As individuals with developmental disabilities live longer, residential providers are increasingly finding themselves in the position of providing services to medically frail, older individuals. In that context, a cooperative effort between hospice providers and providers of care for individuals with developmental disabilities is becoming increasingly common. However, there are significant issues faced by both providers when they attempt to jointly provide care.

Pursuant to a grant provided by the New York State Developmental Disabilities Planning Council in collaboration with the Hospice and Palliative Care Association of New York State, NYSARC Inc., the Center for Excellence in Aging Services at the State University of New York at Albany, and the Office of Mental Retardation and Developmental Disabilities of New York State (OMRDD), a curriculum was developed and a training program provided during the period from September 1, 2005, through February 28, 2007, for hospice and developmental disability workers throughout the state of New York.

Making healthcare decisions for individuals who may lack the mental capacity to make decisions for themselves raises serious legal and ethical considerations. In general, these considerations include determining the capacity of individuals to make decisions for themselves, consideration for the extreme nature of depriving individuals of the right to make a decision for themselves, and determining what principles should guide surrogate decision makers. When those healthcare decisions revolve around the provision of care at the “end of life” and the possible withdrawal or withholding of life sustaining treatment, such decisions (and the guidelines both legal and ethical which surround them) become extremely important and consequential.

For several years self-advocates, the advocacy community, and providers of services for individuals with developmental disabilities including mental retardation, have struggled with these issues. Most significantly, they have struggled with New York case law which severely limits the ability of surrogate decision makers, most frequently family members, to make humane end of life care decisions for an individual who lacks the capacity to make those decisions for him or herself. The effort to address that situation culminated in the passage of the Healthcare Decisions Act for Persons with Mental Retardation effective March, 2003. The impact of that statute will be discussed below in the context of efforts to address end of life care for individuals with developmental disabilities.

A discussion of healthcare decision-making for individuals with developmental disabilities must begin with principles well established in New York State law. Relevant government memoranda and regulations, as well as case law and statute, give foundation to the legal principle that incapacitated persons have the right to make their own medical care decisions. This principle is expressed in decisions handed down by the highest court in New York State, the New York State Court of Appeals, and statutes enacted by

(Continued on page 2)
the New York State Legislature. As early as 1914, the New York State Court of Appeals, in the decision of Schloendorff v. Society of New York Hospital, 211 N.Y. 125, 105 N.E. 92 [1914], provided that physicians who treat individuals without their consent may be guilty of an assault. Public Health Law, Section 2504, provides that individuals may give consent for themselves for medical, dental or hospital care. Thus, under New York State law individuals have the right to make healthcare decisions, including decisions regarding life sustaining treatment, for themselves so long as they have the capacity to make such a decision.

The determination of that capacity most often rests upon a fairly understandable and "common sense" approach. Capacity is the ability to understand and appreciate the nature and consequences of the proposed treatment and the ability to understand and appreciate the benefits and significant risks of the proposed treatment. Capacity does not rest upon the actual decision itself. Individuals who have the ability to meet the above tests can make decisions which others would consider inappropriate or ill-advised. Each of us, assuming we have the capacity to understand and appreciate what is being proposed and its benefits and significant risks, has the right to make idiosyncratic decisions which others would disagree with. The determination of capacity rests upon the process rather than the outcome of the decision.

The second element that goes into medical care decision making by a capacitated individual is that of the ability to give informed consent. The ability to understand a procedure would not validate consent to that procedure unless the consent was "informed". In order to give informed consent the individual must have a full explanation of the proposed procedure, description of any discomforts and risks, description of any benefits, disclosure of alternative procedures, knowledge that he or she is free to withdraw consent at any time and that he or she is exercising the consent in a truly voluntary manner. It is important in reviewing consent from both a legal and ethical perspective that the above precepts of both capacity and that the consent was informed and voluntary are met. Securing consent from an individual who either lacks capacity or whose consent was given without being "informed" would not only raise ethical issues for the medical care provider but would also raise considerable legal issues.

The issue of capacity and informed consent must be addressed in the context of all medical care decision making, but particularly where it relates to end of life care and the acceptance of hospice services. The question which must be addressed, where the individual lacks the capacity to give informed consent, is who has legal authorization to give consent and is he or she authorized to consent to the withdrawal or withholding of life sustaining treatment, including the possible ramifications of enrolling in hospice care.

In reviewing alternative decision making structures, and their authorities, the caregiver in New York State should look to public health law, statutes governing care in an emergency, Article 80 of the Mental Hygiene Law Surrogate Decision Making Committees, OMRDD (New York State Office of Mental Retardation and Developmental Disabilities) regulations, the DNR statute (Do Not Resuscitate), the Healthcare Proxy statute and guardianship. Before looking to these surrogate decision makers to make healthcare decisions, including end of life and hospice care decisions, it is important to understand the framework within the state law that guides those decisions. In New York State the surrogate decision maker is expected to first look for an individual's previously expressed decision or expression of direction concerning the proposed procedure or denial of same made when the individual had capacity. That type of guidance from the individual may be available for individuals who suffer from a variety of mental illnesses, Alzheimer's disease, etc. Seldom, although not always, is a previously expressed capacitated decision available for an individual with a developmental disability, particularly mental retardation, which has existed since minority. In such cases, the surrogate decision maker is directed to look for the person's "best interests." New York State uses the "best interest" standard as the standard by which the surrogate decision maker determines how to make decisions on behalf of an incapacitated person. The surrogate decision maker is not permitted to insert his/her idiosyncratic ideas about what he or she would do under the circumstances. The fact that the surrogate decision maker might decline life sustaining treatment in a particular set of circumstances and enroll in a hospice program is not the guide in New York State.

The "best interest" test does not regularly raise significant ethical/legal issues when applied to routine medical care. It becomes most difficult when applied to the withdrawing or withholding of end of life care. In a series of cases New York State has defined the "best interest" of an individual in such cases in holding that "clear and convincing evidence" of contrary wishes, the surrogate must act to maintain life. The maintenance of life is in the "best interest" of the individual because to do otherwise would be irrevocable. This principle was laid down by the court in New York in 1981 in the case of In re Storer, 32 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64 [1981] and In re Eichner, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.464 [1981]. In

(Continued on page 6)
Lecture Series on Disability and Distributive Justice

Avi Craimer

The Joint Bioethics Colloquium is a lecture series hosted by the National Institutes of Health, Georgetown University, Johns Hopkins University, and University of Maryland. The most recent topic of the series was disability, and the focus was on disability and distributive justice. Distributive justice is the area of ethics which deals with scarce resource distribution. The lecture series explored the special problems that disability raises for theories of distributive justice.

Assessing Welfare of People with Disabilities

In the first lecture, David Wasserman, a research scholar at the Institute for Philosophy and Public Policy of the University of Maryland, presented a very helpful introduction to the philosophy of disability. He focused on the question of assessing the welfare of people with disabilities. He argued that there is often a bias towards viewing the lives of people with disabilities as less flourishing. People without disabilities tend to assess what it would be like to have a disability from their own point of view by imagining what it would be like suddenly to lose certain abilities that they now take for granted. In contrast, people with disabilities usually do not experience themselves as existing in a diminished state relative to some non-disabled norm.

Wasserman applied these ideas by suggesting a modification to the methods used in assessing disability compensation packages. The standard method is to survey people without disabilities about the relative harm they believe they would suffer by acquiring various disabilities. Wasserman argued that this method is morally offensive to people with disabilities because its underlying rationale is that the value judgments of people without disabilities are more reliable than the value judgments of those with the disability in question. Nevertheless, it would be unjust to deny needed financial assistance to people with disabilities on the grounds that those people do not experience their disabilities negatively. Wasserman suggested an alternative method for assessing disability compensation which seeks to avoid relying on the perceived or experienced harm or benefit of the disability entirely. Instead, his method bases compensation upon the added financial burden of living with a disability.

A Defense of the Utilitarian Theory of Distributive Justice

The second lecture was delivered by Mark Stein, adjunct assistant professor in the Department of Political Science at the University of Missouri and author of Distributive Justice and Disability from Yale University Press. He attempted to defend a utilitarian theory of distributive justice against the challenge that such theories cannot adequately account for justice towards people with disabilities. The utilitarian theory of distributive justice says that the just distribution of resources is one in which resources are distributed in such a way as to maximize total welfare. Stein sought to address the objection that such a theory will lead to systematic discrimination against people with disabilities. The thinking behind this objection is that since it requires a greater expenditure of resources to enable people with disabilities to achieve a given level of welfare than is required to enable a comparable level of welfare for people without disabilities, the utilitarian theory will always tell us to give resources to those without disabilities. Therefore, the objection concludes, the utilitarian theory of justice fails because it is intuitively obvious that wholesale discrimination against people with disabilities is unjust.

Stein argued that, in practice, the utilitarian theory of justice will not lead to objectionable discrimination against people with disabilities. He argued that in an affluent society like ours, most people without disabilities are already at a point where allocating additional resources to them impacts their welfare very little. In contrast, people with disabilities can benefit enormously from additional resource expenditure. So although it does require greater total resources to enable an equal level of welfare for a person with disabilities, nevertheless, given our opportunities to improve upon the existing state of affairs, we should still allocate the needed resources to enabling people with disabilities to achieve higher levels of welfare.

Stein's view does have some controversial implications. One example,

(Continued on page 4)
could be provided with an adequate education. Therefore, Stein concluded, prioritizing children without disabilities over those with disabilities is not morally objectionable when the children without disabilities can genuinely benefit more from available resources. This conclusion supports the utilitarian theory against the charge of discrimination by showing that prioritizing people without disabilities is not always morally objectionable in cases where more benefit could be achieved through such prioritization.

However, during the question period a member of the audience raised another case which seemed to reveal a major flaw in Stein’s position. The questioner said that studies have shown that white women benefit more, on average, from breast cancer treatment than black women, even once confounding variables such as quality of care and socio-economic status have been taken into account. If this empirical premise is true, then wherever breast cancer treatment is scarce, the utilitarian theory implies that white women should receive priority for breast cancer treatment over black women.

Stein responded by arguing that a racially discriminatory policy would not, in fact, produce the most overall welfare because such a policy would be harmful in virtue of being perceived as racist. Another audience member objected that according to Stein’s response, utilitarianism only gives the intuitively correct moral answer because people in our society believe that racial discrimination in such cases would be morally wrong. Yet, according to utilitarianism, these beliefs are either unjustified or self-fulfilling, so utilitarianism would advocate racial discrimination if people did not already believe that racial discrimination in such cases was morally wrong. In conversation with Stein later, he agreed that utilitarianism would advocate racial discrimination in such cases. This implication is a serious problem with the theory as it stands.

**The utilitarian theory of distributive justice says that the just distribution of resources is one in which resources are distributed in such a way as to maximize total welfare.**

**Intellectual Disabilities and Liberal Theories of Justice**

The third lecture by Leslie Francis, a philosopher in the College of Law at the University of Utah, focused on the problems that people with lifelong intellectual disabilities raise for liberal theories of justice. Liberal theories of justice are based on the idea of rational negotiators deciding on social policies that can be justified to every member of the community. However, people with lifelong intellectual disabilities may neither be able to function as rational negotiators nor be capable of understanding the justifications offered by others. For example, in John Rawls’ well known version of the liberal theory of justice, members of the community must enter into negotiations behind what he calls a “veil of ignorance,” an imaginary state that prevents the negotiators from knowing to what social group they belong. However, as Francis pointed out, people with lifelong intellectual disabilities cannot be conceptualized as being among those behind the veil of ignorance because unlike having a race, gender, or religion, there is no way that a rational negotiator could be ignorant of having or not having a lifelong intellectual disability. Lacking such a disability is a requirement of being able to function as a rational negotiator.

If people with lifelong intellectual disabilities are excluded from negotiations behind the veil of ignorance, then their interests cannot be taken into account in the Rawlsian theory of justice and an analogous problem arises with other variations on the liberal theory. Francis went on to briefly sketch her own solution to this problem, which involved replacing Rawls’ concept of bargaining over rules of justice with the concept of developing rules in the context of trusting relationships. This suggestion was intriguing but not sufficiently developed in her lecture for a full evaluation of its merits.

**Reciprocity and Rehabilitation**

Lawrence Becker, Kenan Professor in the Humanities and Professor of Philosophy Emeritus, College of William and Mary, and President of the Board of Directors of Post-Polio Health International, gave the fourth and final lecture. He focused on challenging the assumption that people with disabilities are incapable of full reciprocity in the moral community. First, he noted that the ideal of reciprocity is not an ideal of equal exchange. Rather, reciprocity is based upon each person contributing to the community in a manner that is accepted by the community as appropriate for the person.

... reciprocity is based upon each person contributing to the community in a manner that is accepted by the community as appropriate for the person.

CRAIMER (Continued from page 4)

Becker also emphasized that in order for persons with disabilities to be capable of reciprocating, they must have sufficient agency. He described his own experience of suffering physical disability as a result of polio. He explained that only after intensive long-term rehabilitation was he able to regain a large measure of agency. Therefore, Becker argued, the contemporary movement away from long-term intensive rehabilitation towards a focus on restoring health narrowly construed is problematic because this reduces the chances of the person regaining agency and could prevent them from becoming a reciprocator.

During the question period it was noted that Becker’s focus on the restoration of previously existing agency restricts the scope of his argument to people who acquire a disability after having already developed some level of autonomy. In addition, several members of the audience objected that if reciprocity is thought to be the basis of justice, as Becker seemed to presuppose, then those with severe disabilities will fall outside the protection of justice regardless of the efforts made towards their rehabilitation. Becker responded that such cases were extremely rare compared to cases where restoration of agency is possible given a sufficient investment in rehabilitation. So while Becker’s position does not provide an answer to the question of whether justice should extend to those who are permanently incapable of significant agency, it does help to bring many more people under the umbrella of a reciprocity-based theory of justice.

Overall, the four speakers represented a broad spectrum of views about distributive justice and disabilities and each presented his or her arguments with clarity and insight. In addition, the lectures were enhanced by lively debate among the many eminent Washington and Baltimore scholars who attended.

Avi Craimer is a Ph.D. candidate in philosophy at Georgetown University with a concentration in bioethics.

Transplant Surgeon Charged in Organ Procurement Case

Physician, Hootan Roozrokh, has been charged with the hastening the death of a patient in order to procure his organs for transplant. In news reported on July 30, 2007, the physician was accused by San Luis Obispo County, California, prosecutors with administering drugs to 26-year-old Ruben Navarro, who had suffered from adrenoleukodystrophy, a genetic, neurological disorder that had left him mentally and physically impaired and weighing 80 pounds. News reports indicated that, after suffering a cardiac and respiratory arrest, he was left severely brain-damaged, his family had given permission for removal of life-support and organ procurement. The exact details of the permission are in dispute. Dr. Roozrokh is accused of giving 200 milligrams of morphine and 80 milligrams of the sedative Ativan and being in violation of laws prohibiting transplant surgeons being involved in clinical care of patients prior to their death.

District of Columbia Hospital Faces Lawsuit

St. Elizabeth’s Hospital, the facility that provides services for persons with mental illness and mental disability in the District of Columbia, has been sued by a civil rights organization that claims it continues to have an inadequate number of psychiatrists, psychologists, and nurses, and unsanitary conditions. The group, University Legal Services, which serves as a federally mandated advocate for the disabled in the District, claims that court action is needed after three patient deaths. The most recent was the death of 39-year-old Mark Harris who suffered a cardiac arrest after being restrained during an altercation. Previous legal actions and promises to improve staffing have not resolved problems stemming from underfunding of the facility.
End of Life Healthcare . . . The New York Policies

Faulkner (Continued from page 2)

In re Eichner, the court held that since Brother Fox had provided “clear and convincing evidence,” in the form of previous conversations, that he did not want to be kept alive by artificial means, it would be appropriate for a surrogate to decline such treatment on his behalf. On the other hand, John Storer, who was developmentally disabled, never had the capacity to make a healthcare decision and was thus unable to leave “clear and convincing evidence” of his wishes. Therefore, acting in his best interest, the surrogate had no authority to decline life sustaining treatment even if its effect was only to prolong an agonizing death. These principles were reiterated by the court in a later series of cases including the case of In re Westchester County Medical Center ex rel. O'Connor, 72 N.Y.2d 517, 534 N.Y.S.2d 886,531 N.E.2d 607 (1988).

The status of the law in New York State therefore, with one major exception discussed below, places the surrogate decision maker in an extremely difficult ethical position when it comes to withholding or withdrawing life sustaining treatment...

Therefore, for example, spouses faced with the decision to withdraw or withhold life sustaining treatment for their loved ones who have not exercised a healthcare proxy would be unable to withdraw or withhold such treatment unless they established “clear and convincing” evidence of the spouse’s wishes. This would be in spite of the fact that from an ethical perspective the individual might feel their spouse would have declined such treatment on their own behalf, should they have been able to do so.

In an emergency, where the effort to obtain informed consent would be injurious to the individual’s health, medical, dental, health and hospital services may be provided without such consent. See Public Health Law 2504.4 and OMRDD regulations at 14 NYCRR 633.11(1)(ii). This law and the regulations cover only the provision of care, not the declining of care.

Mental Hygiene Law Article 80 provides for the creation of Surrogate Decision Making Committees. These committees, under the jurisdiction of the Commission on Quality of Care and Advocate for the Disabled, are authorized to make healthcare decisions for individuals who are residents of programs operated or licensed by the Department of Mental Hygiene, including the Office of Mental Retardation and Developmental Disabilities. Panels authorized by the statute review and meet with the individual and professionals proposing treatment for the individual and consider whether or not the individual has capacity to make his or her own care decision. If that person does, then the panel will defer to the individual’s decision. Assuming the individuals lack the capacity to make informed healthcare decisions, the panel will consider whether or not there is anyone who is authorized to make healthcare decisions for them. If the individual lacks capacity and there is no other individual authorized to make care decisions for them, then the surrogate decision making committee will consider whether or not the proposed healthcare is in the individual’s “best interest”. The panel, in considering best interest, is limited by the previous discussion of how New York State law has determined best interest. Therefore, the surrogate decision making committees are not authorized to withdraw or withhold life sustaining treatment. They cannot take into consideration the ethical/humane issues that others might wish them to consider.

There are several regulations in New York State, 14 NYCRR 633.11, which give guidelines for OMRDD officials to make healthcare decisions. However, none of these impact upon end of life care decisions and they do not extend decision making authority to make decisions to withdraw or withhold life sustaining treatment or remain in a hospice when such decisions become critical. In addition, the regulations govern OMRDD (Office of Mental Retardation and Developmental Disabilities) programs and not necessarily physicians and/or hospitals.

New York State’s Do Not Resuscitate statute (passed in 1988) provides authorization, under a limited set of circumstances, for surrogates to make the decision to decline cardiopulmonary resuscitation. It does not apply to other forms of life sustaining treatment such as artificial nutrition and hydration, artificial antibiotics, etc. The Do Not (Continued on next page)
End of Life Healthcare . . . The New York Policies

FAULKNER (Continued from page 6)

Resuscitate statute only applies in critical situations where the individual is in a state of cardiopulmonary arrest. Under such circumstances and when the individual is considered to be terminal and permanently unconscious, resuscitation would be medical futile, or resuscitation would impose an extraordinary burden, a surrogate — and, in one limited case, two physicians — can make the decision to decline cardiopulmonary resuscitation. Those surrogates are closely defined in the statute. However, the ability of those surrogates to make such a decision is closely confined by the individual having to have one of the four above described medical conditions and their declination will only apply to cardiopulmonary resuscitation if the individual in fact suffers cardiopulmonary arrest.

Those guardians are to be guided by a decision-making standard as to what is in the “best interest” of the individual.

Keeping in mind the earlier discussion of the authority of an individual with capacity to make healthcare decisions for themselves and legal recognition of the fact, even where end of life care is being considered, that that authority should be respected if the individual, while having capacity, expressed an opinion concerning end of life care, New York State passed a Healthcare Proxy Statute in 1990. That statute provides that individuals may provide direction and appoint a surrogate (a healthcare agent) to make healthcare decisions, including the withholding and withdrawal of life sustaining treatment and enrollment in hospice care, should they lose capacity.

New York State currently has two guardianship statutes. Article 81 of the Mental Hygiene Law, Guardianship, passed in 1993 and Article 17A of the Surrogate’s Court Procedure Act, Guardians of Persons with Mental Retardation and Developmental Disabilities, originally adopted in 1968. Article 81 of the Mental Hygiene Law provides for the appointment of guardians for individuals who lack capacity to make decisions for themselves for any reason. It is not limited to any particular medical diagnosis and, in fact, medical diagnosis is not central to the appointment. Rather, the individual’s ability to make actual decisions in daily life is what the court is charged with considering. Article 80 specifically says that it does not impact upon previously held legal rulings concerning end of life care. Therefore, guardians appointed pursuant to this statute must be guided by the principles discussed above.

Article 17A of the Surrogate’s Court Procedure Act, which only applies to the appointment of guardians for individuals with mental retardation or other developmental disabilities, was significantly amended in 2003 to give such guardians the authority to make end of life care decisions. Since individuals who have mental retardation, and in many cases other developmental disabilities, never had the capacity to leave a previously expressed opinion through the execution of a healthcare proxy, the argument in support of its passage was made that to not provide some mechanism for dignity at the end of life for such individuals would be discriminatory. The Healthcare Decisions Act for Persons with Mental Retardation, later amended to include other persons with developmental disabilities, provides that guardians appointed, unless specifically excluded in the order, are presumed to have the authority to make healthcare decisions. Those guardians are to be guided by a decision-making standard as to what is in the “best interest” of the individual. The legal basis of that decision, as discussed in the statute, should be the dignity and uniqueness of each individual, the preservation, improvement, or restoration of the individual’s health, the relief of suffering or pain, and the unique nature of artificial nutrition and hydration.

When the withdrawal or withholding of life sustaining treatment is being considered, in addition to the above considerations, the individual must have a terminal condition or be permanently unconscious, or have a condition that is irreversible and life sustaining treatment would impose an extraordinary burden in light of the medical condition and expected outcome. In the case of the withdrawal or withholding of nutrition or hydration, in addition to the above, there must be no hope of maintaining life or such treatment would impose an extraordinary burden on the individual. The statute provides a variety of notices and safeguards relating to such a decision.

The statute was further amended in the spring of 2007 to extend the authority to withhold or withdraw life sustaining treatment to involved family members . . . where such persons have not become guardians.

Seldom are law and ethics so closely related as when concerning medical care decision making in general and end of life care in particular. The Healthcare Decisions Act for Individuals with Mental Retardation and Developmental Disabilities, in emphasizing consideration for the “uniqueness and dignity” of each individual, and the relief of suffering and pain is clearly attempting to provide an ethical framework for the decision maker. When engaged in considering end of life.

(Continued on page 8)
End of Life Healthcare

... The New York Policies

FAULKNER (Continued from page 7)

care decisions that framework is enhanced by asking the surrogate decision maker to consider whether or not continued treatment would impose an extraordinary burden upon the individual. In reviewing the parameters, both legal and ethical, of providing or declining aggressive end-of-life treatment, including artificial nutrition and hydration, and enrolling an individual who lacks capacity to make healthcare decisions for themselves in hospice care, the legal and ethical parameters become blurred. It would appear that wherever the law has attempted to confront these issues, it has made its determinations based upon “ethical” considerations. Whether or not those considerations are universally accepted is another issue.

In drafting the Healthcare Decisions Act for Persons with Mental Retardation, the drafters, including this author and NYSARC Inc. (formerly The New York State Association for Retarded Children), attempted to provide an ethical framework within the law to guide surrogate decision makers faced with making humane decisions when it came to the withholding or withdrawing of end of life care for individuals who could never express their personal opinion in advance. The next issue of the Newsletter will review the organization, operation and content of the programs provided jointly to workers from providers of hospice services and residential programs for persons with developmental disabilities.

Bibliography

Harriet Hutson Gray

These books and articles have been added recently to the collections of the National Reference Center for Bioethics Literature (NRCBL). Similar citations may be found online by searching the ETHXWeb database at http://bioethics.georgetown.edu.

Khoshnood, Babak; De Vigan, Catherine; Vodovar, Véronique; Bréart, Gérard; Goffinet, François; and Blondel, Béatrice. Advances in medical technology and creation of disparities: the case of Down Syndrome. American Journal of Public Health 2006 December; 96(12): 2139-2144.

Lawrence R. Faulkner is the General Counsel and Director of Quality Assurance at Westchester ARC. Prior to this position, he was the Deputy General Counsel for the New York State Office of Mental Retardation and Developmental Disabilities.