HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: HB 1655 w/CS Health Care Advance Directive and Blood-Type Recordation
SPONSOR(S): Homan and others
TIED BILLS: None. **IDEN./SIM. BILLS:** SB 2902 (i)

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR
1) Health Care	20 Y, 0 N w/CS	Bench	Collins
2) Transportation	17 Y, 0 N	Garner	Miller
3) Finance & Tax			
4) Appropriations			
5)			

SUMMARY ANALYSIS

"Advance Directive" means a witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's health care.[1]

The concept of advance directives for health care decision making has been judicially condoned, legislatively promoted and systematically implemented by health care institutions, yet the execution rate of advance directives remains low. Whether a patient has any voice at all in the management of the end-of-life "struggle" may depend on whether an advance directive is available.[2]

In Florida, in order to document a principal's desires concerning life-prolonging procedures, an advance directive needs to be completed. However, no central registry for these advance directives currently exists.

HB 1655 creates an Advance Directive and Blood-Type Registry in which the Department of Highway Safety and Motor Vehicles (DHSMV) distributes and collects advance directives and/or blood type and forwards this information on to the Agency for Health Care Administration (AHCA). AHCA would then maintain the registry to be available 24 hours a day, 7 days a week for hospitals and other parties identified by the agency's rule.

Voluntary participation in this registry requires a $10 administration fee per initial advance directive and/or blood type submitted. Funds received from the fees collected shall be used by AHCA to obtain equipment and software to expand or improve the registry and the organ donor program. Participants of this registry would have a label on their driver's license or identification card signifying their advance directive and blood type.

The bill delegates the program's implementation and requires AHCA to study the process and report its findings and recommendations to the Legislature by January 1, 2005. The bill expands the Organ Donor Registry to encompass the advance directives and blood types. The bill requires the Division of Driver Licenses offices to make forms accessible to the public. It also requires forms to be accessible electronically via the Internet.

HB 1655 creates criminal and civil immunity for a health care provider, health care facility, or any person acting under the direction of a provider or facility, carrying out a health care directive. It creates procedures that allow principals to change or remove their forms from the registry.

The bill requires AHCA to fund the program's implementation. It requires AHCA, subject to DHSMV's concurrence, to develop a continuing education panel to create an end-of-life public education campaign. According to AHCA, $50,000 would be needed to fund the required study of the implementation of the registry. This bill takes effect on September 1, 2005.

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[1] s. 765.101, F.S.
[2] Tara Shewchuk, *Completing Advance Directives for Health Care Decisions: Getting to Yes*, Sept. PSYCHOL. PUB. POL'Y, & L., 703-704 (1998).

FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. DOES THE BILL:

1. Reduce government?	Yes[]	No[X]	N/A[]
2. Lower taxes?	Yes[]	No[X]	N/A[]
3. Expand individual freedom?	Yes[X]	No[]	N/A[]
4. Increase personal responsibility?	Yes[X]	No[]	N/A[]
5. Empower families?	Yes[X]	No[]	N/A[]

For any principle that received a "no" above, please explain:

The creation of an electronic registry to capture health care advance directives and the blood type of those wishing to participate in the registry would expand state government's duties and responsibilities.

A user fee and funds from general revenue are required to fund the registry.

B. EFFECT OF PROPOSED CHANGES:

HB 1655 creates an Advance Directive and Blood Type Registry in which the Department of Highway Safety and Motor Vehicles (DHSMV) is required to encourage and allow customers to voluntarily make a health care advance directive and to voluntarily provide their blood type as part of the identification card and driver's license. The DHSMV then forwards this information on to the Agency for Health Care Administration (AHCA). AHCA would then maintain the registry to be available 24 hours a day, 7 days a week for hospitals and other parties identified by the agency's rule.

Voluntary participation in this registry requires a $10 administration fee per initial advance directive and/or blood type submitted. Funds received from the fees collected shall be used by AHCA to obtain equipment and software to expand or improve the registry and the organ donor program. Participants of this registry would have a label on their driver's license or identification card signifying their advance directive and blood type.

The bill requires AHCA to conduct a study of the implementation of the health care advance directive and blood-type registry and report its findings and recommendations to the Speaker of the House of Representatives and the President of the Senate by January 1, 2005. According to AHCA, the fiscal impact on the agency for FY 2004-2005 would be the estimated cost of the study of $50,000. It would be necessary to complete the study before any fees are collected, according to the agency. Pending the results of the study, AHCA will project a cost for the requirements of the bill to be delivered before the beginning of the 2005/2006 legislative session.

The bill expands the Organ Donor Registry to encompass the advance directives and blood types. The bill requires the Division of Driver Licenses offices to make forms accessible to the public. It also requires forms to be accessible electronically via the Internet.

HB 1655 creates criminal and civil immunity for those health care providers relying on the advance directive and blood type information. It creates procedures that allow principals to change or remove their forms from the registry.

The bill requires AHCA to fund the program's implementation. It requires AHCA, subject to DHSMV's concurrence, to develop a continuing education panel to create an end-of-life public education campaign.

According to AHCA, the effect of this bill cannot be fully analyzed until proper studies can be done to assess issues such as the funding and operation of the database; and the types of disclosures and disclaimers necessary to implement the provisions of this bill.
An individual's advance health care directives can change with personal circumstances. Based on information provided by AHAC, "given the probable difficulty in ensuring a person's most current wishes in this regard, such a registry may offer a false sense of security to both the individual and the health care provider, and may lead to continuing controversy regarding advance care directives. The waiver of privacy rights may also be problematic. Further study is needed regarding the development and implementation of an advance health care directive registry as envisioned by this bill. The deposit of sensitive end-of-life documents in a government-sanctioned registry that can be used by health care providers with impunity raises ethical, moral and legal issues which should be addressed in any study done pursuant to this bill."

PRESENT SITUATION

The United Network for Organ Sharing (UNOS) commissioned the "Advance Directives and Donor Card Effectiveness Survey Report" in June 1997 to "examine the feasibility and legal ramifications of enforcing the wishes of deceased individuals who possess validly signed and witnessed organ donor cards or other forms of advance directives" (Wright, 1998). Results indicated that donation is rarely performed without consent of the next of kin, reflecting hesitancy on the part of the medical community to use donor cards as advance directives. Wary attitudes on the part of the donation community or hospital staff could diminish the effectiveness of even the most rigorous donor registry efforts.

States that provide the option of making a voluntary gift to fund donor awareness and educational programs at the time of driver's license renewal include: Alabama, Colorado, Delaware, Florida, Georgia, Hawaii, Illinois, Indiana, Kentucky, Maryland, Michigan, Missouri, Montana, Nebraska, Nevada, Ohio, Pennsylvania, South Carolina, Tennessee, and Texas. Florida and Missouri have created youth education programs in the secondary school system.

States with legislation that reaffirms a signed license as an advance directive or more specifically protects hospitals, and tissue and eye banks in carrying out individuals' advance directives without further consent include: Colorado, Connecticut, Delaware, Florida, Iowa, Illinois, Maryland, Missouri, Pennsylvania, and Tennessee.

Arkansas, Florida, Georgia, Hawaii, Illinois, Louisiana, Pennsylvania, and Tennessee have passed provisions that ensure 24-hour access to the divisions of motor vehicles' donor registries via a toll-free 800-number number or through the World Wide Web.

The first step in developing a state donor registry is determining where the database is to be housed. Registries may be housed in a division of motor vehicles, a state department of health, the state police, or a managed care organization. Compatibility between the various entities that will utilize the registry must be established as the second step to developing a registry – compatibility both in terms of how the information is stored in the database and the interfacing of hardware and software used to maintain the database. Finally, mechanisms must exist for keeping the database up-to-date, including purging those individuals that pass away or opt out, and entering new individuals that have joined. Florida law allows funds from a procurement trust fund to be allocated towards helping to maintain the state organ donor registry. The state's registry contains images of donor wills and signatures.

Some national databases for health care advance directives do exist. For example, users may contact the North American Registry of Living Wills or the U.S. Living Will Registry through a toll-free telephone number or their Web sites. The U.S. Living Will Registry, based in Westfield, NJ, represents on its website that individuals may register their advance directives and organ donation information with the Registry free of charge, giving the registry permission to fax their document to any health care provider. The Registry provides the individual with labels that may be affixed to their insurance card and driver's license stating that the information is registered. Health care providers need to join the Registry in

order to use the automated retrieval system. Nonmembers can access the Registry but must leave a voice message containing identifying information about their facility and the patient. The document will be transmitted only after the information is confirmed, which may take a day. The Registry says it is funded by health care providers who pay a fee to be able to access the registry's automated system. [3]

The effectiveness of advance directives depends in large part on the ease with which hospital and law enforcement personnel are able to access the databases. Spurred on by the federal Patient Self-Determination Act of 1990, by 1993 all 50 states had enacted some form of legislation to address advance directives. This created more public attention to advance directives; however, in 1998, studies showed that only 20% of patients had executed an advance directive.[4]

FLORIDA ADVANCE DIRECTIVES LAW

Chapter 765, F.S., details the use of advance directives in Florida. Section 765.101, F.S., defines "advance directive" as a witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's health care, and includes, but is not limited to, the designation of a health care surrogate, a living will, or an anatomical gift.

Section 765.404, F.S., stipulates that persons in a persistent vegetative state who do not have an advance directive and for whom there is no evidence indicating what the person would have wanted under the circumstances, life-prolonging procedures may be withheld or withdrawn with the consent of a judicially-appointed guardian or the guardian and the person's attending physician in consultation with the medical ethics committee of the facility. They must conclude that there is no reasonable medical probability for recovery and that withholding or withdrawing life-prolonging procedures is in the best interest of the patient.

Section 765.401, F.S., states that if an incapacitated or developmentally disabled patient has not executed an advance directive, or designated a surrogate to execute an advance directive, health care decisions may be made for the patient by:

1. The judicially appointed guardian of the patient or the guardian advocate of the patient having developmental disability who has been authorized to consent to such treatment;
2. The patient's spouse;
3. An adult child of the patient;
4. A parent of the patient;
5. An adult sibling of the patient;
6. An adult relative of the patient who exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs;
7. A close friend of the patient; or
8. A licensed clinical social worker.

Section 765.401(2), F.S., states that any health care decision made under this part must be based on the proxy's informed consent and on the decision the proxy reasonably believes the patient would have made under the circumstances. Therefore, if a person has a written, signed and witnessed advance directive, then this is an indication of the patient's decision he or she would have made under the circumstances. The advance directive does require two witnesses, but it does not require a notary or specifies who could be a witness.

Currently, each individual who has completed advance health care directive documents keeps these documents or shares them with families or surrogates. They are then used as legal documents to guide

[3] www.uslivingwillregistry.com
[4] Shewchuk, *supra*, at 705-706.

health care providers regarding end-of-life issues. These documents are portable and can be used throughout the health care system (hospitals, nursing homes, hospice, etc.) to make the individual's end-of-life wishes known. There is no centralized location where these documents are deposited. No data relating to an individual's blood type is collected in any centralized location. Presently, in Florida, there is no central database where advance directives and blood-types are maintained and can be accessed by medical providers.

FLORIDA ORGAN DONOR PROGRAM

Currently, the Department of Highway Safety and Motor Vehicles (DHSMV) participates in the Organ Donor Program with AHCA. A $1 voluntary fee on drivers' licenses funds the present organ donor registry. This funding source has continually fallen short of predictions, producing between $100,000 and $200,000 per year in operating funds. The present system is handicapped by out-of-date computer technology that, for example, cannot compensate for problems reading human handwriting on the donor wills. This results in as many as 30 percent of the hand signed donor wills in the system remaining unmatched by automated records at DHSMV.

The DHSMV allows persons to make anatomical gifts as a part of the process of issuing identification cards and issuing and renewing driver licenses. The DHSMV provides an Organ Donor Will to customers to complete and the driver record is updated to reflect the customer has made this designation. An identification card or driver's license is issued with the notation on the front of the card or license. If the customer requests that the Organ Donor Will be withdrawn at a later time, the DHSMV will update their file and issue them a no-fee duplicate identification card or driver license that does not reflect the Organ Donor designation.

No data is available to determine the effectiveness of a repository of advance directive documents for use by the health care community. Current accepted blood banking practice does not support the use of blood type documentation in lieu of this testing being carried out at the time of the need for transfusion.

Organ donor wills are mailed to the Agency for Health Care Administration for that agency to maintain the completed forms. The Organ Donor Will form is available in all driver license offices and via the DHSMV's website.

Over the past five years, there has been an average of 658,151 organ donor notations made.

C. SECTION DIRECTORY:

Section 1. Creates s. 320.08049, F.S., to impose an additional fee for persons participating in health care advance directive and blood-type registry. The fee shall be used for the establishment and maintenance of this registry. It lists the specifics for which the fee funds can be used.

Section 2. Amends s. 322.051, F.S., to create a fee for any person choosing to participate in the health care advance directive and blood-type registry.

Section 3. Amends s. 322.08 F.S., to create a fee for any person choosing to submit an initial application to participate in the health care advance directive and blood-type registry.

Section 4. Creates s. 765.3061, F.S., to require the Department of Highway Safety and Motor Vehicles (DHSMV) and the Agency for Health Care Administration (AHCA) to develop and implement a program allowing a person to participate in the health care advance directive and blood-type registry, noting this participation on the person's driver's license.

It requires the DHSMV to distribute the health care advance directive and blood-type confirmation forms. It lists requirements for blood-type verification. It stipulates the required information that a

person completing a health care advance directive or blood-type confirmation form shall have included on his driver's license or identification card. This shall satisfy all requirements concerning life-prolonging procedures and necessary blood-type information for health care providers.

It lists the form distribution and availability requirements. It lists the requirements in the advance directive or blood-type confirmation forms to participate in the registry.

Section 5. Creates s. 765.3062, F.S., to establish the health care advance directive and blood-type registry as an expansion of the current Organ Donor Program, collected by the DHSMV and maintained by AHCA. The registry shall be accessible 24 hours a day, 7 days a week.

Section 6. Creates s. 765.3063, F.S., to stipulate the procedural requirements for amending or revoking a health care advance directive or removal of a blood-type form from the registry.

Section 7. Creates s. 765.3064, F.S., to provide a health care facility or a health care provider or any other person acting under the direction of a health care facility or health care provider immunity from criminal and civil liability for acting in accordance with a properly recorded health care advance directive or blood-type form. This civil and criminal immunity is extended to the DHSMV's and AHCA's employees acting within their scope of employment.

Section 8. Creates s. 765.3065, F.S., to require AHCA and the DHSMV to develop a continuing educational program concerning the use of health care advance directives and blood-type registry.

Section 9. Creates s. 765.3066, F.S., to create a health care advance directive education panel. It sets-up the panel structure and responsibilities. AHCA can determine the most cost effective and cost-efficient means to implement the educational requirements contained in s. 765.3065, F.S., and s. 765.3066, F.S.

Section 10. Effective upon the act becoming law, requires AHCA to conduct a study of the implementation of the health care advance directives and blood-type registry and provides for a report to the Legislature by January 1, 2005. It provides issues for the study to address.

Section 11. Provides an effective date of September 1, 2005.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

   Over the past five years, there has been an average of 658,151 organ donor notations made. If the same number chose to participate in the health care advance directive and blood-type registry, approximately $6,581,514 would be available for AHCA to maintain the registry and implement the requirements of this bill. However, the number of persons that may elect to participate and the resulting revenue is unknown.

2. Expenditures:

The DHSMV would have an unknown fiscal impact for the reissuance of a driver's license or identification card if a person chooses to revoke a health care advance directive or wishes to be removed from the blood-type registry, of which the cost will be absorbed within existing resources. Implementation of this program will require contracted programming modifications to the Driver License Software Systems at a cost of $61,905.

The AHCA indicates the need for $50,000 to complete the required study of the implementation of the health care advance directive and blood-type registry.

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

None.

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

Persons participating in the health care advance directive and blood-type registry will be assessed a $10 fee. Persons submitting an initial application for a drivers' license or an identification card for disabled persons to participate in the registry would pay a $10 fee. Individuals would also have to pay for blood typing, which would require a physician's order. Participating individuals could gain greater assurance that their advance directives related to end-of-life care would be heeded by health care providers.

D. FISCAL COMMENTS:

The creation of the registry would require AHCA to restructure the existing organ donor registry. The computer hardware and software of the current registry is out-of-date. A major hardware purchase and software development would be needed to accommodate the advance directive/blood type registry. A mechanism to fund a health care advance directive registry would also offer the opportunity to update and streamline the organ donor registry. A totally web-based system could be implemented that would allow individuals to file their advance health care directives with the registry without the intervention of AHCA or DHSMV.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

This bill does not require counties or municipalities to spend funds or to take an action requiring the expenditure of funds. This bill does not reduce the percentage of a state tax shared with counties or municipalities. This bill does not reduce the authority that municipalities have to raise revenue.

2. Other:

DHSMV employees may be placed in a position to counsel persons on completing their health care advance directives. Due to the litigious environment, physicians may be uncomfortable relying on patient written preferences without first meeting with the patient to discuss the beliefs elicited by the health care advance directive form in the context of potential medical scenarios. According to the American Medical Association (AMA), physician-directed discussions about advance care planning in the outpatient setting are a relevant component of advance directive completion.[5]

According to AHCA, some may argue conflict with ss. 765.309 and 765.104, F.S., specifically with respect to the immunity provision and anticipated revocation/implementation delays for participants. In addition, s. 765.302, F.S., limits the utilization of advance directives to adults. Many drivers' licenses and license ID's are issued to minors but the bill does not specifically address this issue. Information provided by AHCA's General Counsel's office indicates that "…privacy, protection of life and equal protection (those not able to afford the initial fee moneys would be denied access to the state registry). The costs of administering updates from/for participants could limit access to others. State Attorneys and the Judiciary can anticipate legal challenges and/or prosecutions for abuses and emergency hearings." The agency also indicated that, "…privacy interests, right to life interests , family members with differing opinions, insurance companies and those funding medical care, religious groups and current vendors of medical/blood type registries may challenge the bill or its implementation."

B. RULE-MAKING AUTHORITY:

Rulemaking authority is provided to identify those to be allowed access to the registry.

C. DRAFTING ISSUES OR OTHER COMMENTS:

AHCA recommended an amendment indicating that the "study required in determining the data system requirements for establishing the advance directive registry would also consider the methodologies that could be utilized to carry out a continuing education program as required in the bill."

IV. AMENDMENTS/COMMITTEE SUBSTITUTE CHANGES

On March 23, 2004, the Health Care Committee adopted 4 amendments and reported the bill favorably with a committee substitute. The amendments are as follows:

Amendment #1 – Technical. Corrects directive language.

Amendment #2 – Includes the "identification card" as a form in which the Department of Highway Safety & Motor Vehicles can place information regarding the advance directive and blood-type symbol.

Amendment #3 – Technical. Provides clarity regarding the implementation study.

Amendment #4 - Allows AHCA to determine the most cost effective and cost-efficient means to implement the educational requirements contained in ss. 765.3065 and 765.3066, F.S. It changes the implementation date to September 1, 2005.

[5] American Medical Association Council on Ethical and Judicial Affairs, Optimal Use of Orders Not to Intervene and Advance Directives, 4 PSYCHOL. PUB. POL'Y, & L. 668-675 (1998).