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*LEGAL AND ETHICAL STANDARDS AVAILABLE TO
SURROGATES WHEN IMPLEMENTING A PLAN OF
HOSPICE CARE FOR PEOPLE WITH DEVELOPMENTAL
DISABILITIES IN NEW YORK STATE*

BY

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ABSTRACT

Recent medical advances have enabled people to live longer healthier lives than ever before. As people live longer, they become subject to chronic debilitating medical conditions with age. Hospice and palliative care have become available as viable treatment options for anyone facing an irreversible, terminal condition. In New York State, by virtue of choosing a plan of hospice care which contemplates forgoing aggressive treatment for a person with developmental disabilities who could never express his or her wishes regarding treatment, the choice is complicated by the legal and ethical scheme governing the withholding or withdrawal of life sustaining treatment. This paper will trace the history of patient autonomy and surrogate decision making. It will discuss the ethical principles and legal processes pertaining to surrogate decision making for the person with developmental disabilities and which decision making standard best preserves the person's rights: substituted judgment, best interest, or a medico-legal standard; and will examine what is currently used in New York State when a surrogate is deciding on a plan of hospice care for the person. The current ethical principles and legal standards will be considered in the context of assisting the duly designated surrogate, physicians and advocates in this difficult area where ethics, medicine and the law intersect.

I INTRODUCTION

Recent medical advances have enabled people to live longer healthier lives than ever before. As people live longer, they become subject to chronic debilitating medical conditions with age. Hospice and palliative care have become increasingly available to patients as viable treatment options for anyone facing an irreversible terminal condition. In New York State, by virtue of choosing hospice services for a person with developmental disabilities who could never have expressed his or her wishes regarding treatment, the choice is complicated by the legal and ethical scheme governing the withholding or withdrawal of life sustaining treatment.

The standards governing surrogate decision making in New York State have evolved over the years. Deciding who can provide consent for medical treatment for those who no longer have decisional capacity has been the subject of much debate, both legally and ethically, including priority of family members, court appointed surrogates and the court itself.

The appropriate decision making process has also been considered as to which surrogate decision making standard can best preserve patient autonomy: substituted judgment; the best interest standard; or some other medico-legal standard. Surrogate decision making is further complicated for people with developmental disabilities who never had decisional capacity.¹

This paper will examine those ethical and legal considerations facing the medical profession, surrogates and advocates when a plan of hospice care is considered for a person who, due to a developmental disability, never had capacity to provide informed consent regarding their treatment (hereinafter referred to as people with developmental disabilities).

II BACKGROUND

In our Judea Christian society, life is held as sacrosanct. The state, in its role as *parens patriae*, protects people from actions which may hurt them by intervening through criminal and civil sanctions. While the act of suicide is no longer illegal in New York State, assisting or promoting suicide is punishable under the penal law. (NYS Penal Law §120.30) Assisted suicide is only recently available in a few states, and then, only under limited circumstances. (ORS §127.800 – 127.897) While a person's right to refuse treatment that might sustain their life is recognized, in practice, often the decision to refuse recommended treatment is scrutinized and will be allowed only if it is determined that the person has the capacity to make the decision free from duress and influence.

If we recognize only a person's rights of autonomy and self determination when making treatment decisions, it is only those people who can express their

competent wishes that can decide their treatment. When a person's wishes are not known, our society overwhelmingly protects life, assuming continued life would be desired. However, to require life at all costs for those people who cannot express their wishes place people with developmental disabilities unable to exercise the basic right of choice. In order to recognize some other decision making standard, it must be balanced with protections for these people.

Individuals with developmental disabilities have been victimized throughout the years. At the turn of the 20th century, the eugenics movement had gained favor resulting in groups that promoted specific theories and ideas of procreation, in an attempt to limit the disabled population. (Jonson 1998, 167-172) States had laws allowing the compulsory sterilization of people with developmental disabilities. (Buck v Bell, 274 U.S. 200, (1927)) Shortly afterwards, Germany, under the Nazi regime, targeted many people considered "undesirable," including those had developmental disabilities. (Annas and Grodin 1992, 23-25) In 1972, the horrors of Willowbrook were exposed. (Rivera 1972) Even today, research shows that a person with developmental disabilities is much more likely to be the subject of abuse or neglect than the non disabled person. (Roof and Esser 2011)

It is critical to have protections for people with developmental disabilities at all times, and especially when it comes to end of life decisions, to ensure

abuses don't occur. How to decide when treatment should be withheld or withdrawn, and who should decide, has been the subject of much debate at the bedside and in court among physicians, family members, and advocates.

III. APPLICABLE PRINCIPLES

A. Priority of patient's wishes and patient autonomy

The principle of autonomy is predicated in the basic ethical right of respect for persons and based on the ability of the patient to give informed consent. This ethical principle has been shaped by practice and the legal system.

Albert R. Jonsen traces the history of medical practice and consent in his book, The Birth of Bioethics. (Jonsen 1988) He begins his discussion of the evolution of consent at the time of Plato, when the idea of patient consent was nonexistent. At that time, the physician had the authority to withhold the truth from a patient. Later, under the Hippocratic tradition, it was the physician's duty to withhold information from the patient. It was not until English common law when society determined that the unauthorized touching of a patient by a physician was a trespass. This was the beginning of the concept of informed consent and patient rights as we know them. (Jonsen 1988, 355)

A New York court first addressed the right of informed consent in 1914. (Schloendorff v. Society of New York Hospital, 211 NY 125 (1914)) The court found that if a patient did not give consent for surgery, the surgeon would be guilty of assault and any damages that resulted. (Schloendorff @ 129-30)

The issue was again taken up in 1957, when a person's right to be provided sufficient information to give "informed consent" was articulated in a decision by a California appeals court. (Salgo v Leland Stanford, etc., Bd. Trustees, 154 Cal.App.2d 560 (1957)) In that case, the court found that not only is the patient to be told of any proposed medical treatment, but also the potential risks of the treatment. This decision for the first time effectively imposed an obligation upon the physician to disclose any facts necessary to obtain informed consent from the patient.

The principle of informed consent is codified in the AMA Code of Medical Ethics, which states

[t]he patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an informed choice. The patient should make his or her own determination about treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for the patient's care and to make recommendations for management in accordance with good medical practice.

Opinion 2.08: Informed Consent

While the right to autonomy, informed consent and respect for personhood

became well settled principles in medical ethics, there continued to be debate when applied in the context of refusing potentially life sustaining treatment for those who had lost capacity to exercise their rights.

This issue was first addressed by the New Jersey Supreme Court in 1976. (Matter of Quinlan, 355 A,2d 647 (N.J. 1976)) Ms. Quinlan was a twenty-two-year-old woman who was in what was considered a chronic persistent vegetative state. She was being kept alive by mechanical ventilation and her father wanted to withdraw the life-sustaining treatment. Her physicians refused to stop the treatment and the matter was heard in the court. In this pivotal decision, the Court found that there is a right of privacy guaranteed under the United States Constitution, as well as the New Jersey Constitution, and that this right is not extinguished due to the incapacity of the person but can be exercised by a surrogate. The Court authorized Ms. Quinlan's father to consent to the withdrawal of the life-sustaining treatment under the circumstances presented.

This seminal case was the first time a Court had authorized the termination of treatment on the consent of a surrogate. It became the law in New Jersey and was persuasive in other jurisdictions. As a result, some states tried to address the issue legislatively to provide a consistent result for their residents and guidance for the medical profession.

The state's ability to promulgate rules addressing under what circumstances a surrogate could make end of life decisions for someone else was squarely addressed by the United States Supreme Court in 1990. (Matter of Cruzan, 497 US 261 (1990)) Nancy Cruzan was a young woman who had an automobile accident leaving her in an irreversible vegetative state. She was unable to eat on her own and was sustained on artificial nutrition and hydration. Her family wanted to stop the artificial nutrition and hydration, but Missouri law required a surrogate for a person unable to make their own decisions to provide clear and convincing evidence of the person's prior wishes to allow the discontinuation of life sustaining treatment.

The U.S. Supreme Court upheld Missouri's standard. The Court's decision reinforced the patient's right of autonomy, and that the right cannot be exercised by a surrogate in the absence of the patient's known, prior, competent choice. It also left it to the individual states to decide how to best determine whether or not a person had made a prior competent choice of treatment. A person's right of autonomy and self determination is now known as one of the primary ethical principles in medicine.

B. Standards for surrogate decision making

When informed consent is sought from a person, it is assumed they have

the capacity to understand the information provided by the physician and can make an informed choice regarding their treatment. (AMA CME, Opinion 2.08)

When a person cannot understand the information provided by the physician, it should be ascertained whether the person has made a prior competent choice regarding treatment by executing an advance directive. (AMA CME, Opinion 8.081; NYS PHL Art. 29-C) If so, the person's prior choice can be exercised by the designated health care agent. This recognizes the person's rights of autonomy and self determination. Even when the person is rendered incapable of voicing a decision, an agent can execute the decision. An agent can sign consent forms and discuss treatment options with the physician, with the wishes of the person ultimately governing treatment decisions. If, however, a person's wishes regarding treatment are not known, or she never had the capacity to express her wishes regarding a particular treatment, ethics and law require that a surrogate is sought to make treatment decisions. (AMA CME, Opinion 8.081; NYS PHL Art. 29-CC; NYS SCPA §1750-b)

Substituted judgment standard

When a surrogate is charged with the responsibility of making a decision for a person whose wishes are not known, the substituted judgment standard is often employed. Under this standard, the surrogate is charged with making the

decision he thinks the person would have wanted. Decisions are to be based on the available knowledge of the person; the person's wishes, lifestyle, prior statements, and moral beliefs. The surrogate then makes the decision he believes the person would have made. (Veatch, 2003)

The substituted judgment standard is often used when someone has lost the capacity to make treatment decisions, and is most closely aligned with preserving the person's right of self determination when the surrogate has intimate knowledge of the person. Decisions can then be made based on what the surrogate believes the person would have wanted.

However, there are issues when using the substituted judgment standard. Studies have found that even when the surrogate is familiar with the person, other factors come into play in the decision making process and the surrogate's decision may not always reflect what the person would actually want. (Shalowitz, Garrett-Mayer and Wendler 2006)

Best Interest standard

When a person never had the capacity to make treatment decisions, a surrogate may make decisions based on what he believes would be in the person's best interest. An analysis of the person's best interest entails objectively weighing the risks and benefits of treatment against non treatment and the effects of both on the person. This is the standard most often used

when making treatment decisions for infants. (Veatch 2003, 113).

Multiple issues arise when using the best interest standard for a person with developmental disabilities. Studies have found that surrogates often have their own agenda and beliefs about what treatment should be provided.

(Sulmasy, et al. 1998) The surrogate may be a parent or sibling who has emotional or financial interests' which conflict with the person's wishes.

Additionally, physicians may have strong personal beliefs about treatment, honed over years of practice that may influence their treatment recommendations.

(Christakis and Asch 1995) This may lead to treatment decisions which are not what the person would want or what is in the person's best interest.

Medico-legal standard

While families and physicians have wrestled with how to make decisions for people with developmental disabilities who lack capacity to express their wishes regarding treatment, so have the courts. The Massachusetts Supreme Court was asked to address this issue when faced with the case involving Joseph Saikewicz. (Superintendent of Belchertown State School v. Saikewicz. 373 Mass. 728, 370 N.E.2d 417 (1977)) Mr. Saikewicz was a 60 year old man with profound disabilities and without capacity to make decisions. He had been diagnosed with leukemia and the only possible treatment at the time was to have chemotherapy. The trial court found it was in Mr. Saikewicz's interest not to have

the treatment and the decision was appealed.

The appellate court supported the trial court in making the decision regarding treatment and found that the court is well suited to decide treatment issues. In articulating a decision making standard, it determined that the doctrine of substituted judgment should be followed in cases involving people with developmental disabilities and the court should determine what the patient would have wanted, not the physicians, not the family, nor the state. In reviewing the lower court's decision, the court found

the decision in cases such as this should be that which would be made by the incompetent person, if that person were competent, but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process

Id. @ 752

While this became the law in Massachusetts, New York State law was still unsettled. Since different states can have different rules regarding decision making standards for people with developmental disabilities, the issue can become complicated for the physician who may attend school and then complete their residency in different states and then practice in yet another, when each state may have different rules directing treatment.

The American Medical Association acknowledges in the Code of Medical Ethics that the rules vary from state to state. The Code suggests that, in the first

instance, if the person does not have the capacity to make a decision regarding treatment, and there is no advance directive, the physician should turn to the law of the state to identify appropriate surrogates and ascertain how to proceed to obtain consent in special cases. (AMA Code of Medical Ethics, Opinion 8.081)

It is proposed by this author that this third standard be included in the surrogate decision making standards as the medico-legal standard of decision making. By incorporating this third standard as a term of art into the process, it would have the effect of transforming the decision making process from either the best interests standard or the substituted judgment standard, as made by family and physicians, and focuses it on the patient, in light of state law.

C. Beneficence versus non-maleficence

In some situations, basic ethical principles of beneficence and non-maleficence may conflict, causing tension for the physician. In the first instance, physicians are to be beneficent, do good works. At the same time, they have a responsibility to do no harm to their patients. There are times when treatment of an illness may cause immediate harm to the patient for an overall improvement in health and well-being. Treatments may cause distress to the person and put them at risk of other diseases. However, the risk of the treatment is often outweighed by anticipated benefits of treatment, i.e., the potential cure of the illness and the person's return to the level of functioning that they were

accustomed to prior to the illness.

If the person is unable to understand the need for treatment and requires physical and/or chemical restraints to accept the treatment, the potential harm from treatment may be increased. Even so, most would agree that the benefits of treatment for an acute illness outweigh the potential harm. At some point, the potential harm of treatment may outweigh the potential benefit. It is at this point that the ethical principles may conflict and withholding or withdrawing treatment may be a consideration.

IV. HISTORY OF SURROGATE DECISION MAKING FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES IN NEW YORK STATE

At the beginning of the bioethical revolution in the 1960's, New York State had a guardianship law which authorized court appointed surrogates to make decisions for people who had been adjudicated incompetent. (Mental Hygiene Law Article 78) The procedure was cumbersome, and expensive, to undertake. Parents of the developmentally disabled did not routinely apply to the court to be granted authority to make decisions for their children when they became adults, often relying on their status as parents to continue to make decisions for their children.

In 1969, the legislature passed a law authorizing a relatively simple

procedure to allow the appointment of a guardian for a person who was mentally retarded.ⁱⁱ (Surrogate Court Procedure Act Article 17A). Its primary purpose was to allow parents to obtain guardianship of their mentally retarded adult children so they could continue to make decisions for them and be involved in their care, as they did when they were minors. The law did not grant specific powers to the guardian, but rather granted general guardianship over the person and/or property.

Under this new law, guardians routinely gave consent for medical treatment for their wards. While their authority did not specifically extend to health care decisions relating to withholding or withdrawing life sustaining treatment, the parent/guardian often decided treatment without oversight or objection. During this time, it was only in those situations when family members or a care provider disagreed with the guardian's decision that a court might have been asked to intervene.

This issue came before the Court of Appeals in 1981 when the Court was asked to hear two companion cases. (Matter of Storar and Matter of Eichner v. Dillon, 52 NY2d 363 (1981)) Joseph Storar was a profoundly disabled man who had been diagnosed with terminal bladder cancer. The only recommended treatment was blood transfusions. The question posed to the Court was, even though the transfusions would prolong his life, based on Mr. Storar's inability to

understand the need for treatment, and the terminal nature of his condition, could the transfusions be stopped? The Court found that the blood transfusions should continue because the right to refuse life sustaining treatment was an individual right and, since Mr. Storar never had the capacity to make his wishes known, treatment could not be terminated. In Matter of Eichner, Brother Fox, a retired Franciscan brother, fell seriously ill, resulting in his being placed on a respirator. His advocates wanted to withdraw the treatment and allow death to occur naturally. In his case, the Court found that the evidence showed that Brother Fox, when he had capacity, had clearly and thoughtfully expressed his desire not to be maintained on a respirator. The substituted judgment standard could be applied and life sustaining treatment, in the form of the respiratory support, could be discontinued.

The law after Storar left people who never had decisional capacity unable to exercise rights to refuse aggressive treatment and choose hospice care. It required those who never had capacity to make a decision regarding medical care to undergo any and all life sustaining treatments, even if the treatment was harmful.

This issue gained greater publicity outside of disability circles when, in 1997, the New York Times published the story of Jimmy Wigmore, a profoundly disabled man. At the end of his life, Mr. Wigmore was required to receive

aggressive medical treatment that prolonged his life against medical advice and the wishes of his family, but in accordance with NYS law. (Fein 1997)

Disability advocates tried to address this inequity through legislation, but before a bill could be drafted and introduced there was another case widely publicized in the media regarding a woman who was forced to have life sustaining treatment over her family's objections and against her physicians' recommendations. This case involved Sheila Pouliot, a woman with profound disabilities who never had the ability to make her wishes known. Ms. Pouliot was terminally ill and in the intensive care unit of the hospital. Her organs began shutting down and her family, with the support of her medical provider, requested to discontinue aggressive treatment, including artificial nutrition and hydration.

The state agencyⁱⁱⁱ responsible for Ms. Pouliot's care, determined that treatment could not be withheld absent her prior competent choice. They asked the court to appoint a guardian on Ms. Pouliot's behalf to consent to the treatment, but the lower court agreed with the family that treatment could be stopped. The agency appealed the ruling, arguing the current state of the law did not authorize the discontinuance of life sustaining treatment for someone who never had capacity to make their wishes known. The result was that Ms. Pouliot was forced to receive painful treatments which left her suffering in the last moments of her life. She passed away while the appeal was pending. Facts as

stated in Blouin Estate of Pouliot v Sptizer, 356 F.3d 348 (2004).

These and other cases around New York State helped set the stage for passage of the Health Care Decisions Act (HCDA).

V. NYS HEALTH CARE DECISIONS ACT: SCPA Section 1750-b

The HCDA was passed by the legislature in 2002, becoming effective in March 2003. Under the provisions of this law, a surrogate could now make all health care and end of life decisions for people with developmental disabilities. The law provides for a statutory scheme to be followed in cases where life sustaining treatment is contemplated to be withheld or withdrawn. It was intended to prevent the tragedies that befell Sheila Pouliot and Jimmy Wigmore, but provide sufficient protections for those individuals with developmental disabilities to ensure that any potentially efficacious treatment would not be withheld.

A. Provisions of the HCDA

For the first time, New York State had laws that authorized court appointed guardians to make all health care and medical decisions for another person absent a prior competent choice, including decisions to withhold and withdraw life sustaining treatment in certain prescribed situations. The law attempted to

provide consistent procedures to ensure that medical treatment was not imposed on a person to their detriment, but also that it was not arbitrarily withheld or withdrawn from a person due to their disability and perceived quality of life.

1. Priority of surrogates

As originally enacted, the HCDA provided that only guardians for people who were mentally retarded could be granted the ability to make end of life decisions for their ward if they provided to the court by medical certifications that their ward did not have the capacity to make medical decisions for themselves. (SCPA §1750-b)

The definition of “guardian” was first expanded by the courts. The New York State Court of Appeals, in the decision Matter of MB, found that guardians appointed prior to enactment of the law, who had no duty to provide to the court certifications as to the person's ability to make medical decisions and could make medical decisions, including end of life treatment decisions, for their ward. (6 N.Y.3d 437 (2006)) The law was subsequently extended to people with developmental disabilities as well as to allow not only court appointed guardians the authority to make end of life decisions, but to include additional parties who can now act as surrogate without court oversight, including qualified family members, the Consumer Advisory Board^{iv} and the Surrogate Decision Making Committee.^v (SCPA §1750-b(1)(a))

These changes accommodate the unique status of people with developmental disabilities, those who have families, as well as those who don't. They are not always able to develop and maintain friendships and social relationships with others who could then act on their behalf. The law recognizes this and allows certain institutional entities familiar with the needs of people with developmental disabilities and cognizant of their potential exploitation to act as surrogates.

2. Surrogate responsibilities

The HCDA requires that surrogates “shall base all advocacy and health care decision making *solely and exclusively* on the best interest of the mentally retarded person, and when reasonably known or ascertainable with reasonable diligence, on the . . . person's wishes, including moral and religious beliefs” (emphasis added). (SCPA §1750-b(2)(a)) At first glance, this phrasing is in line with the intent of the guardianship statute as enacted in 1969 to allow parents in the first instance to make decisions for their adult children with developmental disabilities. However, when considered as a whole, the additional criteria allows for some recognition of self-determination in the decision making process.

In assessing “best interest”, the law provides additional guidance for the surrogate, directing the surrogate to consider

- (i) the dignity and uniqueness of every person;
- (ii) the preservation, improvement or restoration of the mentally

- retarded person's health;
- (iii) the relief of the mentally retarded person's suffering by means of palliative care and pain management;
 - (iv) the unique nature of artificially provided nutrition or hydration, and the effect it may have on the mentally retarded person, and
 - (v) the entire medical condition of the person.

SCPA §1750-b(2)(b)

While the law allows for consideration of a person's wishes, the surrogate has great latitude. By stating that decisions are to be based in the first instance on the person's best interest, care must be used to include the individual's wishes to ensure they are not a secondary consideration. If they were ignored, it would reinforce the notion that the wishes of the person with developmental disabilities are not valued and has a lesser standing in the decision making process.

3. Physician findings

Prior to withholding or withdrawing life sustaining treatment, the law provides that additional medical findings need to be made. The attending physician is to determine whether or not the person has the capacity to make health care decisions due to a developmental disability, and, if the physician determines the person does not have capacity, obtain a concurring opinion by a professional familiar with people with developmental disabilities. (SCPA 1750-b(4)(a)) This requirement may seem redundant, but it is recognition of the

obstacles people who have a developmental disability may have in communication and functioning which do not necessarily indicate a lack of capacity, but, rather a mechanism to make their wishes and abilities known.

If the person is determined to have capacity by the concurring professional, any decisions the person makes regarding treatment should be recognized. If the person's incapacity is confirmed, the physician must find that the person has a terminal condition (excepting the developmental disability) that would cause death within a year, or is permanently unconscious, or that the person's condition (excepting the developmental disability) is irreversible and will continue indefinitely AND that the proposed treatment would impose an extraordinary burden on the person (emphasis added) in light of his or her condition (excepting the developmental disability) and the expected outcome of the treatment. (SCPA §1750-b(4)(b)(i) and (ii))

If the treatment proposed to be withdrawn or withheld is artificial nutrition and/or hydration, the surrogate is also required to consider the nature of the treatment and the effect on the person. (SCPA §1750-b(2)(b)(iv)) In addition to the surrogate's findings, the attending physician is to determine whether "there is no reasonable hope of maintaining life; or . . . the artificially provided nutrition or hydration poses an extraordinary burden." (SCPA §1750-b(4)(b)(iii))

These required findings are difficult for family, physicians and advocates who are not familiar with the law to accept and apply in a given situation. To put the law in perspective, one must consider that the HCDA was intended to prevent the kind of treatment imposed on Sheila Pouliot and Jimmy Wigmore. However, there was also concern that treatment may be arbitrarily withheld from the developmentally disabled due to their perceived quality of life. The law attempts to balance these competing interests and is a reflection of society's belief that life should be sustained in all but those situations where treatment would be an extraordinary burden on the person, in the life that they have, and in the case of artificial nutrition and hydration, that there is no reasonable hope of maintaining life.

4. Notice requirements

Under the HCDA, the person is to receive notice of a decision to withhold or withdraw life sustaining treatment, with the caveat that notice does not need to be given if the attending physician, with the concurrence of another practitioner, determines that the person would suffer immediate and severe injury from such notification. (SCPA §1750-b(4)(e)(i)) While it may be argued that this provision is rarely used, it would appear that the person would only suffer 'immediate and severe injury' from such notification if they had some understanding of what

might happen if the treatment was withheld or withdrawn.

There are times when the person with developmental disabilities may not understand the situation or the consequences of a decision to withhold or withdraw life sustaining treatment. It is conceded that it can be difficult to explain these decisions. It may take more than one approach and more than one meeting with the person. However, to fail to notify a person about the decision and provide an opportunity for him to be understood violates the basic precepts in medical ethics of the person's right of self determination and recognition of an individual's abilities.

5. Other parties

The law recognizes that there are other people who have an interest in the well being of the person with developmental disabilities. When someone is residing in a facility operated or certified by the Office of People with Developmental Disabilities^{vi} (OPWDD), notice of any decision to withdraw or withhold life sustaining treatment is to be given to the CEO of the facility and the Mental Hygiene Legal Service.^{vii} (SCPA §1750-b(4)(e)(ii)) If the person is not residing in a facility, notice is to be given to the Commissioner of OPWDD. (SCPA §1750-b(4)(e)(iii))

Although the law only requires notice to the person and the

aforementioned institutional entities, once notice is given, the person or any one of a number or parties identified in the statute can object to the decision to withhold or withdraw treatment.^{viii} (SCPA §1750-b(5)) An objection will suspend implementation of the surrogate's decision until the dispute is resolved through judicial review (SCPA §1750-b (6)) or through the election of another dispute resolution process as outlined in the statute. (SCPA §1750-b (5)(d))

VI. HOSPICE

It has been reported that most people would like to pass away in their own home. Even so, the reality is that most people pass away in the hospitals or nursing homes and receive treatment in the intensive care unit during the last six months of life. (U.S. Dept. of Health, CDC 2010, 43) These findings support promoting the use of hospice care in the home in terminal cases.

A twist to this theory is acknowledged by the bioethicist Rebecca Dresser in the book "Malignant: Medical Ethicists Confront Cancer." (Dresser 2012) The book chronicles seven professional bioethicists who were faced with their own, or a loved one's, cancer diagnosis. In a discussion of the book in the Hastings Center Report, Ms. Dresser noted

we were pulled in two directions—quality of life was important, but so was quantity of life. In the end, quantity of life usually took priority. We were a little surprised at the burdens we were willing to accept in exchange for a better chance of survival.

The recognition that, once someone is faced with a potentially terminal condition, preferences regarding treatment may change and burdens not previously contemplated become acceptable complicates an already difficult area in surrogate decision making. What people think they want to happen when they are well may not necessarily be what they actually choose when faced with a terminal illness. Even so, for those that want to forgo aggressive treatment, hospice care is a service which evolved to support and care for people at the end of life.

A. History of Hospice Care

The term “hospice” has been used since medieval times as an aid to travelers. The idea of providing specialized care to dying patients was first espoused by a British physician, Dame Cicely Saunders. In 1967, she established the first hospital for dying patients, known as hospice, in London, England. (National Hospice Foundation 2013)

The evolution of hospice care in the 1960's coincided with the bioethics revolution and recognition of patient's right of autonomy. It was officially recognized in the United States in 1982, when Congress authorized a four year trial through Medicare to pay for hospice services as a treatment option. This led to a permanent Medicare benefit for hospice services in 1986. 42 CFR Part 418

Hospice services are recognized throughout the country as a viable alternative to aggressive treatment in the end stages of life. In 2010, in recognition of patient choices and the benefit of hospice services at the end of life, the New York legislature passed the New York State Palliative Care Information Act, which requires medical providers to advise their patients of the option of hospice care. (NYS Public Health Law §2997-c)

B. Considerations for Plan of Hospice Care

1. End of life care

Medicare provides that the patient's medical condition meets certain criteria for hospice services to be a covered service. At the outset, the patient is to have a terminal illness such that it is anticipated it will cause their death within six months. (42 CFR 418.22) While this may be imprecise in some situations due to the physician's inability to precisely determine the timing of a patient's death (Luce 2007), a patient can be re-certified for services if they do live beyond the initial six months. (42 CFR 418.24(c))

2. Election of treatment

Under the federal regulations hospice care can be provided to a patient who makes certain elections regarding treatment, which are now incorporated into hospice guidelines. The regulations require that the patient, or their surrogate, must acknowledge an understanding of the nature of hospice as

palliative, not curative. Additionally, the patient, or their surrogate must waive the right to any further treatment for the terminal condition which was certified to by the physician. (42 CFR 418.24(b))

3. Recognized Surrogates

Federal regulations defer to individual state laws as to who is a legally authorized surrogate for the purposes of implementing a plan of hospice care for a patient with physical or mental disabilities. (42 CFR 418.3) In New York State, the Surrogate's Court Procedure Law provides for the priority of surrogates for a person with developmental disabilities. (SCPA §1750-b)

VII. APPLICATION OF HCDA TO A PLAN OF HOSPICE CARE

The law likes rules. Rules to be followed by anyone faced with the same, or similar, situation to ensure a consistent outcome. Medicine is as much an art as a science, and people often defy rules and consistent care does not necessarily result in consistent outcomes. There may be statistics as to rates of success or failure of treatment, but as they apply to a particular situation, the person's condition and individual wishes need to be taken into consideration.

At the outset, in order to consider a plan of hospice care, the physician must certify that the person has a terminal condition that if allowed to run its natural course, will most likely result in the person's death within six (6) months.

(42 CFR 418.22) Under the best of circumstance, this may be difficult to predict. When the person is developmentally disabled, the trajectory of some illnesses may be different than for people without disabilities. For instance, a person with Down syndrome may have multiple co-morbid conditions which complicate their diagnosis. (Rader 2005) On the opposite side of the equation, some people with developmental disabilities may survive well past their expected demise due to unanticipated reactions to care and the availability of alternate treatments.

A. Withholding or Withdrawing life sustaining treatment

On its face, a plan of hospice care may not contemplate the withholding or withdrawal of life sustaining treatment. However, under New York State Law, even cardio-pulmonary resuscitation is considered a life sustaining treatment. (PHL § 2994-a(19)) Other life sustaining treatments may include the administration of antibiotics for an infection, respiratory support or artificial nutrition and hydration.

The implementation of a plan of hospice care will invariably involve the withholding or withdrawal of some, or all, of these life sustaining treatments. If the person has developmental disabilities and is unable to provide consent, the provisions of the HCDA will apply. In order to prevent a delay in providing hospice care a reasonable outcome should first be defined.

B. Use of the MOLST

New York State is one of the states which subscribes to the use of Medical Orders for Life Sustaining Treatment (MOLST)^x for patients nearing the end of their lives. (PHL §2977; Bomba 2011) Comfort care may be one of the treatment plans selected under the MOLST orders, as well as providing for the limitation of treatment. The use of this form is useful to assist in implementing a specific plan of care. Since the provisions of the HCDA apply when the plan of care under the MOLST contemplates withholding or withdrawing life sustaining treatment and providing comfort care for people with developmental disabilities, in those cases, an additional checklist is required before the MOLST is considered complete.

VIII. CASE STUDIES

In order to apply the provisions of the HCDA to a plan of hospice care, it is helpful to look at the clinical setting. While each case will turn on the person and his or her overall medical condition, the following are two examples of how the various principles and standards come into play when proposing a plan of hospice care for the person with developmental disabilities.

Loretta

Loretta was a 65 year old moderately retarded woman with Down syndrome and associated age related health problems. Loretta had spent most

of her life in an institution, but her family kept in close contact with her. Her mother visited regularly and, when she passed away, her sister became the primary family contact.

Loretta spent her days at a day program, interacting with peers and staff. In 2009, she began having significant seizure activity of unknown etiology and was diagnosed with dementia. She became increasingly withdrawn from the activities she used to enjoy and any deviation from her routine became very disruptive. The staff, sensitive to her needs, kept a quiet space for her in the home.

Loretta was admitted to the hospital numerous times after seizure activity. She was closely followed by a neurologist, and over a period of several months, took a sharp decline in functioning. In conjunction with her sister, her attending physician felt it appropriate to implement a plan of hospice care. To do so meant instituting a do not resuscitate order (DNR), do not intubate order (DNI), and withholding artificial nutrition and hydration, if her condition continued to deteriorate. He determined that Loretta had irreversible conditions including advanced dementia, hypertensive heart disease, congestive heart failure, osteoporosis, recurrent pneumonia, seizure disorder, and aspiration. The physician obtained a concurring opinion as to her capacity and medical condition and then provided notice to the necessary parties.

A MOLST form was completed, including DNR/DNI orders, no artificial nutrition or hydration and a plan of hospice care was put in place without objection. Loretta was discharged to her home with hospice care and she passed away four months later, surrounded by supportive staff.

Robert

Robert is a 70 year old man who is severely mentally retarded. He lived most of his life in institutional settings, the last two years he found himself in a community residence with four other gentlemen. Robert enjoyed his day program and outings in the community.

Robert's niece was listed in his file as his advocate at the behest of the agency that cared for him. When he moved into the community residence, a resourceful social worker tracked her down and she reluctantly agreed to be a family contact. She visited him once in his home and signed consents when contacted by the staff.

In 2007, Robert had a series of seizures of unknown etiology resulting in a catatonic state. He was admitted to the local hospital, unable to swallow or interact with his environment. His niece was contacted for permission to allow the placement of a nasogastric tube for artificial nutrition and hydration, which she eventually agreed to. Robert was diagnosed with neuroleptic withdrawal

syndrome. After two weeks, the seizure activity had stopped, but he had made minimal recovery and was still unable to swallow. Placement of a percutaneous endoscopic gastrostomy (PEG) tube was recommended. His niece declined to provide consent for any additional treatment, saying she felt it was in Robert's best interest to not provide any more treatment. She felt he never had much of a life before and couldn't imagine what it would be like with a PEG tube. She requested her uncle receive hospice care at his home.

Robert's attending physician, while conceding that Robert did not meet New York State's legal criteria to withhold or withdraw life sustaining treatment, believed that it was in Robert's best interest not to place a PEG tube for long term nutritional support. He recommended withdrawal of artificial nutrition and hydration and return Robert to his home under a plan of hospice care.

It was determined that since Robert did not meet the statutory standard for withholding or withdrawing life sustaining treatment, and that the provision of treatment would not be an extraordinary burden on him, judicial consent was obtained for placement of a PEG tube.

Robert received the PEG tube and his condition continued to improve. He was discharged to a rehabilitation unit of a nursing home and eventually back to his residence.

IX. DISCUSSION

These case studies demonstrate the strengths and weaknesses of New York State's approach to end of life care for the person with developmental disabilities. They also raise additional questions and warrant discussion in the context of the ethical principles at play and their interface with the law.

- A. Does consideration of hospice services present a particular challenge in the context of the HCDA?

The use of hospice services has increased in recent years and provides an option for patients who no longer want aggressive treatment near the end of their lives. This is an individual choice, and often, a recipient of hospice services does not have to be *in extremis*. Hospice recipients may have chronic conditions such as dementia, COPD, or congestive heart failure. Many chronic conditions lend themselves to choosing hospice services when the person no longer wants aggressive treatment of a medical condition.

Historically, the election of hospice services was a person's choice, or that of a legally authorized surrogate, based on a prior competent choice. "Enough is enough" might be the refrain. Some people would rather not return to the hospital for another bout of pneumonia and another round of antibiotics. Chemotherapy may be refused by someone who has already had two earlier cancers. Even considering that the treatment may prolong life, some may decide

that the burdens of treatment outweigh the potential benefits of additional treatment and instead choose palliative or hospice care.

It is no longer a personal decision that the person has had enough. With the passage of the HCDA, hospice has become a viable treatment choice for people with developmental disabilities. A surrogate can now decide that the person has "had enough." What guidance is there, then, for the surrogate, when asked to make the decision to stop aggressive treatment and choose hospice care?

In Loretta's case, her surrogate knew her well. Her sister had contact with her, visited with her and was aware of her needs. While Loretta never had the legal capacity to make a decision regarding treatment, her sister knew what was important to her. She considered Loretta's situation. She, in consultation with Loretta's physician, became familiar with her medical conditions and how they affected the ultimate outcome of treatment. In the months leading to her decline, her sister could see Loretta's distress and maintained regular contact with her.

Even though Loretta's sister was able to consider Loretta's situation, it is not always an easy task for the surrogate. It can be difficult for always able-bodied people to face a chronic condition which may result in dependence on others. Often, consideration of loss of independence may drive surrogates to make decisions based on what they believe is the best interest of the person with

developmental disabilities, but is rather the decision they would make for themselves. They might refuse artificial nutrition and hydration, risking possible aspiration, to avoid a PEG tube and inconvenience of the device. However, for someone who has always been dependent on others, artificial nutrition and hydration may be an acceptable option, requiring little change in the home environment or functioning.

As seen in Robert's case, his niece made a decision based on what she considered was his best interest, in light of the perceived quality of his life. While the physician supported her decision, he failed to give weight to the additional considerations required by the law. Family members and physicians may say that treatment isn't in someone's best interest. Often the statement is followed up with justifications such as "I wouldn't want to have the treatment" or "I wouldn't want my mother to have the treatment."

Multiple issues arise when using the best interest standard. One is the personal nature of the best interest standard, as evidenced by Robert's niece. As in his case, the personal perceptions of the surrogate and the physician may color decisions. Decisions are then made in the context of what the surrogate thinks is best, without regard to the status of the person with developmental disabilities.

In studies, investigators have found that surrogates may incorporate their

own beliefs and perceptions into the decision making process when determining whether a particular treatment is in someone else's best interest. (Sulmasy, et al. 1998) For instance, living on a respirator long term, requiring a tracheotomy may not be in someone's best interest. Having to relocate away from loved ones, most likely into an institution, not being able to enjoy activities and being dependent on others may be too much for some to accept. The decision would then be to withdraw or withhold treatment. However, for a person who has always been dependent on others and lived in institutional settings, adapting to different levels of dependency and disability may not be an overriding consideration when deciding on treatment that may extend their life. Different people may make different decisions, based on tolerance to burdens.

Under New York's medico-legal standard, when a surrogate is making a best interest determination for a person with developmental disabilities they are to consider the person's level of functioning, the degree of pain resulting from the treatment versus the pain from the condition it is expected to treat, the person's condition and chance for recovery, as well as the risks, side effects and benefits of the treatment. It is up to the surrogate to weigh these various options and then render a determination as to whether hospice services are in the person's "best interest."

Once a surrogate for a person with developmental disabilities decides a

plan of hospice care is in the person's best interest, federal regulations and hospice rules require that the physician must certify that the person has a terminal condition and hospice services are appropriate. In the majority of cases, that is only the first step. Due to the implementation of a do not resuscitate order and the possibility of withholding other life sustaining treatments, the HCDA is necessarily implicated and the additional medical findings are required.

B. Extraordinary burden

If the physician determines that the person has a terminal condition for admission to hospice services, the required initial medical determination for the purposes of the HCDA is met. The next step is to ascertain whether there is any treatment available to the person that may be considered life sustaining that is proposed to be withheld or withdrawn. If so, it has to be considered as to whether administering the proposed treatment would impose an "extraordinary burden" on the person, in light of his or her medical condition and the expected outcome of the treatment. This determination necessarily requires an understanding of the person, the medical condition and the expected trajectory of the condition.

The concept of extraordinary burden is not defined in the law or medicine. It is typically personal to the patient. As found by Dresser, different burdens

become tolerable when people are placed in difficult situations. However, when the person can't tell the physician what they consider to be an extraordinary burden, what guidance is there to make that determination?

When faced with the issue of whether treatment might impose an extraordinary burden on a person, the courts have been careful to analyze the individual facts in the case. In Matter of Elizabeth M., the appellate court upheld the trial court's decision to allow the parents/guardians to request the withholding of dialysis from their twenty-three-year-old daughter. The Court found that, based on the young woman's particular circumstances and her underlying medical conditions, the provision of the treatment would impose an extraordinary burden and the decision to withhold dialysis was supported. (30 A.D.3d 780 (3rd Dept. 2006)) However, contrast that with trial Court's decision in Matter of Gianelli v DH, where the court, relying on the SCPA §1750-b, found that the patient, a fourteen year old boy, had a fatal condition, but it was not yet terminal. Since he was alert, responsive and relatively pain free, the court ruled that the continued treatment did not impose an extraordinary burden and denied the parents' request for withdrawing treatment. (15 Misc.3d 565 (Sup.Ct., Nassau Cty.))

The HCDA was crafted to assist in determining what constitutes an extraordinary burden by requiring consideration of not only the patient's medical

condition, but also the expected outcome of the treatment. These considerations are similar to the concept of proportionate versus disproportionate treatment. If the treatment is proportionate, that is, it is anticipated that the proposed treatment will provide a benefit to the patient which is greater than the risks of treatment, then extraordinary burden is not found. However, if the treatment is disproportionate, that is, it will either not provide a benefit to the patient or the risks and burden of treatment are greater than the benefit received, then extraordinary burden may be found. (McCartney, James J. 1999, 92)

While this analysis is helpful in some cases, such as Loretta's, since the burdens of treatment are personal, it needs further exploration. Decisions may be dependent on family status, life history or the current condition. Even when considering those factors, similarly situated people may choose different courses of action. (Ackerman 2007, 53)

In Robert's case, he was compliant with the administration of artificial nutrition and hydration through a nasogastric tube. He did not interfere with treatment and left the medical equipment alone. His overall health was good and he did not have an underlying terminal condition. It was not known at the time treatment was recommended whether his condition was irreversible. It also didn't appear that to convert delivery of nutrition from the nasogastric tube to a PEG tube would impose an extraordinary burden.

When a patient does not have the capacity to decide their treatment, the physician is asked to determine if the provision of a medical treatment would pose an extraordinary burden. Often these decisions are made at the hospital bedside. It may be the physician's first contact with the patient. Family members come to the bedside with their own prejudices and history which may color their decisions. They initially look to the physician to help make these difficult decisions.

It should also be considered that it is not only the family or surrogate who are involved in these decisions. People with developmental disabilities have often lived their lives in institutions, group homes and family care homes, away from their families. Caretakers who have made a career working with the developmentally disabled may have a different view of what would pose an extraordinary burden on the patient. (Fisher, et al 2009) They are familiar with the accommodations and processes available to those who are developmentally disabled. They are familiar with feeding tubes, respirators, toileting schedules and other therapies that are available to improve lives. While they do not have decision making authority, they are part of the service plan and have insight into what care is available if treatment is provided as well as what may be available if treatment is withdrawn or withheld.

While the law makes no distinction between withdrawing and withholding

treatment, medical and service providers do. Unless the service providers agree with the plan of hospice care, it may cause distress to them and the person they are serving. When people are moved back to their home and treatment is withdrawn, unless the service providers understand and agree, it can be difficult for them to continue to provide daily care to the person while they are on hospice services.

C. Quality of life considerations

The law attempts to provide a mechanism to prevent individual perceptions about a person's quality of life from playing a role in whether or not treatment should be provided to a person with developmental disabilities. It can be difficult for people with disabilities to obtain adequate medical care in the first instance. They are increasingly vulnerable and face many health care inequalities. (Ward, Nichols and Freedman 2010) These can include limited financial resources, geographic obstacles, limited transportation, and the availability of medical providers skilled in the special needs of people with developmental disabilities. Many are on governmental assistance which limits their access to medical providers and choice of care. The issues relating to the inadequate system of health care, along with competing legal precepts, compound the difficulty in evenly applying a uniform system of end of life care.

There is a very real concern that otherwise available treatment will be

withheld or withdrawn from people disabilities due to the perceived quality of their lives. (Francis 2007, 171-72) In Robert's case, the physician felt that Robert's quality of life was poor, equating his situation to a person who had developed advanced dementia. It was his opinion that, even if Robert's condition continued to improve, he would never realize an acceptable level of functioning and, therefore, it was in his best interest to just receive comfort care. He further rationalized that it is now accepted practice to withhold artificial nutrition or hydration in the case of someone with advanced dementia, and so, in Robert's case, it was in his best interest not to have the treatment. Insofar as different people have different tolerances for quality of life considerations, to include the individual's perceived quality of life into the equation when determining whether or not treatment should be provided for people with developmental disabilities would result in inconsistent care.

D. Consideration of the person's wishes and best interest

As previously noted the HCDA directs the surrogate to make medical decisions using the best interest standard in the first instance and then defines the criteria the surrogate is to consider when making a best interest determination. If the surrogate was to use what they considered to be the best interest of the person, without regard to the additional factors, it might preclude any consideration of the person's wishes. The best interest standard, without

more, is subjective and based on the surrogate's determination of what is best for the person. It does not necessarily include what the person thinks is important or what they might want. This subjective standard is arguably based on a paternalistic attitude that the surrogate knows best, and that a developmentally disabled person is unable to have valid wishes and desires.

The courts have tried to address this issue, some focusing on the specific language in the statute. In the lower court's decision in the Matter of Chantel R., the judge took care to reinforce the provisions of the law that are to be followed in making end of life decisions for people with developmental disabilities. (6 Misc. 3d 693 (Surrogate Court NY Cty (2004)) Chantel was a 26 year old woman who was mentally retarded. Her mother applied to be appointed her guardian pursuant to SCPA Art. 17A. When questioned during the investigation into the matter, Chantel expressed a desire that she receive all life sustaining treatment. While the court approved the appointment of a guardian granting the guardian authority to make health care decisions for her, it explained that not only was the guardian to act in Chantel's best interest, but that there were certain medical findings which also were to be made, citing the mandated physician findings in New York's law. (*Id.* @ 702) The Court went further, finding that the guardian had to consider more than Chantel's best interest as determined by the guardian, interposing the state's medico-legal standard, finding the guardian has

independent responsibility with respect to all treatment decisions to take into account the known wishes (including moral and religious beliefs) of the mentally retarded person and to make an independent assessment of her best interests in light of her dignity, her suffering and the efficacy of palliative care and pain management, the effect that artificially provided nutrition and/or hydration may have, and the possibility of preserving, restoring or improving her health.

Id.@ 703

This decision is important because, while it was argued in disability circles that the court discounted Chantel's express wishes, the court stressed the additional safeguards in the statute which must be followed; emphasizing that it is not just up to the guardian on their own to decide what they believe is the person's best interest. New York State law attempts to incorporate a person's wishes and the effect of treatments, independent of the person's developmental disabilities

The HCDA, in directing the surrogate to base decisions on the person's best interest, and, if known, his or her wishes, does allow some recognition of self determination in the decision making process. These additional required findings can help to ensure that treatment is not arbitrarily withheld.

E. Can basic rights of autonomy and self determination be exercised by a surrogate?

Arguably, the developmentally disabled person is unable to exercise the right of autonomy. How can a surrogate best decide when the person's wishes aren't known? As the Massachusetts court held, some believe that the surrogate

should try to stand in the shoes of the disabled patient. (Matter of Saikewicz)

Some may believe that it is sufficient that the “reasonable person” standard be used when making decisions for another. It is argued here that when considering a plan of hospice care for the developmentally disabled, the person’s desires, wishes, life styles and comforts are paramount, and New York’s medico-legal standard should apply.

The New York legislature tried to craft a law that protected the rights of the disabled as well as prevented the harm caused by providing all life sustaining treatment in some situations. The HCDA provides a process to allow surrogates to exercise basic rights of choice for people with developmental disabilities. Even so, caution must still be used when determining whether treatment should be withheld or withdrawn and the law should be carefully applied in individual cases.

In Loretta’s situation, she had a surrogate who knew her well. Her sister had contact with her, visited with her and was aware of her needs. While Loretta never had the legal capacity to make a decision regarding treatment, her sister was aware as to what was important to her. In the months leading to her decline, her sister could see the distress Loretta was in and tried to maintain regular contact with her. Her sister based her decision on Loretta’s best interest, in conjunction with her knowledge of Loretta’s wishes and life goals and the

potential burdens of aggressive treatment. Contrast this with Robert's situation, where his niece based her decision on what she perceived was his quality of life.

In our examples, the person couldn't express his or her wishes or exercise the right of autonomy. In Loretta's case, it fell on the shoulders of her sister to decide what was important to Loretta, and maintain her wishes, life-style and comfort. Care was provided that ensured her interests were protected and she did not unduly suffer. In Robert's case, it was the court that intervened and found that care should be provided. He was eventually able to recover sufficiently to return to his home and enjoy his daily activities. In his case, his interests were protected by the legal system following the provisions of the law.

- F. The physician's role in end of life care and the reconciliation of the biomedical ethical principles with New York State's mandated process.

Under the HCDA in New York State, the physician's role is critical. It is up to the physician to determine whether the person has a terminal condition, is permanently unconscious or has an irreversible condition that life sustaining treatment might remediate. Additionally, the law looks to the physician to determine whether the provision of the treatment would maintain life, or impose an extraordinary burden on the person.

It would be preferable if the physician making these determinations has been involved with the person and has knowledge and insight into the person's

needs and disabilities, as well as the anticipated trajectory of the person's condition. Loretta's physician recognized his duty to her, as well as his responsibility to safely plan for her care. While her sister made the decision for hospice in the first instance, the physician then made his decisions as they related to Loretta's interests, not her sister's. He was familiar with the mandated medico-legal standards and took advantage of the MOLST planning process and forms to assist in formulating a plan of care. He also felt it appropriate to enlist the help of the neurologist who was familiar with Loretta to ensure she was receiving consistent care from providers who were familiar with her. Together, with Loretta's sister, they were able to put a hospice plan of care in place.

Unfortunately, that is not usually the case. All too often, the decision is made in the hospital, by physicians who have only had recent contact with the person, when the person may, or may not, be in a critical state. In Robert's case, there were several physicians involved, each having a different foundation for their recommendations regarding treatment. Some felt it was an easy decision to withhold nutritional support and discharge him home with hospice care. Others felt it appropriate to provide nutritional support to see what recovery he was able to make. Artificial nutrition and hydration would sustain Robert's life. His medical condition was otherwise stable. One physician felt he had an ethical duty to argue for what he considered was in Robert's best interest. In contrast,

Robert's house staff felt he should get the necessary care to give him an opportunity to regain functioning after the acute event, if at all possible. Both of these competing positions are reasonable. By reconciling the decision with the medico-legal standard of decision making, rather than the personalized best interest standard of decision making, a reasoned result can be reached which protects Robert's (and the physicians') interests.

On a day to day basis, the physician is expected to preserve and acknowledge a patient's right to autonomy. The decision making standards most often used include: express interests, substituted judgment, best interest, and the medico-legal standard. Often these standards are couched in terms of "ethical principles" by which the physician renders a decision. Treatment decisions when the patient's wishes aren't clearly known are difficult for all concerned, and yet, are even further complicated by the personal perspectives and attitudes of the involved parties.

The AMA Code of Ethics, in opinion 8.081 - Surrogate Decision Making, sets forth applicable surrogate decision making standards. The first is the patient themselves if they have capacity to make a decision. If the patient does not have the capacity to make a decision, the opinion directs the physician to State law- the medico-legal standard. This is clear recognition that there are differences in state law that must be followed, whether through court order or

other processes. It is this medico-legal standard that should be a part of the discussion when considering decision making standards.

The ethics opinion tries to maintain respect of the person, looking at the decision making process through the eyes of the patient, what is important to the patient, and the quality of the patient's life, as determined by the patient, not as to their perceived social worth. If properly implemented, without regard to perceived social worth, and the burdens of the proposed treatment considered, beneficence should take precedence and there should be no issue of undue harm to the patient.

G. Varying degrees of disability and the HCDA

The HCDA does not differentiate those who may have some modicum of capacity from those who are profoundly impaired. Even so, there should be some recognition that some people with developmental disabilities have the capacity to make some decisions. Some people can express their wishes as to treatment without understanding all of the intricacies of a complicated medical procedure. These wishes may best be effectuated by the execution of health care directives. When properly executed, the health care agent can make health care decisions for those with developmental disabilities in accordance with the Public Health Law. (PHL § 29-C) If a person with developmental disabilities is unable to execute a health care directive, or does not have someone close they

trust to be a health care agent, then the HCDA will apply.

Different theories of how to best recognize the wishes of the person with developmental disabilities and who is the best surrogate have been the subject of much debate. It has been argued that different types of guardians can best recognize the wishes of the person. Eric Miller tries to distinguish “weak guardian” from “strong guardian” and how they may affect the rights of the person. (Miller 2006) This idea is intriguing; however, it makes recognition of the rights of a person with developmental disabilities dependent on their guardian and therefore, unsustainable.

The HCDA does provide some guidance to the surrogate by incorporating the language regarding a person's known wishes, including moral and religious beliefs, and factoring that into the decision making process. This language is personal to the patient and should be recognized and acknowledged by the surrogate. When it is not, however, there should be additional safeguards to ensure that there are sufficient protections for the person.

New York State currently has two different guardianship laws. This discussion has revolved around the one that applies to the developmentally disabled, SCPA Article 17A. It is simpler and less expensive to obtain. It can grant a guardian the ability to make all decisions, including medical decisions, for the ward. There is no consideration in the law for different levels of functioning.

The other guardianship law, Mental Hygiene Law Art 81, is typically used for people who have specific functional limitations. It is often used for those who have lost some capacity due to an accident or infirmity. Under this law, the guardianship order is to be specifically crafted to be the least restrictive intervention to prevent harm.

Advocates have been vocal in calling for reconciliation of the guardianship statutes in New York, including allowing people with developmental disabilities greater tailoring of orders and maintenance of their rights. (Bailey and Nick-Torok 2011/2012) The courts have addressed the differences in the statutes, reviewing the history and conflict and how the legislature has yet to address the inequities of the two laws. (Matter of Mark C.H., 28 Misc.3d 765 (NY County 2010); Matter of Chaim A.K., 26 Misc 3d 837 (NY County 2009))

An appellate court recently addressed this issue and found that an order appointing a guardian for the person with developmental disabilities under the SCPA could allow for specific provisions relating to the guardianship, if it was shown to be in the best interest of the person. In the Matter of Kevin Z., 2013 NYSlipOp 02788 (App.Div., 3d Dept) This decision has not been tested, and it remains to be seen how it will be applied in the lower courts.

While additional rights built into the statute and the tailoring of orders to address specific functional deficits could preserve greater protections for people

with developmental disabilities, caution must be used when granting full health care decision making authority to a surrogate. Continued additional oversight should be an imperative to ensure the prevention of future abuses. (Stith 2006) In any event, until the law in this area is settled, the current framework should be carefully applied.

H. What guidance is there for surrogates when contemplating a plan of hospice care for people with developmental disabilities?

No one; physicians, people with developmental disabilities, their advocates, or their families, want treatment that would cause harm. The HCDA was enacted to prevent tragic consequences from the provision of mandatory treatment and enable surrogate's to make decisions they believe best for people with developmental disabilities. The law was crafted to enable some oversight when end of life decisions are made and to ensure that treatment is not prematurely withheld or withdrawn.

The HCDA requires the surrogate to make decisions in the best interest of the person, as so defined in the law. If the provisions of the HCDA are followed, and the medico-legal standard applied, there should be sufficient safeguards to consider the person's wishes and lifestyle as well as the effect of treatment. It is this author's opinion that when all factors are considered, it provides guidance for the surrogate and the medical provider in deciding on an appropriate plan of

care.

X. CONCLUSION

Hospice care for people with developmental disabilities presents some complex issues for surrogates, physicians, caregivers and advocates. When looking at the best interest of the person, his or her wishes should be taken into account as considered by the New York statute. The surrogate may say what he believes to be in the best interest of the person with developmental disabilities, but it is important that the medico-legal standard is carefully followed. If the medico-legal standards are met, a plan of hospice care can be a viable option and implemented, withholding or withdrawing life sustaining treatment as appropriate, and providing appropriate care for the person with developmental disabilities.

NOTES

- i This paper will address surrogate decision making for adults who are developmentally disabled. Surrogate decision making for children with developmental disabilities may have additional considerations.
- ii So stated in the law and will be used in this paper, except when there is no distinction between mental retardation and developmentally disabled, then the more acceptable term "developmentally disabled" will be used.
- iii The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD)
- iv Consumer Advisory Board was established in 1975 under the Consent Decree which settled the Willowbrook class action lawsuit.
- v Mental Hygiene Law Art 80.
- vi Formerly known as Office of Mental Retardation and Developmental Disabilities (OMRDD)
- vii Mental Hygiene Legal Service is an agency authorized by Article 47 of the Mental Hygiene Law to advocate for people in mental health facilities.
- viii The statute allows the following parties to object to a decision to withhold or withdraw life sustaining treatment: the person, the parent or adult sibling of the person, the attending physician, any other health care practitioner providing services to the person, the chief executive officer, the mental hygiene legal service, the commissioner of mental retardation and developmental disabilities. SCPA 1750-b(5)(a)
- ix Legislation is also referred to as Physician Orders for Life Sustaining Treatment (POLST) in other jurisdictions. <http://www.ohsu.edu/polst/>

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