Opportunities for Improved Health Service Delivery
Healthcare Commission Ideas for Governor Freudenthal
June 29, 2005

End-of-Life Care Document Registry/Database

1) What is the problem?

- **a)** Many citizens have the necessary legal documents that address end-of-life care issues, but the documents are locked away in safe-deposit boxes or file cabinets and not readily available when needed.
- **b)** During critical, emotional moments, these documents are often missing and physicians tend to err on the side of caution – sometimes providing care the patient would have preferred not to receive.
- **c)** The result is millions of dollars in unwanted, unnecessary cost to the healthcare system.
  - **i)** A study published in 2001 found that spending in the last year of life accounted for 26% - 30% of all Medicare outlays for the elderly and that Medicare paid an average of $26,000 for care in the last year of life between 1993 and 1998. Assuming a constant 7% annual inflation rate, that figure would be just under $42,000 in 2005.[1]
  - **ii)** The same study recognized that Medicare paid only 61% of decedents' costs in the last year of life, bringing total average cost in 2005 to approximately $58,000.
  - **iii)** Dr. Robert Monger, President of the Wyoming Medical Society, estimates that one in 20 intubations are unwanted, but patients' wishes are unknown until days afterward. He further estimates that any intubations followed by a minimum two-day stay in an ICU cost between $10,000 and $15,000 per incident. Further study would be required to know with certainty how many patients are intubated each year in Wyoming, but if 25 – 50 unwanted intubations were avoided each year, the cost savings to the system would be $250,000 to $750,000.

2) Describe your ideas.

- **a)** Create or contract for a database into which these end-of-life care documents can be entered.
- **b)** Make the database available to healthcare providers – particularly emergency department physicians – in order to avoid the scenario where heroic measures are taken against a patient's expressed desires.
- **c)** Provide some kind of marking on state drivers' licenses to indicate the individual has end-of-life care documents located in the database or provide a wallet size card with user ID and Password info the individual can carry with them and/or share with family members.
- **d)** Work with community members (physicians, attorneys, accountants, estate planners, insurance agents, etc.) and community agencies (senior centers, AARP, hospitals, nursing homes, etc.) to promote the writing and registering of end-of-life care documents.
- **e)** Look for additional methods to make the content of end-of-life care documents easily accessible to appropriate healthcare personnel and family members when needed.

3) Who are your partners?

- **a)** Patients/Citizens with end-of-life care documents (Advance Directive, Living Will, Durable Power of Attorney).
- **b)** Attorneys, financial planners, accountant, insurance agents and other community members who help educate their clients about the documents, write the documents and educate their clients about the registry and why it is important.
- **c)** Physicians who will use the registry and also help educate patients/family members.
- **d)** Hospital Administrators – the 1990 Patient Self Determination Act (PSDA) requires that all Medicare and Medicaid providers (specifically hospitals, nursing facilities, hospices, home health agencies, and HMOs) to provide each patient with information, drafted by the state, explaining advance directives such as living wills and medical powers of attorney. The information must be provided at the time of admission, and organizations are required to educate their staff and community about advance directives.[2]
- **e)** The Health Department or Secretary of State, or another agency selected to hosts the registry.
- **f)** AARP – providing counseling to members regarding end-of-life care documents.
- **g)** Faith-based organizations and leaders that address end-of-life issues in the context of spiritual counseling. They can increase awareness and encourage members to document their wishes.

4) Please provide supporting evidence and data for the proposal.

a) The case of Terri Schiavo dramatically points to the need for this type of document registry.

b) The state of Arizona launched their registry in March 2005. In the first three months of operation 1,800 people filed documents. The Arizona database is housed in the Secretary of State's office and funded by a local, private hospice organization. They believe part of their success had to do with launching their database at the same time the Terri Schiavo case was in the news.[3]

c) The North Carolina registry is also housed in the Secretary of State's office. For the first 18 months of operation they averaged 5 documents per week. Since the Schiavo case they have been getting 40 -50 documents per week.[4]

d) The State of Vermont has recently completed a study on advance directive registries, in order to select one for use in Vermont. Preliminary findings of an evaluation of their selected database (Choices Bank) include:

- **i)** 42% of registrants indicated they had not previously completed an advance directive prior to depositing an advance directive into the Choices Bank.
- **ii)** User's confidence that they and other key health care decision makers (agents, family members, doctors) could locate their advance directive at any time increased from about 39% before using Choices Bank to about 90% after using Choices Bank.
- **iii)** 97% of depositors reported being Very to Extremely Satisfied with the services.[5]

5) Funding/Staffing needs.

Wyoming can take one of two primary routes to implement this recommendation. It can either build the database capacity within an existing state agency or it can contract with an outside entity to perform the services.

a) <u>To build it within a state agency:</u>

A project manager will be needed to get it started, keep it maintained and promote the service. Consulting IT help to design, build and maintain the database and data retrieval. Once built, a 0.25 to 0.5 FTE document manager who is capable of using necessary software to input documents.

<u>Start-up: (estimate 6 months)</u>	
Project manager at $40,000 annual salary with benefits for 6 months	$28,000
IT consulting to design and build database	$55,000[6]
Web-based retrieval system design and development	$30,000
Promotional campaign to hospitals, physicians, attorneys and public	<u>$250,000</u>
Total Start-up:	$ 363,000
<u>On-going maintenance:</u>	
0.25 Project Manager	$14,000
0.25 FTE Clerical at $25,000 with benefits	$ 7,000
IT support and maintenance	$20,000
Marketing campaign	<u>$100,000</u>
Total maintenance	$141,000

If the costs associated with marketing and promotion are eliminated, start-up costs would be approximately $100,000 and maintenance costs would be approximately $34,000. This is more comparable to the "contract" option described below.

b) <u>To contract with a commercial vendor:</u>

Vermont's registry, through an existing vendor, is anticipated to cost $52,000 for initial deployment, with $26,000-$31,000 annual ongoing cost.[4] This cost does not include marketing and promotion.

North Carolina charges individuals $10 per document registered. Those running the program say that covers their database costs, but also say they have gotten feedback that the fee has prevented some individuals from entering their documents into the database.[3]

6) Who is better off and how could you measure the improvement?

- **a)** The healthcare system avoids spending money on unwanted heroic measures.
- **b)** Patients know the chance of their wishes being followed improves.
- **c)** Physicians who are able to locate documents will have justification for their actions and feel less threatened by family members. This will be true for those who do not provide heroic, save-the-life-at-all-cost measures, and for those who do. The physician can act based upon the wishes expressed in the documents, not the emotions or guilt of family members.
- **d)** Hospitals have to address advance directives to comply with the Patient Self Determination Act and JCAHO Patient Rights and Management Standards. This initiative can help them meet these criteria. In addition, a recent study reports that hospital patients who receive adequate end of life explanations express significantly higher satisfaction with their inpatient experience and are more likely to recommend a hospital to friends and family for care.[1]

7) Could this proposal be included in the Children and Families Initiative?

- **a)** Not directly. However, if this database allows us to avoid significant costs incurred when patients are kept alive against their wishes, a case can be made that significant dollars could be shifted from end-of-life care to preventive and primary care.

8) Potential drawbacks and political considerations.

- **a)** Some will argue that the state is trying to withhold medical care in order to save costs.

9) Alternative possibilities.

- **a)** Continue the system as is.
- **b)** Encourage a private enterprise to develop and market the database. There is a private service based in New Jersey, but they do not offer their service in Wyoming. (Their business model is to charge the professionals who write the documents for registering their clients' information. They do not currently have agreements with professionals outside of the North-Eastern states.)
- **c)** Contract with a company that already has a product (e.g. Choices Bank, or www.uslivingwillregistry.com).
- **d)** Create an awareness campaign only; this can be done even without a database.
- **e)** Promote palliative and hospice care for Wyoming citizens. Create opportunities for Wyoming providers to receive training in end of life care. One new resource is the "Life Quality Institute" at the University of Colorado School of Medicine.[7]
- **f)** Create a wristband or "MedicAlert" type bracelet for people to wear if they have advance directives.
- **g)** Explore a combination of organ donation and advance directive documents in the proposed database.

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[1] Hogan, Christopher; et al "Medicare Beneficiaries' Costs of Care in the Last Year of Life." Health Affairs, July-August 2001

[2] Gavran, Goran. "End of Life Choices as a Vital Part of Patient Care." *HealthLeaders News* June 6, 2005.

[3] Phone interview with Gene Palma, Director of Business Services, Arizona Secretary of State's office. June 7, 2005

[4] Phone interview with George Jeter and Liz Proctor, Information Officers North Carolina Secretary of State's office, June 9, 2005

[5] "Advance Directive Accessibility Study: A Report to the Vermont General Assembly." January 15, 2005. http://www.healthyvermonters.info/admin/pubs/AdvanceDirectiveRpt.pdf.

[6] Larry Biggio, CIO for the State of Wyoming, e-mail concerning IT costs for development of document registry June 14, 2005

[7] "Hospice of Metro Denver granted HALF-MILLION DOLLARS from Department of Health and Human Services." <http://www.denverhospice.org/EOL.asp> June 8, 2005.