



Justice Center for the
Protection of People
with Special Needs

Surrogate Decision-Making Committee (SDMC) Overview

Agenda

- Program History and Overview
- Eligibility and Treatment Covered
- SDMC Process
- SDMC Forms
- Outreach Initiatives

Program History and Overview

History of SDMC

1984	Public hearings established community's need
1985	NYS Legislature creates SDMC pilot program
2001	Expanded statewide
2009	Authorized to make end-of-life care decisions

Prior to SDMC

Untimely court decisions caused delays in health care

People who likely lacked capacity were allowed to sign their own informed consent

Overuse of the “emergency exception” in Public Health Law

No ability to make end-of-life decisions



SDMC Overview

- Alternative to the court system for non-emergency major medical and end-of-life care decisions
- Provides informed consent for service recipients who:
 - Lack the capacity to make their own medical decisions, and
 - Have no legally authorized decision-maker or family member to make the decision
- Utilizes trained volunteers to make decisions
- Authorized by
 - Statute: MHL Article 80 and SCPA Article 17 § 1750-b
 - Regulations: 14 NYCRR § 710.1-710.8

Benefits of SDMC

Free

Timely

Inclusive

Respects
Legal
Rights

Protects
Autonomy



Eligibility and Treatment Covered

Eligibility for SDMC Decisions

Major Medical Care	End of Life Care
<p>Any current or former service recipient at a program licensed, funded or operated by:</p> <ul style="list-style-type: none">• Office for People with Developmental Disabilities (OPWDD)• Office of Mental Health (OMH)• Office of Addiction Services & Supports (OASAS)	<p>A diagnosis of Intellectual/Developmental Disability and</p> <ul style="list-style-type: none">• An illness or injury from which there is no recovery and which reasonably will cause death within 1 year;• permanent unconsciousness; or• ongoing medical condition with a requirement of life-sustaining care that will cause an extraordinary burden.

Eligibility Criteria

The person must:

- Lack the capacity to make their own medical decision, and
- Have no legally-authorized, available and willing surrogate

Major Medical Requests (MHL Article 80)

Medical, surgical, dental, or diagnostic interventions/procedures

- Use of general anesthesia
- Significant invasion of bodily integrity
- Significant risk
- Chemotherapy
- Hospice
- Any other treatment/procedure for which informed consent is required by law

Major Medical Requests Excludes

- Routine treatment or diagnostic tests
- Emergency treatment
- Dental care performed under a local anesthetic
- Electroconvulsive Therapy (ECT)
- Sterilization or termination of pregnancy
- Withdrawal or discontinuation of life sustaining treatment except as provided in the Health Care Decisions Act

SDMC End of Life Care Requests (SCPL Article 17-A § 1750-b)

Withdrawal or withholding of life sustaining treatment for persons with an intellectual or developmental disability

Examples :

- Do Not Resuscitate (DNR) Order (Withhold CPR)
- Do Not Intubate (DNI) Order (Withhold Intubation/Ventilation)
- Comfort care with Hospice services

SDMC Process

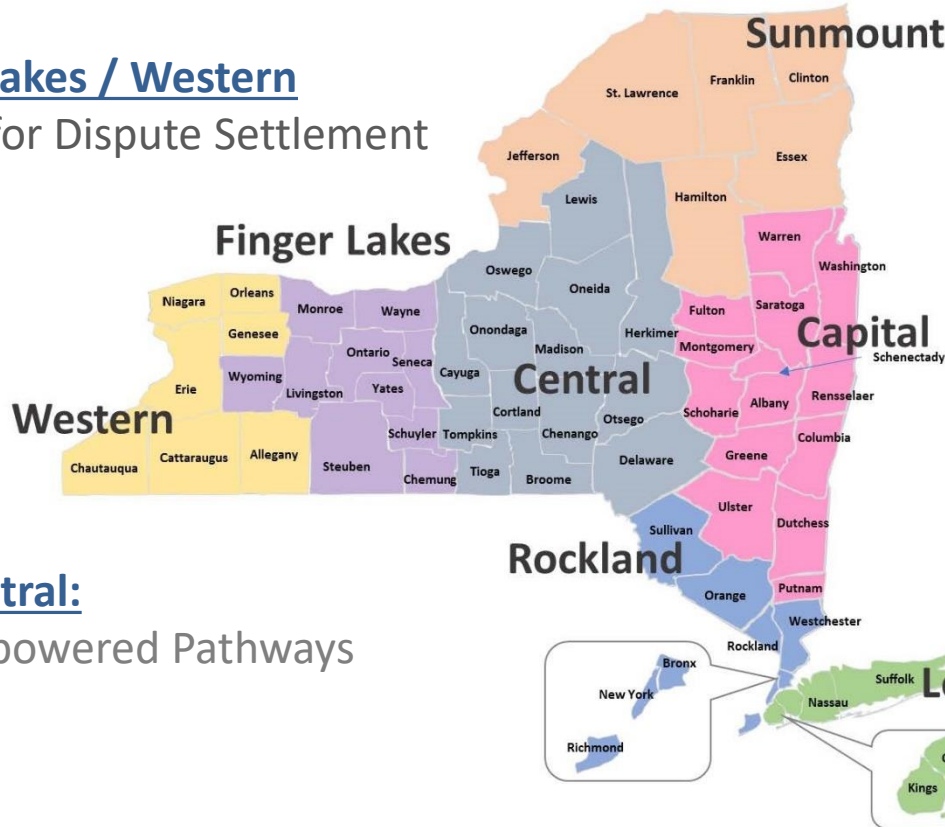


SDMC Regions and Regional Contractors

Finger Lakes / Western

Center for Dispute Settlement

*SDMC Administers
Sunmount Hearings and
Conference Call Proceedings*



Finger Lakes

Capital

Capital

Capital District Center for Independence

Central:

Empowered Pathways

Rockland / Long Island

EAC

Long Island

Requesting a Decision

To request an SDMC decision,

- Physician recommends medical treatment / end of life care
- A psychological evaluation on capacity is completed
- A point-person completes SDMC forms:
 - Referred to as the Declaration
 - Assembled and submitted by Providers

SDMC Process



SDMC Volunteers

- Advocate for the care and treatment of people with disabilities
- 4 volunteers serve on a hearing panel where they act as the decision-maker
- SDMC relies on volunteers from the following categories:
 - ❖ NYS Licensed Medical Professional
 - ❖ NYS Licensed Attorney
 - ❖ Person who Previously Received Services or Family Member of Person with Mental Health or Intellectual Disability
 - ❖ Advocate for Persons with Disabilities

The Hearing

Hearing is held in a convenient location for the person and staff (WebEx)

The person in need of care always attends the Major Medical hearing; possibly attends EOL hearing or is visited by Panel member(s)

Testimony provided by residential staff/care providers

MHLS provides legal representation for the person

Three Hearing Considerations

1. Capacity

- Does this Individual have the capacity to understand the risks, benefits, and alternatives to this medical procedure?

2. Legally Authorized Surrogate

- Is there a legally authorized, willing, and available surrogate who can make this decision?

3. Best Interest

- Is this procedure in the best interests of this Individual?

Surrogate Decision-Maker

Person who is legally-authorized to make the decision and is available and willing to do so

For Major Medical Decisions, consult the list of authorized surrogates in MHL Article 80:

- ✓ Parent
- ✓ Spouse
- ✓ Adult child
- ✓ Court of Competent Jurisdiction

Surrogates by Type of Decision

Major Medical Care	End of Life Care
<p>MHL Article 80 surrogate list:</p> <ul style="list-style-type: none"> • Parent • Spouse • Adult Child • Court of Competent Jurisdiction <p>For People served by OPWDD (if none of the above):</p> <ul style="list-style-type: none"> • OPWDD Hierarchy of surrogates 	<p>OPWDD Hierarchy:</p> <ol style="list-style-type: none"> 1. Guardian/ Health Care Proxy 2. Actively Involved Spouse 3. Actively Involved Parent 4. Actively Involved Adult Child 5. Actively Involved Adult Sibling 6. Actively Involved Adult Family Member 7. Willowbrook Class Consumer Advisory Board 8. SDMC

MHL § 80.07(a)(2)(i)
OPWDD Regulations (14 NYCRR 633.11)

SCPL §1750-b (1)(ii)
OPWDD Regulations (14 NYCRR 633.11)



Best Interest

Promoting personal well-being by the assessment of the risks, benefits and alternatives of a proposed major medical treatment by taking into account:

- Relief of suffering
- Preservation or restoration of functioning
- Person's quality of life with and without treatment
- Personal beliefs and values held by the person

Post-Hearing

- Decision issued at hearing
- If the panel finds that the person has capacity, or identifies a surrogate, the hearing ends at that issue
- Once served by SDMC, the person may continue to utilize SDMC regardless of changes in residence

SDMC Forms:

- Major Medical
- End of Life Care



Declaration for Major Medical Care

Declaration for Surrogate Decision-Making (SDMC Form 200)

Completed by the Declarant

Certification on Capacity (SDMC Form 210)

Completed by the NYS-Licensed Psychologist or Psychiatrist

Certification of Medical Need (SDMC Form 220-A)

Completed by the Physician

Related Medical Information (SDMC Form 220-b)



Declaration for End of Life Care

Declaration for End of Life Care (SDMC Form 300)

Completed by the Declarant

Certification on Capacity for EOL Care (SDMC Form 310)

Completed by the Attending and a Licensed Psychologist or Consulting Physician

Attending and Concurring Certification - EOL Care (SDMC Form 320-AB)

Completed by the Attending and Concurring Physician

Related Medical Information for EOL Care (SDMC Form 330)



Outreach Initiatives

Outreach to Providers

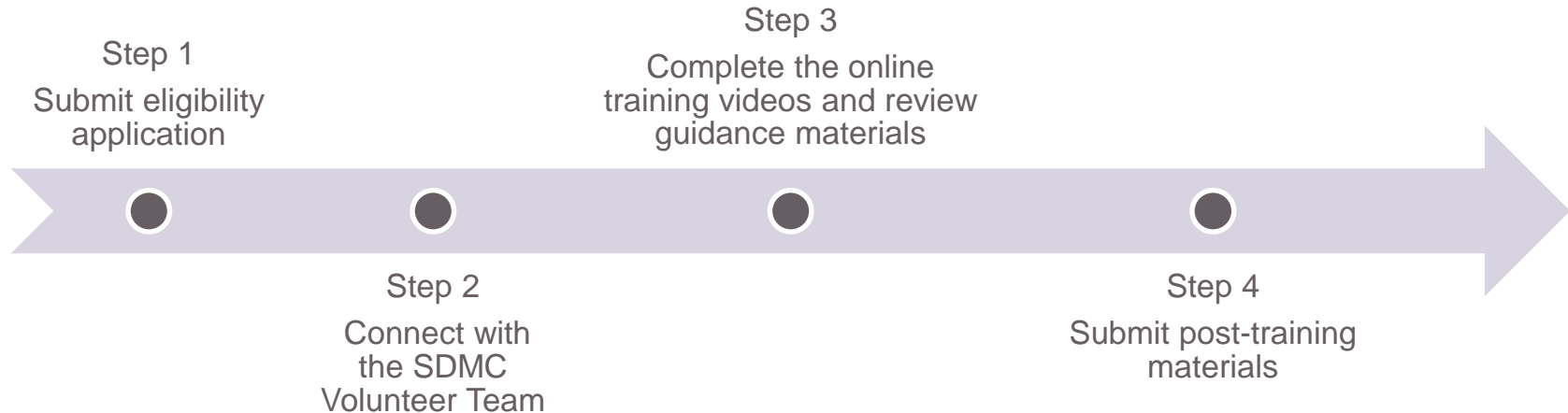
- Provider training on SDMC process, forms, and testifying at a hearing
- Outreach to hospitals and medical providers on the SDMC process and SDMC consents/authority
- Resources on website
 - How to complete forms
 - Mock Hearing
 - Guidance on SDMC Hearing Participation

Recruiting Volunteers

- SDMC seeks outreach opportunities to recruit Volunteers
- Signing up and Introductory Volunteer Panel Member Training is available online
- We offer training opportunities on
 - Service on End of Life Care Hearings
 - Serving in the Chairperson Position
 - Specific Legal and Medical Topics

How to Become an SDMC Volunteer?

Complete the online training process:



More Information

JusticeCenter.ny.gov/Volunteer

- Volunteer Sign-up
- Trainings for Volunteers
- Mock Hearing Video

JusticeCenter.ny.gov/SDMC

- Guidance Documents & Videos
- Forms



Contact Information

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Volunteer Questions

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