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The District of Columbia Amends its Health-Care Decisions Act: Bioethics Committees in the Arena of Public Policy

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CASE 1: MR. B

Mr. B, a 30-something-year-old man, fell down a ladder and incurred severe head injuries that left him comatose and dependent on a respirator. His roommate of several years noted that Mr. B never was the sort of man to organize his papers, and that Mr. B had never executed a durable power of attorney for healthcare, despite frequently stating his intention to do so. Yet, the roommate had heard Mr. B say that he never would wish to be kept alive if he lacked cognition. Another friend affirmed this. Neither the roommate nor the friend had legal standing to authorize a do-not-resuscitate (DNR) order in the District of Columbia. Both were sufficiently uncomfortable with an initial court appearance to request guardianship that they were reluctant to continue the process.

The ethics committee met with them both, and considered them to be reasonable surrogates for the patient. Nevertheless, the hospital, under existing statutes, could not accept their DNR request without judicial authorization, which required further court appearances; both the friend and the roommate declined to participate.

CASE 2: MRS. G

Mrs. G had been widowed for 20 years. For 10 years, she lived with Mr. R, who had grown children and grandchildren. Because of concerns regarding the disposition of their individual estates, as well as their current Social Security income, Mrs. G and Mr. R never married, and they never executed advance directives. When Mrs. G suffered a devastating stroke, Mr. R stayed with her day and night in the hospital. He noted that he and Mrs. G often talked of death, as they were both in their mid-80s, and he pleaded with the physicians to adopt a "comfort care only" approach. However, Mr. R had no legal standing to participate in such decisions. Mrs. G was childless; her only living relative was an 88-year-old

sister who had not seen Mrs. G for several years. Nevertheless, the sister came to the hospital and insisted on aggressive care, based on her personal religious views. (She admitted that her sister might very well not have agreed with her.) The medical staff felt, nevertheless, that they had to accept the sister as a decision maker, given the law in the District of Columbia.

The cases of Mr. B and Mrs. G illustrate situations that repeatedly challenged and frustrated clinicians and ethics committees in the District of Columbia until the spring of 2003. In June 2003, however, the District of Columbia amended its Health-Care Decisions Act in two significant ways. First, the list of statutorily recognized surrogate decision makers was expanded to include "domestic partners" and "close friends." Second, the amendment made the hierarchy of statutorily recognized surrogate decision makers flexible, to account for the possibility that a person lower in the hierarchy might serve the patients' interests better than someone of higher rank. The authors — with the support and participation of fellow members of the Ethics Committee of the George Washington (GW) University Hospital — conceived of and proposed the amendment to the chair of the Judiciary Committee of the D.C. City Council, who introduced the legislation and shepherded it to enactment.

In the following article, the authors not only report the substance of the new law, but also describe how the change occurred. We do so in the hope that readers from jurisdictions with similarly problematic statutes will draw guidance and inspiration from our experience in the District of Columbia. We also believe that our experience reflects the important role that clinical ethics committees can and should play in shaping public policy that affects issues within their realm.

D.C. LAW PRIOR TO JUNE 2003

The D.C. Law, as it existed prior to June 2003, posed two major problems for hospitals and ethics committees. The list of authorized decision makers did not adequately account for the range of common and important social relationships. Second, the hierarchy was inflexible, presuming an unfailing relationship between rank in the hierarchy and appropriate knowledge and emotional ties to make surrogate decisions. At minimum, these two characteristics of the statute assumed that any alternative arrangements should and could appropriately be managed by the judiciary. We will discuss each issue separately below.

AUTHORIZED DECISION MAKERS

Prior to the amendment, the D.C. Health-Care Decisions Act[1] recognized the following hierarchy of potential surrogates for an adult patient who lacks capacity to make healthcare decisions and who had not designated a surrogate in an advance directive:

- Spouse,
- Adult child,
- Parent,
- Sibling,
- Religious superior if the patient is a member of a religious order or a diocesan priest,
- Nearest living relative.

This arrangement, common to similar acts in other jurisdictions,[2] posed problems familiar to many urban ethics committees. First, the act was blind to domestic arrangements that have become increasingly prevalent in our society. Second, it failed to acknowledge the potentially critical role of friends as surrogate decision makers for those not involved in a partnership. As a result of these inadequacies, hospitals and their ethics committees found themselves either having to go to court with unacceptable frequency, or having to quietly ignore the law. These unpalatable alternatives prompted the GW Hospital Ethics Committee to seek changes in the statutory hierarchy of potential surrogates.

ALTERNATIVE DOMESTIC RELATIONSHIPS

In the last half century, the prevalence of unconventional households has increased dramatically. Although gay and lesbian couples are an obvious example of relationships that are disenfranchised in jurisdictions where gay marriage is not recognized, the challenge extends further. Increasingly, elderly heterosexual couples, for a variety of reasons, elect to live together unmarried. Under the prior D.C. statute, neither a gay man's partner nor an elderly woman's male companion of many years would have been recognized as a legitimate decision maker.

In the case of a gay couple, the hospital was precluded from recognizing a gay patient's domestic partner as a surrogate decision maker in the absence of a properly executed durable power of attorney for healthcare. Furthermore, in order to abide by the statute, the hospital might well have to accept as a surrogate a family member who was troubled by the patient's homosexuality, might not have seen the patient for several years, or might never have discussed the management of serious illness with the patient.

Similarly, in the case of two cohabiting but unmarried adults (for example, an elderly couple for whom marriage would impose a "marriage tax," or perhaps lead to conflict among adult children), neither would be recognized as a potential surrogate for the other. On the other hand, a sibling or adult children who disapproved of the patient's relationship would have qualified under the statute. In either case, if the ethics committee chose to challenge the established hierarchy, the hospital felt compelled to obtain judicial authorization of such a choice — with the potential for additional distress for all involved.

FRIENDS WHO KNOW BETTER

In addition to its blindness to newer household arrangements, the statute failed to include "close friend" as a category of potential surrogate. A single adult patient without family and without active religious affiliation would be without a potential surrogate. Even a very close friend would not have been recognized under the statute. The high rate of divorce and the mobility of the population in the U.S., among other things, increase the probability that a single adult may have friends who know the patient better and care about the patient as much as (or more than) the family members recognized in the existing statutory hierarchy. Absent a formal durable power of attorney, the hospital would effectively be flouting the law whenever it turned to such individuals for guidance in the care of a patient. Worse yet, to have such a close friend acknowledged as a surrogate required the court to appoint the friend as a "guardian" — necessitating frequent court appearances and reevaluations that would, in fact, prove intimidating to many appropriate surrogates.

Clearly, the list of decision makers in the statute needed to be revised to reflect current societal norms.

THE INFLEXIBLE HIERARCHY OF AUTHORIZED DECISION MAKERS

Not only were critical individuals missing from the hierarchy, but the rigidity of the statutory hierarchy posed problems as well. Under the statute, a person higher in the hierarchy had automatic and virtually unchallengeable priority over a potential surrogate of lower rank in the hierarchy. The important concept of appropriate surrogacy based on knowledge of a person's values was supplanted by a formula without attention to the quality of a relationship between the patient and the decision maker. For example, an adult child who had only intermittent contact with a patient for several years might appear at the hospital and insist that treatment be withdrawn because "this is what my father would have wanted." This patient's brother, who had lived nearby and had seen the patient regularly during his illness over the past several years, might appear asking that treatment be continued, because the patient wanted to continue aggressive treatment despite the obvious burdens of treatment. Before the law was changed, a healthcare provider would have been prohibited from (or at least would have had difficulty) abiding by the obviously better informed directive of the sibling, because the adult child would have had unchallengeable priority.

Over a number of years, we sought mechanisms whereby the hierarchy might be made more responsive to our needs without formal change in the law. We consulted outside legal authorities who emphatically

rejected the non-mandatory interpretations we attempted to devise; we researched, but could not find, any legal authority for the proposition that the statute was not mandatory; and, finally, hospital counsel was repeatedly reluctant to interpret the law as anything other than mandatory. If the ethics committee could not achieve internal resolution of such situations, the hospital would have to obtain judicial authorization of decision-making status for the person lower in the hierarchy. The authors believe that the amendment described below significantly reduces the likelihood of having to obtain such authorization.

THE AMENDMENT TO THE D.C. LAW

The amendment remedied the identified problems as follows.

1. INCLUDING "DOMESTIC PARTNER"

The D.C. Health-Care Decisions Act now recognizes a "spouse or domestic partner" as a potential surrogate.[3] "Domestic partner" is defined as "an adult person living with, but not married to, another adult person in a committed, intimate relationship."[4] This is the definition used in the District of Columbia law recognizing the status of domestic partner.[5]

2. INCLUDING "CLOSE FRIEND"

The D.C. Health Care Decisions Act now recognizes a *close friend* of the patient as a potential surrogate, following a religious superior and preceding a nearest living relative in priority.[6] A "close friend" is defined as "any adult who has exhibited significant care and concern for the patient, and has maintained regular contact with the patient so as to be familiar with his or her activities, health, and religious and moral beliefs."[7]

Prior to the amendment, a healthcare provider wishing to obtain and abide by the guidance of a domestic partner or close friend would have been required to seek judicial appointment of that person before relying on that person as a surrogate decision maker for the patient. Resort to court in these situations is an inefficient use of hospital resources, does not improve the quality of the healthcare decision to be made for the patient, and unnecessarily burdens our courts. Now, resort to court in these situations is unnecessary in the District of Columbia.

3. MAKING THE HIERARCHY FLEXIBLE

Under the amendment, the order of priority laid out in the hierarchy simply creates a presumption that may be rebutted "if a person of lower priority is found to have better knowledge of the wishes of the patient, or, if the wishes of the patient are unknown and cannot be ascertained, is better able to demonstrate a good faith belief as to the interests of the patient."[8] For example, if an estranged spouse and a sibling with an ongoing close relationship to the incapacitated patient both appeared at the bed site, now a healthcare provider could treat the close sibling as the surrogate, because the presumption flowing from the estranged spouse's status would be rebutted either by the close sibling's better knowledge of the wishes of the patient or by that sibling's superior ability to demonstrate a good faith belief as to the patient's interests.

The amended law recognizes that a person lower in the hierarchy might be a better surrogate than a person who is higher. The amendment addresses that reality by striking a balance: on the one hand, it is helpful to have a hierarchy of potential surrogates, so that a healthcare provider knows where to begin to look if more than one potential surrogate materializes and there is conflict among those persons; on the other hand, that hierarchy should be flexible, so that a healthcare provider may recognize as a surrogate a person lower in the hierarchy who gives evidence of being a better surrogate, because that person, in the words of the amendment, demonstrates "better knowledge of the wishes of the patient, or, if the wishes of the patient are unknown and cannot be ascertained, is better able to demonstrate a good faith belief as to the interests of the patient."[9]

THE LAW ELSEWHERE

With this amendment, the District of Columbia has joined the ranks of a minority of jurisdictions that include domestic partners and close friends as potential surrogates.

The Uniform Health-Care Decisions Act recognizes as a potential surrogate "an adult who has exhibited special care and concern for the patient, who is familiar with a patient's personal values, and who is reasonably available. . . ."[10] As of 1 July 2004, the District of Columbia and 40 states had adopted, in some form, the provisions of the Uniform Act that recognize potential surrogates in the absence of an advance designation of a surrogate; of those 41 jurisdictions, however, only 18 recognized "close friend" as a category of potential surrogates (see table 1).[11] Of these, only four separately recognized "domestic partner" or its equivalent: Arizona, D.C., Maine (adult in spouse-like relationship), and New Mexico (individual in long-term, spouse-like relationship). Although the "close friend" language in the amendment to the D.C. statute includes a domestic partner, the amendment identifies "domestic partner" separately, enabling "domestic partner" to be included with "spouse" at the top of the hierarchy. The "rebuttable presumption" to the statutory hierarchy is, insofar as the authors can determine, unique. We are unaware of any jurisdiction that has adopted such an approach.

"HOW WE DID IT"

The making of public policy can seem daunting to those who have not participated in the process (and, indeed, to those who have). It need not be. Although our experience undoubtedly was more straightforward and less frustrating than one might have expected, it reinforces the importance of optimism and opportunism in effecting legislative change.

This change began in the spring of 2003 with a chance meeting with D.C. City Councilmember Kathleen Patterson. Councilmember Patterson is (and was) the Chair of the Councils Judiciary Committee, with jurisdiction over the Health-Care Decisions Act. Our ethics committee met with one of her staff, described the problems with the statute, conferred

Table 1
States with Some Form of Uniform Health-Care Decisions Act

State	Recognizes close friend	Recognizes domestic partner or equiv.
Alabama		
Alaska	x	
Arizona	x	x
Arkansas		
California		
Colorado	x	
Connecticut		
Delaware	x	
District of Columbia	x	x
Florida	x	
Georgia		
Hawaii	x	
Idaho		
Illinois	x	
Indiana		
Iowa		
Kentucky		
Louisiana		
Maine	x	x
Maryland	x	
Michigan		
Mississippi	x	
Montana		
Nevada		
New Mexico	x	x
New York	x	
North Carolina		
North Dakota	x	
Ohio		
Oklahoma		
Oregon	x	
South Carolina		
South Dakota		
Tennessee	x	
Texas		
Utah		
Virginia		
Washington		
West Virginia	x	
Wisconsin	x	
Wyoming		

Source: *http://www.abanet.org/aging/HCPA-CHT04.pdf*

about solutions, and then prepared initial drafts of the amendment ultimately enacted. In the meantime, one of the authors (GP) sought and received support from other ethics committees and others in the community. Both authors also prepared extensive written comments outlining the legal and clinical problems remedied by the proposed amendment. In the end, the amendment passed without opposition and took effect 21 June 2003.

AFTER ENACTMENT: MORE TO DO

Although in legal terms the new law "took effect" on 21 June 2003, the new law could have no practical effect until healthcare providers were properly informed. Toward that end, we prepared a brief summary of the law (a "what practitioners need to know" memo) for our hospital's newsletter and adapted that article for dissemination by the D.C. Medical Society. The hospital issued a press release (as did Councilmember Patterson). And the authors ultimately sent notice of the amendment to the American Bar Association Commission on Legal Problems of the Elderly for inclusion in its valuable summary of Health Care Power of Attorney and Combined Advance Directive Legislation.

At the clinical level, the most obvious challenge created by the new legislation will be appropriately defining and including "close friend." The changes made to the D.C. law in fact impose on hospitals and clinicians the sober responsibility for wisely and carefully evaluating those who might meet the criteria for being a "close friend." As a practical matter, our ethics committee believes that we should assist clinicians by interviewing the candidate and that case-management specialists should attempt to corroborate the status of the person through interviews with other friends/family of the patient.

Similarly, the mere fact that the hierarchy is no longer rigid does not imply that it can or should be overridden out of concerns for convenience. Social workers and case managers will still have to make reasonable efforts to identify well-meaning and appropriate family members who might not immediately present themselves when a patient arrives at the hospital's door. Flexibility is also not intended to permit clinicians to pick and choose among potential surrogates for the one most likely to accept and implement the clinician's viewpoint. Flexibility also does not obviate the need to maintain appropriate relationships with the various family and friends who may be concerned about the patient's welfare. As in most cases, increased freedom (in the form of a more inclusive and more flexible legal environment) carries with it the burden to "get it right" at the bedside. This includes not only identifying the best surrogate for the patient, but also ensuring that the healthcare team, including the ethics committee, effectively manages any potential conflict arising from the selection of that surrogate. Thus, ethics committees can serve important roles in ensuring that the spirit as well as the letter of the new Health Care Decisions Act is respected.

THE FOUR MORALS OF THE STORY

Upon reflection, we believe that there are four morals to this story.

MORAL #1: THE EXISTING LAW IS DEFECTIVE IN MOST JURISDICTIONS

We have no doubt that the experiences on the GW Hospital Ethics Committee that prompted us to propose this amendment are not peculiar to the District of Columbia. Healthcare decisions laws in any jurisdiction should recognize domestic partners and close friends as surrogates for adult patients who have not signed advance directives. In the absence of such recognition, healthcare decision making unnecessarily excludes persons who can add to the quality of end-of-life decisions, and may even invite dreaded litigation over the decision-making process.

MORAL #2: POLITICIANS WILL TAKE THESE ISSUES SERIOUSLY

Skepticism about the political process must not obscure an encouraging truth: there are plenty of elected officials who are prepared to make important changes when they are presented with the right issue, the right

supporting arguments, and detailed preparation. In addition, we are aware that our effort to change the law succeeded in no small part by the fact that: (1) everyone involved in the care of a patient is helped by expanding the pool of possible surrogates to include those currently disenfranchised who might be very well situated to speak for a patient who lacks capacity; (2) no one is significantly burdened; and (3) it costs virtually nothing to implement.

MORAL #3: ADVANCE DIRECTIVES CONTINUE TO BE IMPORTANT

Remedying the defects in the D.C. and similar statutes should not detract from the importance of encouraging adults (particularly the elderly and chronically and/or seriously ill) to execute advance directives, and, in particular, to appoint a durable power of attorney in any situation when the issue of who should be the surrogate might be in doubt. Many of the problems the amended D.C. statute seeks to resolve could be avoided altogether were more individuals to complete these documents.

MORAL #4: ETHICS COMMITTEES CAN HELP SHAPE PUBLIC POLICY

By dint of their multidisciplinary nature, clinical ethics committees occupy a special place in the institutions they serve. Into that special place come individual case consultations, hospital policy review, and educational responsibilities. That blend of activities leaves ethics committees well situated to extend their mission into the community that the institution itself serves. When the law or public policy fails to recognize important patient care values, an ethics committee can be a valuable agent for change.

ACKNOWLEDGMENT

The authors acknowledge the significant contributions of their fellow committee members in the development of the proposed amendment that was ultimately enacted.

NOTES

1. *D.C. Code Ann.* §§21-2201 et seq. (2004).
2. The Committee for the National Conference of Commissioners on Uniform State Laws, *Uniform Health-Care Decisions Act,* "Section 5. Decisions by Surrogate," *http://www.law.upenn. edu/bll/ulc/fnact99/1990s/uhcda93.htm.*
3. *D.C. Code* §§21-2210 (2).
4. *D.C. Code* §§ 21-2202 (2A).
5. *D.C. Code* §§ 32-701.
6. *D.C. Code* §§ 21-2210 (5B).
7. *D.C. Code* §§ 21-2202 (1A).
8. *D.C. Code* §§ 21-2210 (f).
9. *D.C. Code* §§ 21-2210 (f).
10. See note 2 above.
11. Idaho's informed consent statute provides that in the case of a never-married minor or mentally incompetent person, any individual representing him/herself to be responsible for the healthcare of the person may be recognized as a surrogate.