



**Justice Center for the
Protection of People
with Special Needs**

An Overview for SDMC Volunteer Panel Members

October 2018

Surrogate Decision Making Committee (SDMC)

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Surrogate Decision-Making Committee

The Surrogate Decision-Making Committee (SDMC) Program is an alternative to the court system for individuals who are in need of non-emergency major medical procedures or end of life decisions making but lack the capacity to provide their own informed consent and also do not have a legally authorized decision maker to act on their behalf.

Who Qualifies for SDMC?

Individuals become eligible for SDMC major medical decision making if they are, or have ever been in a residential program or received services from a program operated, licensed or funded by the **Office for People with Developmental Disabilities (OPWDD)**. This includes case management, family care, and day programs.

Individuals can also qualify for SDMC if they have ever had an inpatient admission to a psychiatric unit or a facility under the auspices of the **Office of Mental Health (OMH)**.

The SDMC Program will also serve anyone currently receiving or who has previously received treatment in a residential alcohol or drug treatment facility operated, licensed or funded by the **Office of Alcoholism and Substance Abuse Services (OASAS)**.

If the individual is determined to lack the capacity to make his/her own treatment decision, the SDMC then determines whether there is a legally authorized decision maker such as an actively involved family member, a court appointed guardian, or Health Care Agent, who is available and willing to make the decision on his/her behalf. If there is an available surrogate, SDMC does not proceed; the authorized surrogate makes the decision.

Informed Consent

The physician or health care provider must explain:

1. The health problem and diagnosis
2. The reason for the proposed treatment and whether treatment is necessary now or if it can wait
3. What will happen during the treatment
4. The risks and benefits of the treatment and how likely they are to occur
5. Any alternative options for treating the health problem
6. Any possible side effects or adverse events that may occur as a result of the treatment

To provide informed consent, the individual must:

1. Demonstrate an understanding of the proposed procedure
2. Realize and assess the risks and benefits
3. Appreciate the anticipated level of discomfort and the effect on functioning
4. Understand that his/her consent is voluntary and that it may be withdrawn at any time

Included Major Medical Procedures

Medical, Surgical, Dental and Diagnostic Interventions/Procedures

- **Treatments with a significant risk** — this includes certain diagnostics tests and procedures.
- **Use of anesthesia** — Medical, surgical, dental, or routine examinations conducted under anesthesia; informed consent is required for routine care when anesthesia is anticipated to be used to facilitate patient compliance.
- **Any significant invasion of bodily integrity requiring an incision or producing pain, discomfort, debilitation, or having a significant recovery period** — This includes surgeries, biopsies, dental extractions with the removal of bone or possibility of sutures.
- **Any other treatment or procedure for which informed consent is required** — The physician has the discretion to determine whether informed consent is required for a particular procedure or treatment.
- **Chemotherapy** — Informed consent is required for disclosure and understanding of the risks and benefits of chemotherapy.
- **Hospice** — Hospice care and treatment is typically attached to end of life decisions, but can also be considered on the major medical forms. Hospice may be considered for any individual qualifying for SDMC decision-making.

Excluded Major Medical Procedures

- **Routine diagnosis or treatment** such as the administration of medications other than chemotherapy, including the extraction of bodily fluids for analysis. (i.e. procedures and treatments that are considered so routine that the risks are minimal and so well known as to not warrant a disclosure).
- **Consent for HIV testing** is not provided by SDMC. HIV testing is classified under the Public Health Law as routine medical care.
- **Emergency treatment** — Public Health Law allows a physician to proceed in an emergency situation without delay, when, in the physician's judgment, a delay, in order to secure informed consent, would increase the risk to the individual's life or health.
- **Dental care performed under a local anesthetic**
- **Electroconvulsive Therapy (ECT)**
- **Sterilization or termination of pregnancy**
- **Withdrawal of life sustaining treatment for non-qualifying individuals** — SDMC has jurisdiction for end of life decisions ONLY for persons with intellectual or developmental disabilities.

Withdrawal/Withholding of Life Sustaining Treatment

In 2009, the SDMC Program was given the authority to make decisions to withdraw/withhold life sustaining treatment for individuals with intellectual and/or developmental disabilities through the Health Care Decisions Act. This includes but is not limited to:

- CPR- Do Not Resuscitate - (DNR) Orders
- Intubation and Mechanical Ventilation - Do Not Intubate (DNI) Orders
- Withhold/Withdraw life sustaining treatment

Three Decisions for Panel Members

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 interest of this individual?

1. Capacity

Capacity is presumed; an individual lacks the ability to consent or refuse major medical treatment if he/she cannot:

- Understand the proposed medical treatment
- Understand the risks, benefits and alternatives of the treatment
- Make an informed decision about the proposed treatment in a knowing and voluntary manner

Three Elements of Capacity

KNOWLEDGE

Has the procedure or treatment been explained?

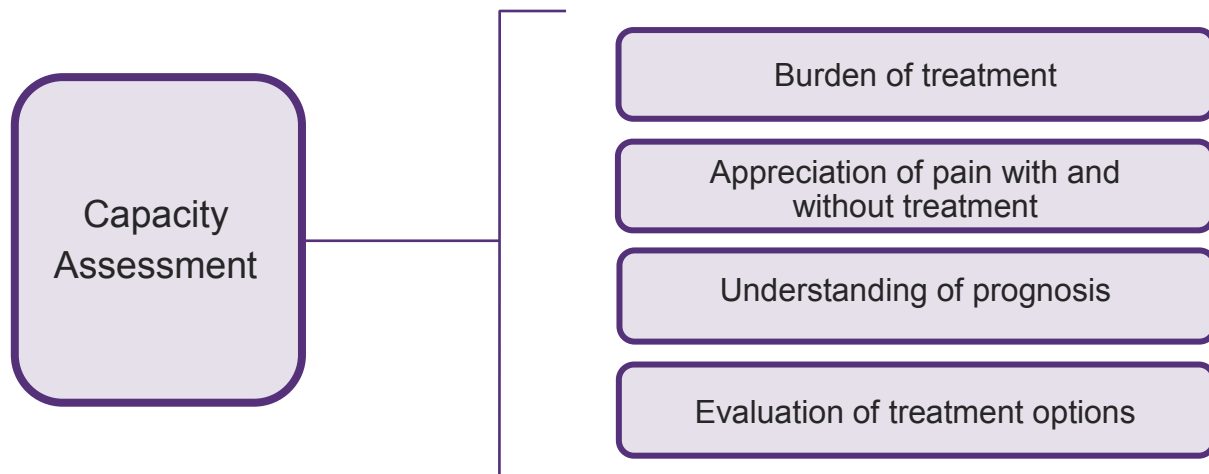
INTELLIGENCE

Can the individual demonstrate an understanding of the treatment?

VOLUNTARINESS

Is the decision being made without outside influence?

Evaluation of Capacity



2. Legally Authorized Surrogate

The surrogate is the person who is available and willing to make the medical treatment decision. Mental Hygiene Law Article 80 recognizes the following as legally authorized surrogates:

- Parents
- Spouse
- Adult child
- Legal guardian
- Court appointed guardian
- Health Care Proxy

Depending upon the mental hygiene program (OPWDD, OMH, or OASAS) which qualifies the individual for SDMC, the list of potential surrogates will differ.

Correspondent ≠ Surrogate

A correspondent does not have the legal authority to make the decision, but a correspondent could attend and participate in the hearing process.

A correspondent is a person who has demonstrated a genuine interest in an individual's care by maintaining a personal relationship or participating in his/her treatment planning, visiting, and regularly communicating with the individual.

Correspondents could include any of the following interested parties:

- Friends in the community
- Family care providers
- Family members who do not wish to be the decision-maker
- Community advocates

OPWDD Criteria

Hierarchy of surrogates defined by OPWDD regulation:

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. Consumer Advisory Board for Willowbrook Class Individuals
8. Surrogate Decision-Making Committee

Actively Involved is defined as “significant and ongoing involvement in a person’s life so as to have sufficient knowledge of the person’s needs.”

OMH & OASAS Criteria

For individuals under the jurisdiction of the OMH or OASAS the following may make these decisions on behalf of those individuals who lack the capacity to make their own medical decisions and also do not object to the proposed treatment:

- Spouse
- Parent
- Adult Child
- Court of Competent Jurisdiction

There is no hierarchy, no requirement for active involvement, and siblings are not included on the list of legally authorized surrogate decision makers.

3. Best Interest

Best interest means “promoting personal well-being by the assessment of the risks, benefits and alternatives to the patient of a proposed medical decision.” For major medical decision cases, the SDMC panel members should take into account factors such as:

- Relief of suffering
- Preservation or restoration of functioning
- Improvement in the quality of life with and without the proposed major medical treatment
- Consistency with the personal beliefs and values known to be held by the individual

The individual’s opinion regarding the proposed major medical treatment is to be given full consideration by the panel and balanced against the best interest needs of the individual, as well as his/her ability to understand and appreciate the consequences of his/her preferences. The panel is not bound by the individual’s opinion or preferences, however, the panel needs to balance the best interest of the individual against those stated preferences when making this determination.

Best Interest Standards

The decision by panel members should be made as if they were standing in that individual's shoes, with consideration of the individualized circumstances. If it's beneficial for one individual, it doesn't mean it will have the same impact, or the same risks and benefits, for another individual.

Burden of treatment — Will subjecting the individual to the burdens that are associated with the treatment result in a benefit that's worth enduring this pain/suffering? Or, is the treatment merely going to prolong the suffering already experienced? If the individual undergoes this treatment, how will this impact his/her quality of life?

Appreciation of pain — What is the degree, expected duration, and constancy of pain, with and without treatment? Is there a possibility that the pain could be mitigated by less intrusive forms of medical treatment or medications?

Prognosis — What is the likely prognosis, expected level of functioning, degree of humiliation and dependency with or without the proposed major medical treatment?

Treatment option alternatives — Has the physician evaluated treatment options, including nontreatment and the benefits and risks of these alternatives compared to those of the proposed major medical treatment?

Notice of Hearing

The **Notice of Hearing** (SDMC Form 250) includes the date, time, and location of the hearing; and is sent five days prior to the hearing to Mental Hygiene Legal Service (MHLS), the individual, all potential surrogates, and the panel members. **All potential surrogates will receive a notice of hearing and waiver letter.**

The SDMC hearing may proceed if:

- the authorized surrogate affirmatively waives his/her right to make the decision; or if
- the authorized surrogate fails to respond to the Notice of Hearing

The SDMC hearing would cease if a surrogate came forward and was opposed to the SDMC proceeding. SDMC would defer to the authorized surrogate in compliance with Mental Hygiene Law, Article 80.

SDMC hearings are quasi-judicial.

- Similar to court proceedings in their reliance on documentary and testimonial evidence
- All parties providing testimony are sworn in
- The panel may hear and rely upon hearsay in their decision making
- Due process rights are recognized – all interested parties receive notice of the hearing and have the right to come forward and participate
- All information (documents and/or testimony) considered by the panel must be on the record and available to all interested parties

Preparing for the Hearing

Volunteers receive a copy of the case packet from the local SDMC Coordinator with the hearing notice. This hearing notice includes the date, time, and location of the hearing. Please review the information in the case packet in order to:

- Ensure you have no conflicts or biases which could impact your impartiality
- Formulate questions for the hearing

Avoid ex-parte communication:

- Contact the SDMC nurse if you have questions regarding the case; do not discuss or seek opinions from others; do not conduct research, or call the physician
- Do not discuss the case with anyone while waiting for the hearing to begin
- Maintain impartiality - as a panel member, it is important to *always* avoid the appearance of a lack of impartiality; even if there is no wrongdoing, the appearance can have a negative impact

During the Hearing

At the hearing, SDMC Program staff provides assistance and support should any questions or unusual situations occur at a hearing and legal assistance and support to the panel at the hearing when questions arise.

The panel chairperson maintains order and professionalism during the hearing and may redirect panel members as needed during the hearing.

The following should be considered during the hearing:

- **Clarification vs. Redundancy in questioning** — If an issue has not been sufficiently addressed in one person's testimony, please reword the question, ask another participant, or call the physician for the information.
- **Avoid providing testimony** — Panel members may not provide testimony or offer information from their own knowledge or experience during the hearing. Please formulate your questions to obtain the information needed to establish the record of the panel decision.
- **Avoid Treatment Planning** — The panel must consider the treatment plan before them; they may not limit or add conditions to the consent regarding the medical provider, anesthesia plan, the aftercare plan, or new procedures that are not listed as alternatives on the declaration.

Deliberation

During the deliberation process, the panel has sole discretion as to the weight to be accorded to any evidence presented, upon which its decisions are made. Panel members may not provide testimony at the hearing, and may not offer information from their own knowledge or experience during the hearing. However, this is acceptable during deliberation.

- Only the four panel members participate in the deliberation
- Recording of the hearing is paused
- Objections may be considered
- Deliberation of capacity, surrogacy, and then best interest
- Hearing may be reopened for additional testimony and information

Voting Process

The panel must address three issues in the following order: 1) capacity, 2) legally authorized surrogate, and 3) best interest. Three votes are necessary for each decision for the SDMC to make a determination that consent should be granted:

- Three votes that the individual does not have capacity
- Three votes that the individual does not have a legally authorized surrogate
- Three votes that the procedure is in the individual's best interest

Absences and Delays Impact Voting

Voting issues — Three votes are required to determine the individual does not have capacity, to agree that an authorized surrogate is not available, and that the procedure is in the individual's best interest. If there are only three panel members, rather than four, the voting must be unanimous.

Panel determination and medical care could be delayed — The determination could be delayed if an unexpected conflict comes up for one of the panel members. This results in an unnecessary delay in the individual receiving medical care.

Delays affect other hearings as well — There may be multiple cases heard during a hearing and if one is delayed, the others that follow will be delayed. It can be very hard for some individuals to wait, especially in unfamiliar settings.

Voting Standards

Clear and Convincing Evidence Standard — Refers to evidence that is highly reliable and upon which reasonable persons may rely with confidence in the probability of its correctness. [Capacity and Surrogacy Decisions]

Preponderance of the Evidence Standard — Refers to evidence that when weighed for its quality rather than quantity, tips the scale to provide or deny consent. [Best Interest Decision]

Possible Hearing Outcomes

- Consent is issued
- Consent is denied
- No decision (2-2 vote for a four person panel or 2-1 vote for a three person panel)
- Person has capacity to make the decision
- Person lacks capacity, but does have a surrogate
- Conference call: When additional information is needed to make a decision

SDMC Consents

- Typically valid for 60 days
- Not issued to a specific health care provider
- Not specific to the type of anesthesia
- Contain a clause allowing a physician to move forward with related procedure so additional consents are not required
- Usually begins on the day of the hearing

Conference Calls

- Same panel members from the original hearing participate in the conference call
- Case information will be sent by mail, fax, or encrypted mail
- Phone number and conference code will be sent with the case information

SDMC consent, if granted, is conditioned upon the sound practice of medicine and a preoperative screening regarding the person's ability to withstand the procedure, related procedures, and anesthesia.

Objections, Denials and Appeals

Objections

Any interested party may issue an objection, including MHLS, correspondents, or potential surrogates. However, only an objection by a legally authorized surrogate may actually stop a proceeding. If a legally authorized surrogate objects to the panel acting upon the declaration, the objection is noted as part of the record and panel proceedings stop.

If an objection is made by MHLS, correspondents, or other interested parties, the objection is noted on the record and considered during deliberation, but it does not stop the hearing. The only exception would be an MHLS objection concerning receiving notice of the hearing. If this occurs, the hearing should stop pending resolution/proof of notice of the hearing.

Denials

If consent is denied, the agency may resubmit the case immediately with additional information or it may wait 60 days and resubmit the case to a new panel. Providers and declarants have the opportunity to bring new information to the hearing.

Appeals

The individual, MHLS, provider, declarant, interested parties, and correspondents have the right to appeal. Panel members have an ethical responsibility to make the best decision they can at the time of the hearing. They have an opportunity to adjourn the hearing in order to request more information if that is necessary to make the decision.

Health Insurance Portability & Accountability Act (HIPAA)

The major goal of this federal law is two-fold: It is crucial that an individual's sensitive health information be protected from unlawful and potentially harmful disclosure; and "covered entities" that need this information for continuity of health care have access to the information. SDMC is considered a covered entity.

The law allows the information to flow as necessary between the providers of health care for the individual as appropriate while protecting the confidentiality.

Confidentiality of Records

Mental Hygiene Law requires that panel members maintain the confidentiality of the information received in the case. This includes information pertaining to the individual's service recipient status, his/her medical condition and records, the proposed treatment plan, and his/her protected personal information.

While SDMC panels are required to maintain the confidentiality of all medical and clinical information received or acquired in the performance of their responsibilities as panel members pursuant to a number of state and federal laws and regulations, there are additional and more specific requirements governing HIV/AIDS related information.

Human Immunodeficiency Virus (HIV) and Confidentiality

A panel may be provided with HIV-related information when HIV or AIDS information is relevant to a proposed medical procedure or treatment before SDMC.

- Article 27-F of the Public Health Law sets forth requirements regarding HIV testing and the release and/or disclosure of HIV and AIDS related information (Public Health Law §§ 2781, 2781-a, and 2782). In addition, Public Health Law § 2783 provides for criminal and civil penalties of up to \$5,000.00 and/or up to one year of incarceration for unauthorized disclosure.
- The SDMC regulations also have specific rules related to the confidentiality of HIV, AIDS and AIDS-related information, including the fact that a person has been the subject of HIV testing.

Public Officers Law § 74 and Oath of Office

Roles and Responsibilities of Panel Members

It is required that all panel members sign an Oath of Office as a Public Officer and confirm receipt of certain sections of the Public Officers Law. Panel members are required to uphold and follow the Federal and State Constitution and maintain their impartiality as a decision maker.

As Public Officers, SDMC Panel Members May Not...

- Accept other employment which will impair their independence of judgment
- Disclose confidential information
- Use their official position to secure unwarranted privileges
- Engage in ex-parte communication

Conflict of Interest

A conflict of interest is any interest or benefit which is in conflict with the impartial discharge of your duties as a panel member. A panel member is not to serve on a panel reviewing a declaration when they have a conflict of interest. The following are noted as conflicts of interest:

- If you are a relative of the individual or another panel member at the hearing
- If you have a business affiliation with the residential or the medical provider or facility
- If you are an employee, officer, or board member of the licensed provider on the case
- If you hold a strong bias against a specific procedure, treatment, or diagnostic test