

Surrogate Decision Making Committee Program

**Justice Center Welcome and
Introduction**

Panel Member Refresher Training

July 2013



Agenda

Welcome to the Justice Center

Overview of the Creation, Vision and Objectives

SDMC Program – Legislative and Regulatory Changes

Panel Member Overview – Your Role and Responsibilities

SDMC Hearings

Questions & Answers

Welcome

Today, we will provide you with an introduction to the Justice Center and its vision and objectives.

“The creation of the Justice Center for the Protection of People with Special Needs will give New York State the strongest standards and practices in the country for protecting those who are often the most vulnerable to abuse and mistreatment.”

- Governor Andrew M. Cuomo



Justice Center Creation, Vision, and Objectives

Legislation Creating Justice Center

Through the “Protection of People with Special Needs Act”, Governor Cuomo established the Justice Center to address the historical challenges around the care of people with special needs.

Key Elements of the Legislation:

- Creates the Justice Center
- Creates Standard Definitions of Abuse and Neglect
- Provides for Proportional and Progressive Discipline including Termination, for Custodians Responsible for Abuse or Neglect
- Strengthens Penal Laws
- Consolidates Background Check Functions
- Promotes Transparency



Justice Center Vision

*People with special needs shall be **protected** from abuse, neglect, and mistreatment. This will be accomplished by assuring that the **state maintains the nation's highest standards** of health, safety, and dignity; and by supporting the dedicated men and women who provide services.*

Objectives of the Justice Center

As specified in the Protection of People with Special Needs Act, the Justice Center has the following statutory responsibilities:



Advocate on behalf of people with special needs and provide oversight of quality of care



Operate a centralized, statewide **24-hour hotline** and incident reporting system staffed by trained personnel



Maintain a **state-wide register** that contains the names of individuals found responsible for serious or repeated acts of abuse or neglect



Centralize and perform functions relating to criminal history **background checks**



Develop and implement **consistent standards** for investigative activities including staff qualifications and training, and training for mandated reporters



Analyze **abuse patterns and trends** in order to prevent future occurrences

People Served and Incidents Covered by the Justice Center

Characteristics of People Served

Over 1 million New Yorkers are in state operated, certified, or licensed facilities and programs, including:

- Individuals with:
 - Physical disabilities
 - Mental illness
 - Developmental disabilities
 - Substance use disorders
- Children in residential facilities
- Older adults



Types of Incidents Covered by the Justice Center

Non-Reportable, not an incident

General Referrals & Inquiries: These are not incidents but general referrals or inquiries that are the responsibility of the SOA. The Justice Center will transfer the call to the appropriate SOA (no changes entailed for SOAs).

Non-Reportable, Non-Justice Center Incident

Non-Justice Center Incident: An incident that does not fall within the jurisdiction of the Justice Center, but may require follow-up on the part of a SOA depending upon the relevant SOA's policies.

Significant Incident

A reportable incident that may result in harm to health, safety, or welfare of a person receiving services, but does not qualify as abuse / neglect*. In most cases, Justice Center delegates significant incidents to SOAs.

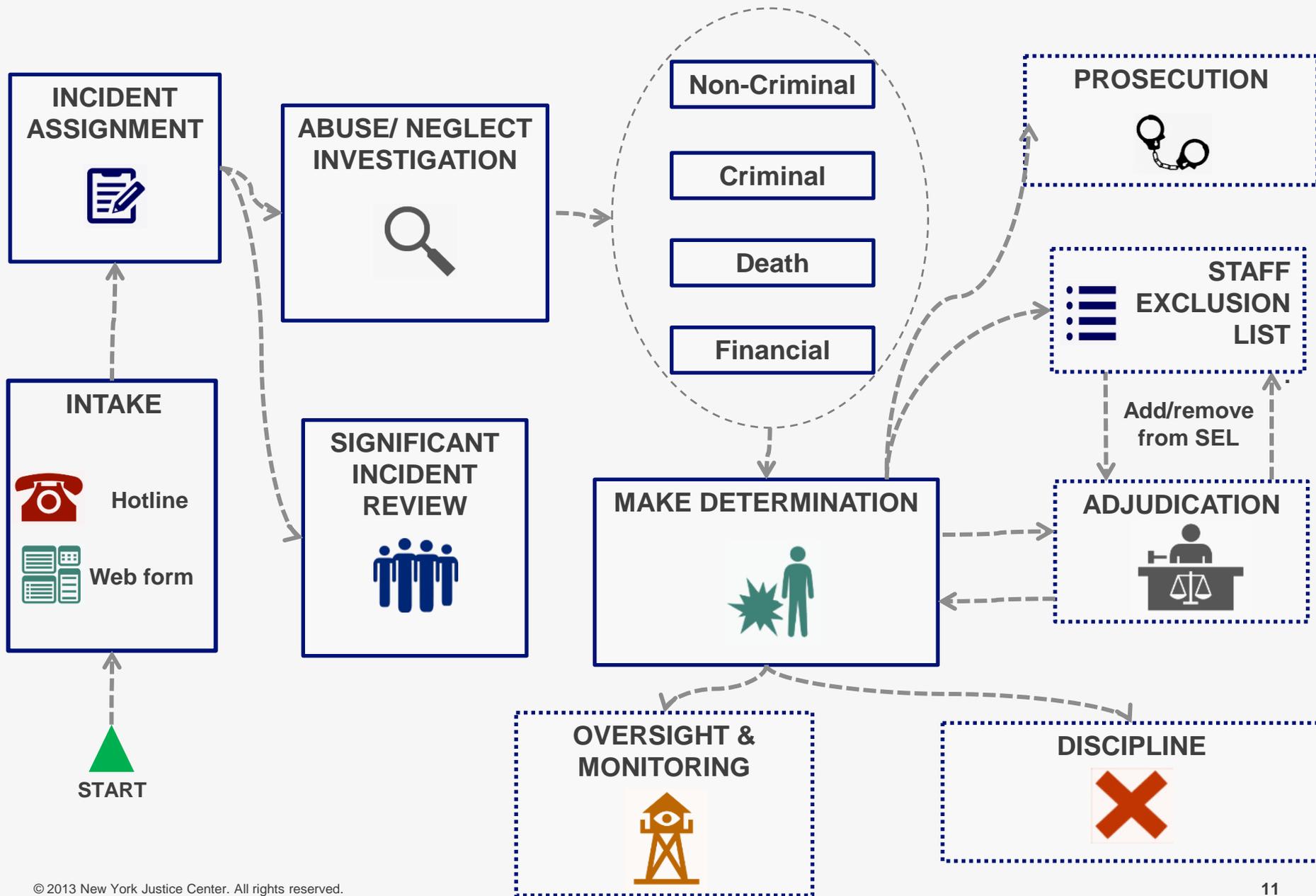
Abuse/Neglect Incident

An incident where a person receiving services was harmed physically, sexually, or psychologically by a custodian. Neglect includes action, inaction, or lack of attention on the part of the custodian that results or is likely to result in physical injury or serious impairment to the physical, mental, or emotional condition of the person receiving services.

*For complete definitions, please reference section 488 of the Social Services Law, as added by the Justice Center legislation

Justice Center Process – Start to Finish

Justice Center Process – Start to Finish



Q & A



SDMC Volunteer Refresher Training

SDMC Program – Legislative and
Regulatory Changes

Panel Member Overview – Your Role and
Responsibilities

SDMC Hearings

Questions & Answers

Statutory and Regulatory Changes

Justice Center Legislation

The SDMC Program

- Created by Article 80 of the MHL
- Justice Center Legislation includes functions, powers and duties of the SDMC
- Program Operations remain essentially the same

Other Legislative Changes

Recap of Legislation over the last several years

Continuing Jurisdiction

Conform to recognize other relatives per OPWDD Regulations

Case Management/Service Coordination

Health Care Decisions Act

Family Health Care Decisions Act

Regulatory Changes

SDMC Operations – Title 14 NYCRR

- Procedures and Standards for implementation of HCDA
- Elimination of conflict of interest for BOV Members
- Amendment of major medical treatment definition to clarify professional diagnosis/treatment including withdrawal/withholding life sustaining treatment
- Authorization of Podiatrist to submit a request on 280-A
- Incorporation of administrative provisions regarding amendments and resubmissions of declarations

The Three Determinations

Capacity to make the Decision

A Surrogate to Act on Their Behalf

Is the Treatment in their Best Interest

Capacity

Lack of ability to consent to or refuse major medical treatment means the patient cannot adequately *understand* and *appreciate* the nature and consequences of a *proposed major medical treatment*, including the *benefits and risks of and alternatives* to such treatment, and cannot thereby reach an informed decision to consent to or to refuse such treatment in a *knowing and voluntary* manner that promotes the patient's *well-being*"

Capacity

Essential Decision

Must be determined at each hearing

Review using relevant questions

See Memo 6 of Handbook for guidance

Surrogacy

The patient does not have a parent, spouse, adult child, committee of the person, conservator, or legal guardian of the person or other surrogate who is legally **authorized, willing and available** to the make the major medical treatment decision.

Surrogacy

Expanded list of authorized surrogates

Reasonably available/actively involved

Efforts to contact

Time factors to consider

Best Interest

promoting personal well-being by the assessment of the **risks, benefits and alternatives** to the patient of a proposed major medical treatment, taking into account factors including the **relief of suffering**, the preservation or restoration of functioning, improvement in the quality of the patient's life with and without the proposed major medical treatment and consistency with the personal beliefs and values known to be held by the patient

Best Interest

Objective review

Risks vs. Benefits

Patient's Unique Needs

Standard of Care

HIV Cases

2010 Amendment to Public Health Law:

- All persons 13 – 65 must be offered testing in Hospital and/or primary care setting
- Intended to integrate HIV Testing into routine health care
- Still requires informed consent and confidentiality

SDMC has jurisdiction to hear cases for HIV Testing

- Jurisdiction was clarified by both law and regulation
- SDMC has made adjustments to MD certification to facilitate case paperwork

HIV Cases

- OPWDD guidelines intend to facilitate testing of all individuals served:
 - High risk individuals are a priority for testing
 - Self-Consenting individuals should be educated and encouraged to consent
 - Non-Consenting individuals - consent should be sought in accordance with 633.11 regulations from guardians and surrogates on their behalf
- SDMC Applications
 - Staff should work with Primary Care Physicians – evaluate and prioritize for testing
 - Submit applications together to be combined into one hearing
 - Applications for other health care should include HIV Test

End of Life Cases

Health Care Decisions Act (HCDA)

SCPA Article 17-A, §1750-b

Clarifies the decision-making authority of Article 17-A Guardians to make health care decisions for persons with mental retardation, including decisions regarding life sustaining treatment

End of Life Cases

Health Care Decisions Act

1. to clarify that decisions regarding life-sustaining treatment are part of the natural continuum of all health care decisions
2. to allow decisions to end life-sustaining treatment only where the need is clearest (i.e. where patients are profoundly ill and never had the ability to make such decisions for themselves)
3. to utilize existing legal standards wherever possible, and
4. to maintain judicial oversight of close decisions, with a statutory structure incorporating a workable standard for the court.

Regulatory Guidelines – Part 710.04

Can the **patient** adequately understand and appreciate:

- The **burdens of treatment** to the person in terms of pain and suffering outweighing the benefits, or whether the proposed treatment would merely prolong the person's suffering and not provide any net benefit.
- The degree, expected **duration and constancy of pain** with and without treatment, and the possibility that the pain could be mitigated by less intrusive forms of medical treatment including the administration of medications.
- The likely **prognosis**, expectant level of functioning, degree of humiliation and dependency with or without the proposed medical treatment.
- Evaluation of **treatment options**, including non-treatment and their benefits and risks compared to those of the proposed major medical treatment.

Regulatory Guidelines – Part 710.02

The guardian shall base all advocacy and health care decision-making solely and exclusively on the **best interests** of the person with MR

Best interests (NYCRR Part 710.2) shall include consideration of:

- i. the dignity and uniqueness of every person;
- ii. the relief of the suffering of the person with mental retardation / DD by means of palliative care and pain management;
- iii. the unique nature of artificially provided nutrition or hydration, and the effect it may have on the person; and,
- iv. the entire medical condition of the person.

HCDA Provisions/Protections

Attending Physician and Consulting Physician/Licensed Psychologist must –

- confirm to a reasonable degree of medical certainty that the person lacks capacity to make health care decisions.
- record the cause and nature of the person's incapacity and its extent and probable duration.

HCDA Provisions/Protections

The attending physician who makes the confirmation, or the consulting physician or licensed psychologist must:

- (i) be employed by a DDSO, or
- (ii) have been employed for a minimum of two years in a facility or program operated, licensed or authorized by OMRDD, or
- (iii) have been approved by the OMRDD Commissioner (3 years of specialized training or experience).

HCDA Provisions/Protections

The attending physician with the concurrence of another physician must determine to a reasonable degree of medical certainty and record that the person with MR/DD has a medical condition:

- **terminal condition** (means an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year), or
- **permanent unconsciousness**; or,
- a **medical condition** other than such person's mental retardation which requires life-sustaining treatment, is irreversible and which will continue indefinitely.

HCDA Provisions/Protections

AND the life-sustaining treatment would impose an **EXTRAORDINARY BURDEN** on the person, in light of:

- A.** the person's medical condition, other than the person's mental retardation;
- B.** the expected outcome of the life-sustaining treatment, notwithstanding such person's mental retardation.

HCDA Provisions/Protections

If the decision is to withdraw or withhold artificially provided nutrition or hydration doctors must also determine:

- A. there is **no reasonable hope of maintaining life**; or
- B. the artificially provided nutrition or hydration **poses an extraordinary burden.**

SDMC Case Packet and Hearing Forms

Case Packet Forms

Series 200 Forms

- SDMC Form 200
- SDMC Form 220-A
- SDMC Form 280-B

Series 300 Forms

- SDMC Form 300
- SDMC Forms 320-A and 320-B

Hearing Forms

SDMC 272

SDMC 272-H

SDMC 380-A

SDMC Hearings

Creating a Record of the Hearing

- Sign-in Sheet – all present must sign-in
- All Proceedings are recorded – exception is deliberations
- All 3 Questions must be addressed
- Testimony
- Maintaining Order

SDMC Hearings

Creating a Record

The 3 Questions: Capacity

- Please ensure questions are addressed directly to the patient first
- Ensure questions to the patient are relevant to the procedure that is being proposed
- Ensure that someone familiar/known to the patient has discussed the procedure with them

SDMC Hearings

Creating a Record

The 3 Questions: **Surrogacy**

- Expanded OPWDD Regulations allow for “other family members” – no need for court appointment
- Actively Involved
- Reasonably Available
- Willing to Act
- Pending Guardianship application

SDMC Hearings

Creating a Record

The 3 Questions: **Best Interest**

- Individual Care Planning/Standard of Care
- Preventive Health Screening Guidelines
- Unique Characteristics
- Risks vs. Benefits
- Alternatives
- Restoration of functioning
- Quality of Life
- Relief of Suffering
- Patient Preferences

SDMC Hearings

Reviewing the Evidence

Testimony

- Clarification vs. Redundancy
- The Hearsay Rule
- Sources of Testimony

Documentation

- Case Packet
- Information brought to hearing

SDMC Hearings

Difficult Cases

- Care Planning
 - Article 80 provides for a plan of care to be proposed
 - No limitations or conditions placed on consent
 - Consent is conditioned on the sound practice of medicine
 - Amended regulations allow for Panel to consider each procedure request separately
 - Panel is not authorized to order other testing/procedures
 - Aftercare – cannot be ordered but can impact Best Interest decision
 - Anesthesia – not proximate to care/plan will be dictated by pre-operative screening

SDMC Hearings

Difficult Cases

- Available Remedies
 - Contact MD/Health Care Provider
 - Amending the Time Frame
 - Contact SDMC Program/Legal Staff
 - Re-Open Hearing for Additional Testimony
 - Amending the Request
 - Re-Submit Application – 710.04(c)(9) and (10)
 - Applying the Correct Legal Standard to the Issue

SDMC Hearings

Voting

- Avoid Bias – Objective Review
- Promote Discussions
- Balance Risks vs. Benefits
- Assess Risks of Non-Treatment or Treatment Delay
- Review Best Interest Definition
- Conference Call vs. Denying Consent
- New Information/Second Opinion

SDMC Hearings

Objections

- Patients/Surrogates – proceedings should cease
- MHLS –
 - Note for the Record and Move On
 - Not required to rule on objections at the hearing
 - Should give full consideration during deliberations
 - Contact SDMC Program Staff
- Notice Objections – hearing should stop pending resolution/proof of notice/waiver of notice
- SDMC Panel is the Sole Decision-Maker

SDMC Hearings

Ex-Parte Communication

- **The Case Packet**
 - Don't – Research and/or Discuss
 - Do – Review and Formulate Questions
- **MHLS**
 - Quasi-Judicial
 - Impartial/Fair Hearing
 - Appearance of Impropriety
 - Due Process
 - Attorney for the Patient
 - SDMC Provides Legal Assistance and Support to Panel

SDMC Staff Contact Information

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Q & A

