More often at the discretion of the RN responsible for the residence's supervision



18

Putting People First

Weekly Visits

"What am I supposed to do when I visit the residence?"

Review

- The Communication/Shift Change Log & Incident Log
- Staff notes
- BM chart
- Weight chart
- Vital sign records
- Intake and output records/diet records
- Menses sheets
- Seizure records



19

Putting People First

Weekly Visits

Review medication administration records

- New orders are correctly transcribed and individual-specific medication sheet completed
- Meds are signed for
- Refused medications
- PRN sheets
- Controlled drug sheets/count



Review ALL reports from health care providers, labs, x-rays, etc. Initial and date

- Follow up on any abnormal results
- Note any other follow up needed



20

Putting People First

Weekly Visits

- Nursing assessments of individuals as needed
- Observation of care and procedures
- Staff training/in-services; use sign-in sheet
- Instruction to staff (verbal or in communication book)





21

Professional Nursing Availability



- An RN must be available 24 hours per day and 7 days a week
- On site or immediately available by telephone (defined as responding within 30 minutes)
- RN will be called immediately for changes in medical/medication orders or for changes in a individual's health status

22

Plan of Nursing Service (PONS)

- Intended to provide direction to direct care staff in providing care to individuals
- Only includes real problems staff have to be concerned about today
- Simple language
- Only information relevant to what the staff are doing



23

What Tasks/Conditions Require a Plan of Nursing Service?



- Any nursing task that is delegated to a direct care staff person
- Any diagnosed chronic medical condition
- Any medication being administered to prevent a medical condition
- Any task that an LPN or RN would be required to perform within a system that does not have an exempt clause (e.g., medication administration, g-tube feedings, trach care, oxygen administration)

24

Diagnosed Chronic Medical Condition

The easiest to figure out. Includes all diagnosed chronic medical conditions such as:

- GERD
- Diabetes
- Seizures
- Hypothyroidism



25

Elements of a Plan of Nursing Service



- Individualized approach
- Step by step direction to staff for providing care
- No medical terms/jargon
- Tells staff what does worse look like in terms of observable signs and symptoms
- When should staff call the RN/911

26

Medication to Prevent a Medical Condition

- Probably most difficult to conceptualize
- Medication is prescribed either to treat a medical condition or to prevent the development of a medical condition
- Need to provide instruction to staff not only on medication, but on the signs/symptoms of the condition we are trying to prevent

Example: Coumadin

- Purpose is to increase clotting time to prevent the development of blood clots.
- Plan of Nursing Service includes: specifics for Coumadin administration; observation for signs of bleeding; observation for signs/symptoms of blood clots



27

Putting People First

When to Call for Help



- Always include the caveat
- If any event occurs that causes concern for the individual's well-being immediately notify the RN!
- If any event occurs that may represent a threat to the individual's health/well-being, activate the emergency medical services by calling...

28

Putting People First

Plan of Nursing Services (PONS)



- RN shall document that direct care staff have been educated regarding:
 - Health conditions of each individual
 - Related health care needs of each individual
- RN shall ensure that there is an individual specific medication sheet for each medication that is administered

29

Putting People First

Nursing Procedures

It shall be the responsibility of the RN to determine:

- Which nursing procedures unlicensed direct care staff will be allowed to perform (never beyond the scope of an LPN)
- Which unlicensed staff will be allowed to perform them



30


 NYS Office For People With Developmental Disabilities
Putting People First

Nursing Procedures



The RN must assess:

- Complexity of the task; *and*
- Condition/stability of the individual; *and*
- Training, skill and experience of the staff involved including relevant factors related to the individual's ability to safely provide nursing services.

31


 NYS Office For People With Developmental Disabilities
Putting People First

Nursing Procedures

- The RN is to determine when delegation is safe or unsafe and/or not in the best interest of the individual
- In no case will an RN allow direct care staff to perform a nursing procedure that is outside the scope of practice of an LPN in a community setting
- New York Professional Misconduct Enforcement System Complaint Hot Line: 1-800-442-8106 or conduct@mail.nysed.gov



32


 NYS Office For People With Developmental Disabilities
Putting People First

RN Training



- RNs who do not have previous experience in the field of ID/DD nursing will be required to complete an orientation for registered nurses in ID/DD nursing within three months of being hired.
- OPWDD to determine content of orientation training.

33

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Direct Care Staff Training

- RN to provide initial and on-going training in all nursing tasks and/or functions
- RN must periodically review the performance of direct care staff to ensure consistency with standards of care and training



34

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Diabetic Care Training

Diabetic care will be taught by either:

A Certified Diabetic Educator (CDE). In those instances where the CDE is not a RN, the administration of insulin shall be taught by an RN;

OR

An RN who has successfully completed an OPWDD approved train-the-trainer course to teach diabetes care to unlicensed direct care staff. Approval to teach diabetic care to unlicensed direct care staff shall be for a period of one year. Continued approval will be dependent upon completion of annual knowledge/skill maintenance training.

35

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Direct Care Staff Training



- Medication administration, tube feeding and diabetic care shall be taught using a standardized curriculum approved by OPWDD
- Staff separately certified for each of these activities
- Recertified on an annual basis

36

Clinical Evaluations



- RN shall conduct annual clinical performance evaluations for unlicensed direct care staff for nursing procedures including but are not limited to medication administration
- The evaluation shall become part of the employee's annual performance evaluation

37

Staffing Ratios

- Maximum ratio: **1:50** (1 full time RN to fifty individuals)
- If an RN is the supervising nurse for the agency and also has responsibility for one or more residences, only that portion of her/his time that is devoted to the residences may be used in calculating the ratio
- Some ratios will need to be significantly less based upon the need of the individuals

1 : 50

38

Staffing Ratios

Considerations for RN staffing ratios in community-based residences:

- The health status/stability of the individuals
- The type of residential facility



39

Putting People First

Staffing Ratios



- Geographic location of the residences
- Proximity of the residences to each other
- Proximity of the residences to health care providers
- The degree of additional nursing services provided by external nursing agencies
- The actual number of direct care staff, both full and part time, who are to be trained and supervised

40

Putting People First

Staffing Ratios

- The actual number of Licensed Practical Nurses to be supervised
- The number of certified residences involved
- Agency is to establish RN/individual ratios that ensure consistently adequate registered nursing supervision
- Ratios must be reevaluated within one week if there are significant changes
- RN assignments must be adjusted accordingly



41

Putting People First

Questions & Answers



42

Laws, Rules, and Regulations



43

Laws

Passed by both houses of the legislature and signed by the executive



44

Regulations

- A governmental order having the force of law.
- Regulations are proposed by state agencies, often pursuant to a law, and reviewed according to the process outlined in the State Administrative Procedures Act.



45

NYS Office For People With Developmental Disabilities
Putting People First

Administrative Directives



- Often referred to as "ADMs"
- Written by state agencies to address specific issues
- May interpret regulations or laws
- Do not go through the process established in the State Administrative Procedure Act
- Do not carry the weight of law

46

NYS Office For People With Developmental Disabilities
Putting People First

Alerts and Guidelines



- Alerts are periodically issued to "alert" agencies about potentially dangerous situations and how to avoid them.
- Guidelines are occasionally issued by state agencies to provide advice and guidance to agencies regarding best practices.
- http://www.opwdd.ny.gov/opwdd_resources/safety_alerts

47

NYS Office For People With Developmental Disabilities
Putting People First

What Applies?

Some sections of the laws, rules and regulations of many state and federal agencies may apply:

Federal	State
Drug Enforcement Administration (DEA)	Office for People With Developmental Disabilities (OPWDD)
Occupational Safety and Health Administration (OSHA)	Department of Health (DOH)
Health and Human Services (HHS)	State Education Department (SED)

48

Putting People First

NYS Regulations

Generic
Applies to all programs and services

- Part 624
- Part 633
- Part 635

Program Specific
Applies to specific programs and services only

- Part 679



Click the "Regulations & Guidelines" tab near the top of the OPWDD homepage

49

Putting People First

Accessing Current Regulations



- New York Codes, Rules, and Regulations (NYCRR) are centrally located on the NYS Department of State Division of Administrative Rules webpage: <http://www.dos.ny.gov/info/nycrr.html>
- Online regulations (unofficial): <http://government.westlaw.com/linkedslice/default.asp?SP=nycrr-1000>
- To ensure that you are viewing the most current regulations, check the weekly New York State Register for recent rule adoptions that have not yet been published in the unofficial online NYCRR.

50

Putting People First

Part 624: Reportable Incidents

Definition
Significant event or situation endangering a person's well-being, which are reported, investigated and reviewed within the agency.

Part 624 Handbook
http://www.opwdd.ny.gov/opwdd_resources/incident_management/documents/maual_part624_handbook

51

Part 624: Reportable Incidents

- Applies to any facility certified or operated by OPWDD (including facilities that provide waiver services).
- Sets forth the minimum requirements for the management of incidents and abuse allegation.
- Agencies are required to use Form OPWDD 147 to document reportable incidents, serious reportable incidents and all allegations of abuse. Agencies may develop their own forms to report occurrences that do not rise to the level of a reportable incident.

52

Part 624: Agency Reportable Incidents



- The agency has the responsibility for defining what events or situations are to be reported
- Based on individual's characteristics, physical environment, program focus and needs
- Must ensure the safety and welfare of all individuals

53

Part 624: Serious Reportable Incidents

- **Definition:** Any injury which results in the admission of a person to a hospital or 24-hour infirmary for treatment or observation because of the injury. Note: If the injury is suspected to have been caused by abuse, the abuse is to be reported; see subdivision 624.4(c).
- Must be reported to the DDSOO/DDRO immediately and entered into the Incident Reporting Management Application (IRMA).
- "Immediately" means that the situation is to be reported without delay.



54

OPWDD Putting People First

Part 624: Reportable Injury



- Any suspected or confirmed harm, hurt, or damage to a person receiving services caused by the act of another
- May be intentional or by accident
- Results in a person **requiring** medical or dental treatment by a physician, dentist, PA or NP
- Treatment is more than first aid



55

OPWDD Putting People First

Part 624: Missing Persons

- Unexpected or unauthorized absence of a person for whom formal search procedures have been initiated
- Always a serious reportable incident



56

OPWDD Putting People First

Part 624: Death

Reportable Incident
All loss of life, regardless of cause must be reported to both OPWDD and to the Commission on Quality of Care (CQC)

Serious Reportable Incident

- Homicide or suicide
- Unexplained death
- Accidental death
- Treatment not in accordance with accepted medical standards

Agencies must submit the OPWDD 147 and the QCC100 (reporting form for deaths issued by CQC) to the DDSOO/DDRO for all reportable and serious reportable deaths, regardless of cause.

57

Putting People First

Part 624: Restraint

Act of limiting or controlling a person's behavior through the use of any device which:

- Prevents free movement of both arms or both legs
- Totally immobilizes a person
- Is ordered for the express purpose of controlling behavior in an emergency
- Any medication which renders a person unable to satisfactorily participate in programming, leisure, or other activities
- Always a serious reportable incident

58

Putting People First

Part 624: Medication Error



Reportable Incident
Any medication error that results in marked adverse effects or a person's health or welfare is in jeopardy

Serious Reportable Incident
Any medication error which results in the admission of a person to a hospital or 24-hour infirmary for treatment or observation

59

Putting People First

Part 624: Possible Criminal Act

- Actions by persons receiving services which are or appear to be a crime under New York State or Federal law
- Always a serious reportable incident



60

Putting People First

Part 624: Sensitive Situations



Reportable Incidents
Situations involving an individual which are of a delicate nature to the agency

Serious Reportable Incidents
Sensitive situations which, in the judgment of the chief executive officer, need to be brought to the attention of OPWDD

61

Putting People First

Part 624: Abuse



- Maltreatment or mishandling of an individual which endangers his/her physical or emotional well-being
- The failure to exercise one's duty to intercede on behalf of a person receiving services also constitutes abuse
- Report immediately without delay to DDSO/DDRO

http://www.opwdd.ny.gov/opwdd_resources/i_spoke_out

62

Putting People First

Part 624: Abuse

It is essential that it is understood that the words "maltreatment" and "mishandling" are an important part of the definition of abuse. For the purposes of Part 624 reporting:

- "Mishandling" is to manage wrongly or ignorantly
- "Maltreatment" is cruel or rough treatment (or handling) of a person receiving services

Forms of Abuse
Physical abuse, sexual abuse, psychological abuse, seclusion, all circumstances of aversive conditioning, violation of a person's civil rights, mistreatment, neglect, unauthorized or inappropriate use of restraint and/or time-out

63

Putting People First

Part 633

Protection of Individuals Receiving Services in Facilities Operated and/or Certified by OPWDD



64

Putting People First

Part 633.4

Rights of A Person Receiving Services

Part 633.4 lists 26 rights for persons receiving services

No Person Shall Be Denied:

- A safe and sanitary environment
- Freedom from physical or psychological abuse
- Freedom from corporal punishment
- Freedom from unnecessary use of mechanical restraining devices
- Freedom from unnecessary or excessive medication
- Confidentiality of information

65

Putting People First

Part 633.4

No Person Shall Be Denied:

- A written plan of services
- Services from staff who are appropriately trained
- Appropriate and humane health care
- Input into the choice of physicians and dentists
- Opportunity to obtain a second opinion
- Access to clinically sound sexuality training
- Access to family planning service and information
- Participate in a religion of the person's choice
- Freedom from discrimination based on HIV status

66

Part 633.4

No Person Shall Be Denied:

- Information prior to admission regarding the supplies and services that a facility will provide, including any additional charges
- A balanced and nutritious diet, served at appropriate times and in as normal a manner as possible, which is not altered or denied for behavior management or disciplinary purposes
- Opportunity to make an informed decision regarding life-sustaining treatment (LST)
- Opportunity to create a health care proxy. This also includes ensuring that the health care agent is appointed voluntarily and that the health care proxy becomes part of the clinical record

67

Part 633.4



Communication Needs of Non-English Speaking Individuals Receiving Services

- Cannot deny access based on language used
- Information must be provided in appropriate language
- Interpreters are provided in a timely manner without charge to the person or his/her family
- Non-English speaking includes persons who are deaf or hard-of-hearing



68

Part 633.5 Applicant Backgrounds



- Criminal background checks (fingerprinting) of anyone who will have regular and substantial unsupervised or unrestricted physical contact with people receiving services
- Child abuse registry check if having contact with children

69

Putting People First

Part 633.6 Supervisory Requirements

- Line and onsite supervisors must be identified to staff
- Supervisory responsibilities must be clear
- Periodic supervisory consultation with employees and volunteers
- Designate the method of evaluation, managerial and supervisory skills of supervisors
- Provide appropriate assistance to supervisors whose evaluation indicates need for improvement

70

Putting People First

Part 633.7 Conduct of Staff and Volunteers

- No alcohol or illegal substances while at work
- Shall not come to work if their ability is impaired
- No personal financial transactions between staff or volunteers and individuals receiving services



71

Putting People First

Part 633.8 Staff Training

Employees and volunteers must receive training in the first three months of employment

- Principles of human growth and development
- Characteristics of persons served
- Abuse prevention
- Incident reporting and processing
- The facility's safety and security procedures
- Other topics specified by the OPWDD and your agency

72

Part 633.9 Allegation of Abuse

- Each situation shall be evaluated immediately
- If an allegation of child abuse it must be reported to the New York State Child Abuse Registry
- If it appears that a crime may have been committed against a person receiving services, irrespective of who the perpetrator is, it shall be reported to law enforcement officials

73

Part 633.10 Care and Treatment

- **Individuals shall receive care and treatment that is suited to his or her needs which is delivered skillfully, safely and humanely**
- **Notification of parent, guardian or correspondent if the person is suspected or diagnosed as having a health problem which requires:**
 - Emergency room services ;
 - Admission to a hospital; or
 - If the person cannot participate in regular activities for seven days

74

Part 633.10

- Written plan to deal with life threatening emergencies
- Must address:
 - First aid
 - CPR
 - Access to emergency medical services
- Inspection and maintenance of emergency medical equipment in conformance with the manufacturers' recommendations is required



75

Part 633.10



Incorporates the requirements of the Health Care Decisions Act (HCDA) related to how physicians and psychologists are approved by the commissioner to serve as the attending physician, or a consulting physician or psychologist for decisions about withholding or withdrawing life-sustaining treatment.

Part 633.11 Medical Treatment

- Consent for professional medical treatment
- Informed consent
- Sterilization
- Consent for HIV Testing
- N/G tube feedings
- Requires day programs to notify residential providers of emergencies or sudden illnesses.

Health Care Choices Booklet:
<http://www.opwdd.ny.gov/node/70>

Part 633.12 Objection to Services Process



- Requires a mechanism for informal dispute resolution
- Ability to submit a formal written objection that results in a hearing
- May appeal decision of hearing officer to the Commissioner
- Emergency treatment may be given despite objection when the treatment is deemed necessary to avoid serious harm to life or limb

Putting People First

Part 633.14 Control of Tuberculosis



- Repealed NYCRR 635.8
- Updated and revised the regulations for the screening for active tuberculosis in OPWDD facilities
- Applies to developmental centers and facilities certified by OPWDD

79

Putting People First

Part 633.14 Screening for Tuberculosis

Allows any TB test approved by the CDC and FDA for screening of tuberculosis

Current Tests

- TST (tuberculin skin test) with purified protein derivative (PPD)
- Quantiferon Gold: blood assay test



80

Putting People First

Part 633.14 Initial Testing for TB

- **Either a two-step PPD OR a Quantiferon Gold**
- **Employee/Contractor/Volunteer/Family Care Provider:**
 - If using PPD, first step of two step must be completed prior to the first day of employment
- **Individual Receiving Services:**
 - Preferably prior to first day of receipt of services
 - If not possible, RN must screen on the first day for signs/symptoms and if none, have up to one week to complete first step

81

Putting People First

Part 633.14 Subsequent Testing

- For most staff/individuals. Only if there is a known exposure to a person with active pulmonary or laryngeal TB
- Annual testing **only** for staff/individuals in developmental centers operated by the State of New York



82

Putting People First

633.14 Exclusions to Testing

- Prior documented significant reaction to TB testing; or
- Adequate treatment for active pulmonary tuberculosis; or
- Completion of adequate preventive therapy
- Statement by MD, NP or PA of a contraindication that includes:
 - A recommendation as to when and if testing would be appropriate at a designated point in the future; and
 - How the party will be evaluated for active pulmonary tuberculosis in the interim.

83

Putting People First

More Information on TB Testing

The link below provides more information, including “frequently asked questions”

http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/infection_control/tuberculosis



84

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Part 633.17 Medication

- All medications must be stored, administered and disposed of safely
- Medication must be prescribed by a physician, RPA, nurse practitioner or dentist
- Semi-annual medication regimen review required for IRAs and Family Care. Quarterly medication regimen review required in ICF
- Annual evaluation of ability to self-administer medications required
- AMAP = Approved Medication Administration Personnel
- RN supervision required

85

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Part 633.17 Electronic Rx's

With the advent of e-scripts it has become a challenge to get paper copies of scripts. There are several ways to obtain required order for the residence:

1. Have a place on your consult sheet for the MD to fill in that says: New/reordered medications
2. Ask the pharmacy to print out the e-script
3. Ask the office nurse to print out the e-script
4. Take a verbal order from the MD and transcribe onto order sheet
5. List the medication, strength, dose, frequency and fax to MD office. Request that MD sign to verify order

Frequently asked questions about physician's orders:
<http://www.opwdd.ny.gov/node/746>

86

OPWDD NYS Office For People With Developmental Disabilities
Putting People First

Part 633.17 Over-the-Counter Medication (OTC)

- Approval must be received at least once a year
- Reason for OTC is stated
- Administration does not exceed two days unless a prescriber has ordered on a regular or routine basis



87

Putting People First

Part 633.17

Who Can Administer Medications?



- An individual assessed to be capable of self-medication administration
- Licensed nurses, physicians, PAs, dentists
- Approved Medication Administration Personnel (AMAPs)
- Family members
- Family care providers and approved respite providers

88

Putting People First

Self-Administration Assessment

- Must be done by an RN Residential
- Individuals must be assessed within 3 months of admission
- Required notification of the following designation:
 - Other providers of service
 - Primary care physician



89

Putting People First

Self-Administration Assessment

Individuals in residential settings who attend OPWDD-certified programs (i.e. Day Hab):

- Accept determination of residence or evaluate
- Must evaluate all persons who do not live in an OPWDD-certified residence



90

Putting People First

Self-Medication Assessment



Assessments must be documented in the person's record

Must be re-assessed:

- At least once a year
- If there is a change in the person's abilities

91

Putting People First

Part 633.99 Glossary

Definition of Independent Self-Administration

Six Required Elements:

1. Recognize the time the med is to be taken
2. Recognize the correct container/bottle/blister pack/med organizer
3. Open the correct container/bottle/blister pack/med organizer-correct compartment
4. Remove the correct dose (in the case of a med organizer, to remove the medication)
5. Close the container
6. Return the meds to the appropriate storage

92

Putting People First

Self-Administration vs. Self-Management



- Self-administration is a rote skill/task
- Self-management includes an ability to know:
 - The name of the medication
 - The purpose of each medication
 - Possible side effects
 - Possible interactions/contraindications
 - What things to report to the nurse/doctor
 - How to maintain a supply of medication

93

Putting People First

Self-Administration vs. Self-Management

- A person can be determined to be self-administering without being self-managing
- A person can be determined to be self-administering even if they rely on technology to assist them

More Information:
http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/medication_administration

94

Putting People First

Part 633.17 Medication Regime Review



- Required on a semi-annual basis IRA & FC and quarterly in ICF
- May be completed by an MD, pharmacist or RN (in an ICF must be a pharmacist)

95

Putting People First

Medication Regime Review

- Must include:
 - All of the medication a person has taken during the review period, including short-term and/or discontinued medication
 - Review of the reason/purpose the medication is being given
 - Review contraindications and interactions, including those created by simultaneous administration of medications
 - Review of laboratory results as they relate to medications being taken
 - An evaluation of the effectiveness of each medication
- Recommendations are to be made to the prescriber as appropriate

96

Putting People First

Medication Storage 633.17 (a) (19)

- Medication shall be maintained in original container(s)
- Safe, secure, appropriate, and adequate storage space shall be provided
 - locked/double locked storage as appropriate
 - cabinet of "substantial construction"
 - medication shall never be left unattended



17

Putting People First

Medication Storage

- Outdated medication shall not be kept by a facility
- Discontinued medication may not be kept by a facility **unless** a prescribing practitioner has specifically instructed that it be retained for possible future use



98

Putting People First

Medication Storage Exceptions



Pill Organizer (Med Bar or Pill Minder) can be used for:

- A person who self administers medication
- A person who is on a training program to learn to self administer medication must be labeled with the person's name

EpiPens can be stored in such a manner as to:

- Not be generally accessible
- Not pose a danger to the individual or staff

99

Putting People First

633.18 DNRs

Still exists in the regulations but has been superseded by Family Health Care Decisions Act (Article 29-B)




100

Putting People First

Part 633.19 HIV Confidentiality and Protective Measures

Facility must have policies and procedures

- Confidentiality
- To prevent transmission
- For management of potential exposure
- No discrimination

Employees and volunteers are trained in:

- Confidentiality
- Procedures to prevent transmission
- Procedures to manage a person who is exposed



Right to Confidentiality

101

Putting People First

Amended HIV Testing Law



- Effective September 1, 2010
- On July 30, 2010, Gov. David Patterson signed Chapter 308 of the Laws of 2010 authorizing significant changes to HIV testing in NYS
- This law was enacted to increase HIV testing and to promote HIV-positive persons entering into treatment

102

 **Putting People First**

Key Provisions

- 1) HIV testing must be offered to all persons between the ages of 13 and 64 receiving emergency, hospital, or primary care
- 2) NYS DOH has provided model forms for obtaining informed consent and providing for disclosure
- 3) Consent for HIV testing can be part of a general durable consent to medical care, though specific opt-out language for HIV testing must be included

103

 **Putting People First**

Key Provisions

- 4) Consent for rapid HIV testing can be oral and noted in the medical record
- 5) Prior to asking for consent for HIV testing, the patient must be provided the 7 points of information about HIV required by the Public Health Law
- 6) Must arrange a medical appointment for medical care for persons confirmed positive with the person's consent

104

 **Putting People First**

Key Provisions

- 7) HIV test requisition forms submitted to labs have been simplified
- 8) Deceased, comatose, or persons otherwise incapable of giving consent, and who are the source of an occupational exposure, may now be tested for HIV in certain circumstances without consent
- 9) Confidential HIV information may be released without a written statement prohibiting re-disclosure when routine disclosures are made to treating providers or to health insurers to obtain payment

105

Putting People First

Informed Consent

- Informed consent for HIV testing is to be obtained for our individuals in the same manner used for any other procedure requiring informed consent
- In a case where an individual cannot consent for themselves or has no consentor per the 633.11 Regulations, the Surrogate Decision Making Committee (SDMC) may be utilized



106

Putting People First

Seven Points of Information

- 1) HIV is the virus that causes AIDS and can be transmitted through:
 - Unprotected sex (vaginal, anal, or oral sex) with someone who has HIV
 - Contact with blood as in sharing needles (piercing, tattooing, drug equipment including needles)
 - By HIV-infected pregnant women to their infants during pregnancy or delivery; or while breast feeding
- 2) There are treatments for HIV/AIDS that can help an individual stay healthy
- 3) Individuals with HIV/AIDS can adopt safe practices to protect uninfected persons from acquiring HIV and infected people from acquiring additional strains of HIV

107

Putting People First

Seven Points of Information

- 4) Testing is voluntary and can be done anonymously at a public testing center
- 5) The law protects the confidentiality of HIV test results and other related information
- 6) The law prohibits discrimination based on an individual's HIV status and services are available to help with such consequences
- 7) Consent for HIV related testing remains in effect until it is withdrawn verbally or in writing. If the consent was given for a specific period of time, it remains in effect for that time period only. In any case, persons may withdraw their consent at any time

108

Putting People First

Additional Information

The NYS DOH FAQ for the amended HIV Testing Law is available on the NYS DOH website:
http://www.health.state.ny.us/diseases/aids/testing/amended_law/faqs.htm



109

Putting People First

MIPS

Medical Immobilization and Protective Stabilization



110

Putting People First

What is MIPS?

- MIPS is Necessary to protect individuals and others from harm during a medical or dental appointment
- The partial or complete control/support of an individual's arms, legs, head, or torso
- MIPS includes the use of manual techniques, mechanical devices and the use of a papoose board
- MIPS may be used with or without sedation

111

Putting People First

Why Was MIPS Developed?

- Individuals with developmental disabilities may need medical immobilization and protective stabilization (and/or sedation) to successfully receive medical or dental care and treatment
- MIPS training identifies appropriate use of manual techniques, mechanical devices and the use of a papoose board



112

Putting People First

Important!

- MIPS is **only** to be used for the duration of the medical/dental appointment! It is not to be used on the way to, while waiting for, or after exam or treatment
- MIPS does not include brief holds for such procedures as blood draws, administration of eye/ear drops, injections, tooth brushing, etc.
- MIPS techniques and sedation used in accordance with the MIPS ADM are **not considered restraints** for the purposes of 14 NYCRR 624 & do not require a 147 incident report

113

Putting People First

General Information

MIPS ADM #2010-2
http://www.opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/documents/adm2010-02

Forms
A copy of both forms should be provided to you by your agency

- 1) Interventions Outcome Form
http://www.opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/documents/adm2010-02mipsoutcome
- 2) Order Plan
http://www.opwdd.ny.gov/opwdd_regulations_guidance/adm_memoranda/documents/adm2010-02mipsorderplan

114

Putting People First

General Information

Training

- Training should be provided to any staff involved in obtaining consent for MIPS and/or sedation AND any staff member accompanying individuals to medical and/or dental appointments
- Online training is being developed, but you should receive your agency-specific training
- Please check our website or your local DDSO/DDRO for assistance



115

Putting People First

Decisions in Health Care: A Matter of Consent



116

Putting People First

Objectives

At the conclusion of this presentation, you will be able to:

- Define informed consent
- List the elements of informed consent
- Identify situations that require informed consent
- List who can provide informed consent for an individual with ID/DD for:
 - Major medical/dental procedures
 - Psychotropic medications
 - End-of-life, including with-holding and with-drawing life sustaining treatment
- Explain MOLST: Medical Orders for Life Sustaining Treatment

117

Putting People First

What Is Informed Consent?

14 NYCRR 633.99(af)(1):
 "Effective knowing consent by a person (or his/her legally empowered surrogate, parent or adult child) with sufficient capacity to consent and so situated as to be able to exercise free power of choice without undue inducement or any element of force, fraud, deceit, duress, or other form of constraint or coercion."

118

Putting People First

The Language of Informed Consent

- Must be in the person's primary language
- Must use common language (6th grade comprehension level)



119

Putting People First

Requirements for Informed Consent

Person giving consent must be told:

- Purpose of the intervention
- Benefits
- Risks (those that are reasonably foreseeable)
- Alternatives to the proposed intervention, if any
- Right to refuse
- Consequences of refusal



120

Putting People First

When is Informed Consent Needed?

Sometimes informed consent is required by law. Examples include:

- HIV testing
- Immunizations pursuant to a non-patient specific order
- Research involving human subjects



121

Putting People First

When is Informed Consent Needed?



NYCRR 633.11 requires informed consent for major medical treatment defined in 633.99 as any medical, dental, surgical or diagnostic intervention or procedure that:

- Requires general anesthesia; or
- Has a significant invasion of bodily integrity requiring an incision or produces substantial pain, discomfort or debilitation; or
- Has a significant recovery period; or
- Medical Immobilization and Protective Stabilization

122

Putting People First

When is Informed Consent Needed?

ICF Regulations 42 CFR 483.440(f)(3)(ii)
 Informed consent for any program designed to decrease inappropriate behavior which include:

- Use of restraints;
- Aversive conditioning;
- Any medication that modifies or controls maladaptive or inappropriate behavior including for pre-sedation for medical and dental appointments;
- Denial of any right;
- "Earning" of a right as a way to shape behavior;
- Behavioral consequences involving issues of client dignity

123

Putting People First

When is Informed Consent Needed?

July 2000 “Kietzman Memo”
 Extended protections of 42 CFR 483.440(f)(3) to all individuals in OPWDD operated or licensed facilities



124

Putting People First

When is Informed Consent Not Needed?

To provide routine medical care

- Annual physicals
- Routine specialist appointments
- X-rays not requiring contrast media/dyes
- Routine blood work
- Routine dental care



125

Putting People First

When is Informed Consent Not Needed?

- In any situation that is considered a medical emergency
- OPWDD uses the definition in Public Health Law § 2504(4) to define an emergency:
 - the person is in immediate need of medical attention
 - AND
 - an attempt to secure consent would result in delay of treatment which would increase the risk to the person's life or health
- In emergency situations the chief executive officer of the individual's residential facility, or his/her designee, may provide authorization to render necessary care

126

Putting People First

Who Can Decide?

The person making the decisions must:

- Have the ability to understand the information provided
- Be competent to make the decision at hand
- Be fully informed
- Give consent voluntarily without undue influence or duress



It depends...

- Different list of possible consenters for medical/dental consent than for consent for programs/drugs that are intended to modify behavior.
- Different list for individuals under 18 years of age

127

Putting People First

Who Can Decide (Medical/Dental) Under 18 Years of Age?

For persons under the age of 18, the hierarchy in order:

- 1) The person (sometimes)
- 2) A guardian with authority to make health care decisions
- 3) An actively involved spouse
- 4) A parent
- 5) An actively involved adult sibling
- 6) An actively involved adult family member
- 7) A local commissioner of Social Services with custody over the person
- 8) A Surrogate Decision Making Committee (SDMC)
- 9) A court of competent jurisdiction

128

Putting People First

Who Can Decide (Medical/Dental) Over 18 Years of Age?

The hierarchy for persons over the age of 18, in order:

- 1) The person (sometimes)
- 2) A Health Care Agent
- 3) A Guardian of the person or alternate agent
- 4) An actively involved spouse
- 5) An actively involved parent
- 6) An actively involved adult child
- 7) An actively involved adult sibling
- 8) An actively involved adult family member
- 9) The Consumer Advocacy Board for Willowbrook class members it fully represents
- 10) A Surrogate Decision Making Committee (SDMC)
- 11) A court of competent jurisdiction

129

Putting People First

Who Can Decide?

Medications That Modify or Control Behavior



For persons *under* the age of 18:

- 1) The person (sometimes)
- 2) A court-appointed guardian with the authority to give such consent
- 3) An actively involved adult spouse
- 4) An actively involved parent
- 5) An actively involved adult family member
- 6) A consent committee created pursuant to 14NYCRR 681.13(a)(10)
- 7) A court of competent jurisdiction

130

Putting People First

Who Can Decide?

Medications that Modify or Control Behavior

For a person *over* the age of 18:

- 1) The person (sometimes)
- 2) A court-appointed guardian with the authority to give such consent
- 3) An actively involved spouse
- 4) An actively involved adult child
- 5) An actively involved parent
- 6) An actively involved family member
- 7) The Consumer Advisory Board for a Willowbrook class member that it actively represents
- 8) A Consent committee created pursuant to 14 NYCRR 681.13(a)(10)
- 9) A court of competent jurisdiction

131

Putting People First

Who Can Decide?

What is “actively involved?”
 “Significant and ongoing involvement in a person’s life so as to have sufficient knowledge of the person’s needs”

What if there is more than one surrogate within a category?

- Agency is to use the standard of “actively involved”
- Consent must be sought from the party with the higher level of active involvement
- If equally involved, consent may be obtained from any of the parties.

132

Putting People First

Who Can Decide?

Order of the List

- Must go down the list in the order listed
- If first available party on the list is not reasonably available and/or willing, and is not expected to become reasonably available and willing in a timely manner, go to the next surrogate on the list.
- If the first available surrogate objects to the proposed treatment, cannot continue on down the list.
- If there is an objection, and in the opinion of the medical provider the treatment is necessary, must petition the court for a court order (or go to SDMC if consenters agree).

133

Putting People First

The Person



The person must be:

- Over the age of 18
- Under the age of 18, either
 - Married
 - The parent of a child
- Evaluated as capable of consenting on his or her own
- Evaluation must be in writing, and documented in the person's clinical record

134

Putting People First

The Person

- The person must be evaluated as capable of consenting on his or her own including:
 - The purpose of the procedure
 - The benefits and risks
 - The likely consequence(s) of refusing
- Evaluation must be in writing and documented in the person's clinical record
- Refer to the SDMC if uncertain

135

Guardian

- A guardian is a person or organization that is designated by the court to act on behalf of a person who cannot manage his/her affairs without assistance
- Guardians have the legal authority to make decisions on behalf of the individual



136

“Standby” Guardian



- A person or persons appointed by a legal guardian and approved by the surrogate court



- Assumes the legal authority to make decisions on behalf of a person when the legal guardian is no longer able to do so

137

“Alternate” Guardian



- A person appointed by the guardian and approved by the surrogate court
- Assumes legal authority to make decisions on behalf of the person if the stand-by guardian dies, or becomes unable or unwilling to make decisions on behalf of the person

138

Putting People First

Who Can Be a Guardian?



- Parents have priority
- Can be:
 - Sibling
 - Another family member
 - Any interested person and/or friend
 - A qualified organization

139

Putting People First

Guardians

Legal guardian who has the authority to make health care decisions:

- Must be a guardian of the person
- Includes 17A guardians unless specifically excluded
- Includes Article 81 guardians only if it is specifically listed as a power of the guardian

Can consent to:

- Medical/dental care
- Use of psychotropic medication
- Use of medication for pre-sedation
- End-of-life decisions if certain criteria are met

140

Putting People First

Health Care Agent

- A person chosen by the individual to make decisions if and when the individual is determined to be incapable of making medical care decisions
- Has the legal authority to make treatment decisions



141

Putting People First

Who Can Appoint a Health Care Agent?

- A person over the age of 18
- Does not need to have the capability of making and/or understanding all medical care decisions
- Person needs to understand that he/she is giving the authority to someone else to make medical care decisions if they are not able to
- **NO ONE CAN APPOINT A HEALTH CARE AGENT FOR ANOTHER PERSON!**

142

Putting People First

Who Can Appoint a Health Care Agent?

Anyone over the age of 18

In an OPWDD operated or certified facility, a health care agent cannot be:

- A member of the governing board
- Any officer
- A chief executive officer
- An employee of the facility
- A physician affiliate with the facility

143

Putting People First

How is a Health Care Agent Appointed?

- A form called a health care proxy must be signed and dated by the person in the presence of two adult witnesses who must sign the form
- Assistance can be given to the person in completing the form.
- Another party can date and sign a health care proxy for the person if the person is unable to do so but asks the party to do so in the presence of two adult witnesses

144

Putting People First

Who Can Witness a Health Care Agent?

If the person resides in an OPWDD certified facility:

- 1) One person not affiliated with the facility
- 2) At least one NYS licensed MD or psychologist who:
 - Is employed by the DDSO; or
 - Has been employed for at least 2 yrs. in an OPWDD facility; or
 - Has specialized training and 2 yrs. experience serving persons with developmental disabilities; or
 - Has at least 3 yrs. experience serving persons with developmental disabilities

145

Putting People First

What Decisions Can the Health Care Agent Make?

Any and all health care decisions on the individual's behalf that the individual would make if he/she were able, EXCEPT refusal of nutrition and hydration unless the person has made his/her wishes known

Examples:

- Artificial respiration
- Withholding or withdrawal of life support
- Admission to hospice
- DNR orders

146

Putting People First

When Does the Health Care Agent's Authority Begin?

- When a determination is made that the individual lacks the capacity to make a health care decision
- Determination of lack of capacity is to be made by the attending physician to a reasonable degree of medical certainty
- If lack of capacity is because of a ID/DD or for the purpose of withdrawing or with-holding life sustaining treatment, the attending physician must consult with an MD or licensed psychologist with ID/DD experience listed above

147

Putting People First

Who Can Object to the Health Care Agent's Decision?

- Only the individual can object to the decision of the health care agent
- Objection of individual prevails unless it is determined by a court of competent jurisprudence that the person lacks the capacity to make health care decisions



148

Putting People First

What is a Surrogate Decision Making Committee (SDMC)?

Committees of trained volunteers that exercise medical decision-making authority on behalf of incompetent mentally disabled persons who lacked authorized family members or guardians



Mental Hygiene Law Article 80: Surrogate Decision-Making for Medical Care and Treatment
<http://public.leginfo.state.ny.us/LAW/SSEAF.cgi?QUERYTYPE=LAWS+&QUERYDATA=@SLMHY0TEA80+&LIST=LAW+&BROWSER=EXPLORER+&TOKEN=19734112+&TAR GET=VIEW>

149

Putting People First

SDMC Role

SDMC will determine:

- Is the person competent to make the decision at hand?
- Is there a legal surrogate who is reasonably available and willing to make the decision?
- Is the proposed major medical treatment is in the best interest of the patient?



150

Putting People First

SDMC Panels

Four-member panels that must include one member from each of the following groups:

- 1) MDs, nurses, psychologists or other health care professionals licensed in New York State
- 2) Former patients or parents, spouses, adult children, siblings or advocates of persons who are mentally disabled
- 3) Attorneys admitted to the practice of law in NYS
- 4) Other persons with recognized expertise or demonstrated interest in the care and treatment of persons with mental disabilities



151

Putting People First

SDMC Jurisdiction



Major Medical Treatment
 "A medical, surgical or diagnostic intervention or procedure where a general anesthetic is used or which involves any significant risk or an significant invasion of bodily integrity requiring an incision or producing substantial pain, discomfort, debilitation or having significant recovery period."

152

Putting People First

SDMC Jurisdiction

Excluded Medical Treatments

- Routine diagnosis or treatment
- Electroconvulsive Therapy
- Dental Care with a local anesthetic
- Emergencies
- Sterilization
- Termination of pregnancy
- Routine medication administration other than chemotherapy
- Medications that control or modify behavior



153

Putting People First

SDMC and Life-Sustaining Treatment (LST)



- New Law signed by the Governor July 7, 2008
- Allows the SDMC to make a decision to withhold or withdraw life-sustaining treatment if a guardian or involved family member is not available.

154

Putting People First

SDMC Forms



- Must complete and submit SDMC forms to CQCAPD Headquarters in Schenectady, NY
- Obtain forms and instructions at: <http://cqc.ny.gov/advocacy/surrogate-decision-making/sdmcdecs>

155

Putting People First

What is the Consumer Advisory Board? (CAB)

A group established by the Federal Court in the 1975 Consent Judgment to act *in loco parentis* for Willowbrook Class members having no family, guardian or involved friends



156


 NYS Office For People With Developmental Disabilities
Putting People First

Consumer Advisory Board

- When CAB is the identified surrogate for a class member, the CAB Informed Consent Submission Checklist (Revised 4/15/09) must be completed
- For dental procedures: Dental Consent Overview (Revised 4/15/09)
- For medical procedures: Medical Consent Overview (Revised 4/15/09)
- The compiled information is submitted to CAB Central Office in Staten Island, NY

Willowbrook Informed Consent Resources:
http://www.opwdd.ny.gov/opwdd_resources/willowbrook_class/informed_consent

157


 NYS Office For People With Developmental Disabilities
Putting People First

What is a Consent Committee?



- **Only** used for consent for plans designed to manage challenging behavior which may include the use of medication and/or physical interventions
- **Only** used if a guardian or other party authorized to give consent is unavailable

158


 NYS Office For People With Developmental Disabilities
Putting People First

Consent Committee

- Need not be a "standing" committee
- May be convened on an as-needed basis with appropriate representation
- Must consist of :
 - At least three members not involved in the care of the person
 - Majority not affiliated in any way with the agency
 - At least one Qualified Intellectual Disability Professional (QIDP)

159

Putting People First

Health Care Decisions Act



Effective March 16, 2003

160

Putting People First

The Health Care Decisions Act



- The Health Care Decisions Act for Persons with Mental Retardation (HCDA) amended the New York Surrogate's Court Decisions Act (SCDA)
- This legislation eliminates discrimination against individuals with intellectual disabilities in regard to health care by providing them with the option to have life-sustaining treatment withdrawn or withheld at their guardian's request
- Provides for the certification of an individual's capacity to make his/her own health care decisions prior to the appointment of a guardian
- In the absence of such capacity, the act authorizes guardians to make health care decisions, including authorization to withhold or withdraw life-sustaining treatment, on behalf of the individual

161

Putting People First

The Health Care Decisions Act

- Prior to HCDA, individuals with intellectual disabilities were unable to have life-sustaining treatment withdrawn because it could not be determined under what circumstances they would personally make such a decision had they the capacity to make their medical preferences known
- HCDA fills the gap in State law that required individuals with intellectual disabilities to be kept alive regardless of their level of suffering, which in many instances can be caused or aggravated by the life sustaining devices themselves
- The act clarifies and ensures a guardian's right to make health care decisions which are in the best interests of an individual with an intellectual disability and which support that individual's uniqueness and dignity

162

Putting People First

Surrogate's Court Procedure Act: Amendments Following the HCDA

- Amended to include all persons with developmental disabilities
- Chapter 105 of the Laws of 2007 enabled certain qualified, non-guardian, family members with a significant and ongoing involvement in such a person's life to act as surrogates for the purposes of withholding or withdrawing life supporting treatment

163

Putting People First

Six Required Steps

Health Care Choices Booklet
Describes 6 steps to follow in accordance with the HCDA for medical decisions which involve the withholding/withdrawing of life sustaining treatment for individuals with DD who lack capacity and do not have a health care proxy

Link to booklet: <http://www.opwdd.ny.gov/health-care-choices-brochure>

164

Putting People First

Step 1

Identification of Appropriate 1750-b Surrogate from Prioritized List

- 1) Article 17-A guardian
- 2) An actively involved spouse;
- 3) An actively involved parent;
- 4) An actively involved adult child;
- 5) An actively involved adult sibling;
- 6) An actively involved adult family member;
- 7) The Consumer Advisory Board for the Willowbrook Class (only for class members it fully represents);
- 8) A surrogate decision making committee (SDMC) or a court

165

Putting People First

Step 1

- Must go down the list in the order listed
- If more than one qualified family member exists within a category on the list:
 - Higher level of active involvement first
 - If equally actively involved, any one can make the decision
- If the first reasonably available and willing qualified family member makes a decision to withhold or withdraw life-sustaining treatment (LST), other family members cannot overturn the decision. However, they can object to such decision pursuant to Surrogate's Court Procedure Act (SCPA) section 1750-b(5)(ii)

166

Putting People First

Step 2

1750-b Surrogate Makes the Decision to Withhold or Withdraw LST

- If orally: to the attending physician in the presence of one other person over the age of 18
- In writing: must be dated, signed and witnessed by a person over the age of 18 and sent/given to the attending physician

167

Putting People First

Step 3



Confirm Individual's Lack of Capacity to Make Health Care Decisions

- Attending physician must determine the person lacks capacity to make the decision
- Must consult with another physician or a psychologist to confirm person's lack of capacity

168

Putting People First

Step 3

Physician and/or Psychologist's Qualifications

One of the two must be familiar with or have professional knowledge in the care and treatment of persons with ID/DD defined as:

- Employed by the DDSO;
- Employed for a minimum of 2 years in an OPWDD certified facility; or
- Have specialized training or three years experience in treating ID/DD and be approved by the Commissioner of OPWDD

169

Putting People First

Step 4

Determination of Necessary Medical Criteria

Both of the following conditions 1 and 2 must be met

1. The person must have one of the following medical conditions:

- A terminal condition; or
- Permanent unconsciousness; or
- A medical condition other than ID/DD which requires life-sustaining treatment is irreversible and will continue indefinitely

AND

2. 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 life-sustaining treatment (LST), not withstanding the person's DD

170

Putting People First

Step 4

If the 1750-b surrogate requests that artificially provided nutrition or hydration be withdrawn or withheld, one of the following criteria must also be met:

- There is no reasonable hope of maintaining life; or
- The artificially provided nutrition or hydration poses an extraordinary burden on the person

171

Putting People First

Step 5

Notifications



At least 48 hours prior to the implementation of a decision to withdraw LST, or at the earliest possible time prior to a decision to withhold LST, the attending physician must notify the following parties:

- 1) The person with ID/DD, unless therapeutic exception applies
- 2) If the person is in or was transferred from an OPWDD residential facility: Facility Director and MHLS (Mental Hygiene Legal Services)
- 3) If the person is not in and was not transferred from an OPWDD residential facility: the director of the local DDSOO/DDRO

172

Putting People First

Step 6

Who Can Object?

- 1) The person
- 2) A parent or adult sibling who either resides with or has maintained substantial and continuous contact
- 3) The attending physician
- 4) Any other health care provider providing services to the person
- 5) The executive director of the agency operating the person's residence
- 6) MHLS if the person lives in a certified residence
- 7) The Commissioner of OPWDD or his/her designee if the person lives in a non-OPWDD certified setting



173

Putting People First

Step 6

Objections

- Must be made within 48 hours of notification
- May be either orally or in writing
- Results in suspension of the guardian's decision until a court can review and decide



174


 NYS Office For People With Developmental Disabilities
Putting People First

MOLST

Medical Orders for Life-Sustaining Treatment



175


 NYS Office For People With Developmental Disabilities
Putting People First

What is MOLST?

- A way of documenting a person's treatment preferences concerning life-sustaining treatment
- The New York Department of Health MOLST form is the **only** authorized form for documenting both non-hospital DNR and DNI orders in New York State
- The form provides specific medical orders and is recognized and used in a variety of health care settings.

176


 NYS Office For People With Developmental Disabilities
Putting People First

MOLST Forms

MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities

- <http://www.opwdd.ny.gov/node/753>
- The OPWDD approved checklist "MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities" **must** be attached in order for the MOLST to be used for persons with ID/DD who are incapable of making their own health care choices and do not have a health care proxy

Department of Health MOLST Form

- <http://www.health.ny.gov/forms/doh-5003.pdf>
- Approved by OPWDD for use as a non-hospital DNR/DNI form for persons with developmental disabilities

177

Putting People First

MOLST: Who Can Decide?

- The person if they are competent to make the decision
- Health Care Proxy (does not have to go through the 1750-B process)
- Legally designated surrogates (must go through the 1750-B process and use the OPWDD checklist)

178

Putting People First

Surrogate List for MOLST

Same as for other medical consent

- 1) 17-A guardian
- 2) actively involved spouse
- 3) actively involved parent
- 4) actively involved adult child
- 5) actively involved adult sibling
- 6) actively involved family member
- 7) Willowbrook CAB (full representation)
- 8) Surrogate Decision Making Committee

179

Putting People First

MOLST Requirements

Completed based on the person's current:

- Medical conditions
- Values
- Wishes

A licensed MD must:

- Confer with person and/or Health Care Agent and/or surrogate regarding: (1) diagnosis and prognosis, (2) goals for care, (3) treatment preferences
- Sign the MOLST orders

180

OPWDD Putting People First
 NYS Office For People With Developmental Disabilities

The Department of Health MOLST Form

- Page 1 addresses CPR/DNR
- Page 2 contains other treatment options:
 - Treatment measures (comfort only, limited medical, full medical)
 - Intubation and mechanical ventilation
 - Future hospitalizations/transfers
 - Artificial hydration/nutrition
 - Antibiotics
 - “Fill in” for other treatments (such as dialysis, transfusions, etc.)

181

OPWDD Putting People First
 NYS Office For People With Developmental Disabilities

The Department of Health MOLST Form



- Decisions about each section do not have to be made
- Can decide on some issues and not others
- Need to cross out sections of form where a decision is not made
- Can make the decision later but will need to complete a new form

182

OPWDD Putting People First
 NYS Office For People With Developmental Disabilities

OPWDD MOLST

Legal Requirements Checklist for Individuals with DD

- Identify the appropriate surrogate
- Confirmation of person’s lack of capacity to make health care decisions
- The person has either:
 - A terminal condition, **or**
 - Is permanently unconscious, **or**
 - Has a medical condition which requires LST, is irreversible and will continue indefinitely
- Attestation that the LST will pose an extraordinary burden on the individual in light of his/her:
 - Medical condition, **and**
 - Expected outcome of the LST

183

OPWDD Putting People First

OPWDD MOLST

Legal Requirements Checklist for Individuals with DD

In addition, one of these factors must be met if withholding artificial nutrition/hydration:

- No reasonable hope of maintaining life

OR

- The artificially provided nutrition or hydration poses an extraordinary burden

184

OPWDD Putting People First

MOLST Notifications

Timing

- At least 48 hours before withdrawing LST
- Earliest possible time if withholding LST

Attending MD must notify

- Person
- If the person resides in an OPWDD certified setting:
 - Facility director or designee
 - MHLS
- If the person resides in a non-certified setting:
 - CEO or designee

185

OPWDD Putting People First

Other Facts About the MOLST

MOLST remains valid when the person goes from one setting to another (e.g., residence to hospital)

MOLST is reviewed:

- At least every 90 days by an MD if it contains a non-hospital DNR
- When person transitions between health care settings
- When there is a major change in health status
- When the person or other health care decision-maker changes his/her mind about a treatment

186

 NYS Office For People With Developmental Disabilities
Putting People First

Advantages of MOLST

- Is valid from one setting to another
- Decisions can be made before the person is placed on life-sustaining treatment



187

 NYS Office For People With Developmental Disabilities
Putting People First

What Should a Nurse Do?



- Know the ability of the individuals you care for to give consent
- Educate individuals and families about health care agents and/or legal guardianship
- Actively pursue the appointment of a health care agent or guardian of the person **before** you need it!

188

 NYS Office For People With Developmental Disabilities
Putting People First

Questions & Answers



189


