

## **The Choices Bank: A Community-Based Advance Directives Repository**

### **1) Project Purpose**

The Missoula Demonstration Project: The Quality of Life's End (MDP), in collaboration with seven community partners, proposes a three-year project to develop, implement, and evaluate an electronic, community-based repository for advance health care directives. These documents assist families and health care professionals in making life-or-death decisions. Currently these documents often cannot be found when they are urgently needed. To address this problem, MDP and its partners will pioneer the Choices Bank to make advance directives universally accessible to anyone with security clearance, from anywhere, 24 hours a day, seven days a week.

MDP is a non-profit, research and advocacy organization working to improve the quality of life for dying people and their families. Since its inception in 1996, MDP has conducted extensive research on living with serious illness, dying, death, caregiving, and grief in Missoula County, Montana. (See Appendix 1: Research and Publications) MDP uses task forces and community-based programs to involve citizens in identifying needs and developing resources to meet them. In its early work, our Advance Care Planning Task Force identified access to advance directives as a significant barrier to honoring health care choices at life's end. Since late 1999, task force members have met monthly to develop the Choices Bank concept.

The Choices Bank *end users* include a) staff at each of the 22 "portals" who accept advance directives from the public, b) professionals who help individuals and their families make advance health care plans or carry them out, and c) individuals with advance directives in the Choices Bank and those authorized to access their advance directives. With such diverse end users of various capabilities, we recognized the need for a simple system capitalizing on existing technology and infrastructure. Representatives from each portal will participate in the development of the Choices Bank.

The *beneficiaries* of the project are the end users above who receive health care in western Montana. More than 40 percent of the patients treated at Missoula County's two tertiary care hospitals reside outside the county in western Montana — a catchment area of 16,932 square miles with 281,588 people.<sup>1</sup> Conservatively, the organizations that will offer the initial portals alone serve 35,621 people annually in this region. In addition, the Choices Bank will store advance directives for individuals who may not have previously been hospitalized.

**Problem:** Seriously ill or injured people and their families who must make decisions for them are an unrecognized, underserved and vulnerable population. People who have lost the capacity to speak for themselves need others to speak for them. At present, such patients – even more so their families – are poorly served by our health care systems. People in life-or-death situations and those who must make decisions for them enter a foreboding world and are at the mercy of others. They are surrounded by

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<sup>1</sup> 1999 Population Estimates and Land Area. *State and County Quick Facts*. U.S. Census Bureau. Retrieved March 14, 2001, from <http://quickfacts.census.gov/qfd/states/30000.html>.

caring people, but may not receive the care they would have wanted. Families are thrust into decision-making roles that are highly stressful and burdensome. Uncertainty and conflicts within families and between families and health care providers can arise when patients are not able to communicate, and when evidence of their wishes, in the form of advance directives, cannot be found. The emotional pain from this experience can take years for family members to heal.<sup>2</sup>

Written advance directives, which include living wills and powers of attorney for health care, allow people to record their preferences for health care and legally designate proxies to make decisions for them if they ever become incapacitated. Even when individuals have completed such documents, at times of crisis they are often not accessible or cannot be located at all. Extensive interviews with surviving family members of 216 people who died in Missoula County in 1996 and 1997 revealed 65 percent of their loved ones had a living will. However, comprehensive reviews of the deceaseds' medical charts found that only 30 percent of these charts actually contained a copy of the reported living will. Similarly, 65 percent of the deceaseds' families reported their loved one had a power of attorney for health care, yet only 34 percent of these documents were actually in the charts.<sup>3</sup>

In practice, written advance directives are invaluable to those who must make decisions for another. Advance directives can also serve as a stimulus and guide for discussions, first clarifying the pertinent issues, then conveying the individual's preferences. Our research indicates 40 percent of those who die are not able to make their own decisions at life's end. Sixty-four percent of surviving family members who had access to their loved ones' living wills report they were useful, and 71 percent with access to powers of attorney for health care report they were useful. Further, 77 percent of physicians with access to these living wills report they were useful.<sup>4</sup> However, to be useful, they must be found when needed.

With the passage of the federal Patient Self-Determination Act of 1991, health care providers who receive Medicare reimbursement, including hospitals, nursing homes, home health agencies, and hospice programs are required to ask patients if they have an advance directive. Additionally, the Joint Commission on Accreditation of Healthcare Organizations requires information on the existence of advance directives. These regulations do not address the actual placement of advance directives in a person's chart. Developing a means to assure accessibility of advance directives is left to the individual institutions. The job of finding patients' directives regularly falls to social workers and chaplains who, in Missoula, recount time-consuming challenges of hunting for reported advance directives and acquiring a copy, if one actually exists. Many people store their directives in locations that are inaccessible in the evenings, on weekends, or holidays, such as physicians' or attorneys' offices or safe deposit boxes.

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<sup>2</sup>From Contract to Covenant Advance Care Planning Study, funded by the Fan Fox and Leslie R. Samuels Foundation. Missoula Demonstration Project. 2000-2001.

<sup>3</sup>Family After-death Interviews, medical chart reviews of the same cases, and case-specific physician surveys from the Clinical Experience Study. Missoula Demonstration Project. 1998-1999.

<sup>4</sup>*Ibid.*

Others file them in their homes where they may not be found. Similarity of terms for health care planning and financial planning tools adds confusion. Social work and pastoral care staff in Missoula report patients and families commonly provide wills and financial powers of attorney when asked for copies of their *living* wills and powers of attorney *for health care*. Research conducted in Missoula County found 64 percent of people who said they had a living will could not correctly define what one is, nor could 67 percent of those who said they had a power of attorney for health care define one.<sup>5</sup>

People at the end of life frequently need medical care provided in different facilities at different times, requiring different staff to repeat an advance directive search. In research related to non-sudden deaths, surviving family reported 71 percent of their loved ones were hospitalized a median of twice in the last year of life, 65 percent were treated in an emergency room, and 46 percent were admitted to long-term care or other facilities.<sup>6</sup> Ideally, advance directives should be periodically reviewed and updated. Unfortunately, updating increases the likelihood of outdated versions on file in multiple locations and held by different family members. All of these factors contribute to a critical need for a system that makes advance directives for health care accessible 24 hours a day, seven days a week.

***Solution:*** To address this problem, a group of concerned professionals led by the Missoula Demonstration Project proposes to create the *Choices Bank*, a community-based system to store, retrieve, and make copies of advance directives instantly available at any time from anywhere with Internet access or a telephone and facsimile machine.

The public in Missoula County and western Montana will be offered their choice of *portals* which will accept completed advance directives for deposit. Staff at these portals will be available to provide advance health care planning information, review documents for completeness, and transfer them to the data entry site for scanning and entering into the system. The first 22 portals will be located within existing community facilities: the two hospitals in Missoula County, Community Medical Center Hospital and St. Patrick Hospital and Health Sciences Center; the Western Montana Clinic with 15 locations throughout western Montana; Missoula Aging Services, our area agency on aging; Partners in Home Care, Inc. and its hospice program; Nightingale Nursing Services; Christ the King Church with its active parish nurse program; and the MDP office. The project will train existing staff within these organizations to serve these portal functions. In year two of the project, additional portals will be added, including the rural hospitals throughout western Montana that are affiliated with Missoula hospitals. (See Appendix 2: Western Montana Portal Sites) People with directives in the Choices Bank will be periodically reminded to review them and deposit revised directives through a portal.

At any time, day or night, a reliable, scanned copy of a person's advance directive that has been deposited in the Choices Bank will be available to individuals, families, or care providers with Internet access and the necessary security information. Even without Internet access, a distant doctor for an

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<sup>5</sup> Advance Care Planning Terminology Study. Missoula Demonstration Project. 1998.

<sup>6</sup> Family After-death Interviews from the Clinical Experience Study. Missoula Demonstration Project. 1999.

unconscious patient or a frantic loved one will be able to call one of the two hospital emergency departments in Missoula and, with requisite security information, obtain a faxed copy of the advance directive. As patients are transferred between health care facilities, the same, most recently deposited advance directive will be available to all simultaneously.

**Outcomes:** As a result, health care providers and staff, including those in emergency departments, will instantly be able to check for the most current deposited advance directive to identify their patients' designated proxy decision makers and preferences for health care.

The Choices Bank project will accomplish the following measurable outcomes:

- 1) Increased number of accessible advance directives, 24 hours a day, seven days a week to anyone, anywhere with appropriate security clearance;
- 2) Increased institutional staff efficiency in locating, preparing, or revising advance directives;
- 3) Increased staff assurance that people are accurately reporting the existence of health care planning documents rather than financial planning documents;
- 4) Increased confidence by depositors that advance directives will be accessible to them as well as to their designated proxy decision makers, health care providers, and other professionals;
- 5) At least 75 percent of proxies surveyed will report confidence that their authority will be recognized because the advance directive is accessible;
- 6) At least 75 percent of depositors will discuss their wishes with their proxies, family members, health care providers or attorneys, and familiarize them with the Choices Bank and how to access it;
- 7) At least 75 percent of end users will rate the Choices Bank as very useful and will be very satisfied with the services it provides; and
- 8) At least 75 percent of deposits will be made by seniors and adult children of aging parents.

## **2) Innovation**

The Choices Bank project will demonstrate how creative integration and application of simple technology with real-world systems and community processes can cost-effectively solve a serious and all-too-common problem. It combines browser-based technology, a server, a scanner, a laser printer, a system of portals integrated within existing community organizations, and resources such as the United States Postal Service or existing internal courier services. Additionally, it makes use of readily available Internet access in organizations and professional offices, at public Internet access locations such as public libraries, and in private homes.

Storing patient information electronically is not a new idea. Facilities within a health care provider's network such as that between Missoula's St. Patrick Hospital and 17 affiliated facilities throughout western Montana make access to patient information within the network routine. However, Choices Bank users will not be bound by a single network. Previous TOP grantees, for example, the Rio Arriba Family Care Network, Inc., and the Children's Hospital of Pittsburgh Special Vision Project, are using the Internet to store and retrieve medical record information and thus provide a seamless service system to improve the provision of health care. Additionally, the Association of Kansas Hospices Telehospice project is currently using POTS (Plain Old Telephone System) technology to coordinate and improve

services for dying people. What makes the Choices Bank unique is a) *everyone* with appropriate clearance and access to the Internet, *regardless of where they are*, can read advance directives in the Choices Bank *at any time* without charge, whether they are the person who has deposited the advance directive, a proxy decision maker, loved one, or professional providing services, and b) anyone who desires to become part of the system or revise an already deposited directive need only print an advance directive form from the website, complete it, and deposit it at a Choices Bank portal.

In recent years, several companies have offered advance directive registration or storage services on the Internet. These services vary widely in what they offer and cost, as well as in who may access the stored directives and how. Few use the Internet to actually store and produce scanned copies of advance directives. Some merely store information about the location of a directive or the names of people with copies of it (Age Net/Living Will Registration/Advance Directive.com and National Will Registry). Others provide copies of stored directives only to hospitals or health care providers (Gateway File Systems and US Living Will Registry). Still others only provide copies via facsimile (Healthcare Decisions, LLC and North American Registry of Living Wills). Nearly all charge storage fees to individuals that range from a high of \$55.00 to a low of \$9.95 for varying periods of time (National Will Registry and Gateway File Systems). Further, Internet companies can come and go at a rapid and unpredictable rate. For example, one commercial company, Net Directives/Jasperon, offered a free Internet repository that ceased operation within months of its August 2000 launch. While national Internet-based repositories exist, none are community-owned or have community-based portals and marketing to encourage their widespread and consistent use.

Additionally, because these Internet options vary, they can be confusing to both consumers and professionals. This confusion can cause delay in retrieving directives. A community-based system not only offers a single location in which to search for any community member's directive, but it is also backed by the trust already earned by its community partners whose names and faces are well known. These partners have a stake in the community and in the solution to its problems. They have been in existence for many years and will continue be here. People who deposit their advance directives in a repository must have confidence that it will still exist when their directives are needed. Our community will be able to sustain the Choices Bank beyond the grant period with modest continuing investment.

### **3) Diffusion Potential**

The Choices Bank model will have application and is needed in every community because everyone is affected by the end-of-life experience. Many of us or our loved ones will not be able to make decisions at life's end. Advance directives can speak for us or designate others to do so when we cannot speak for ourselves. Virtually all health care organizations are required by federal law or national policies to ask adult patients if they have an advance directive. Too often advance directives are difficult to find when needed. The Choices Bank will fill that gap. Because the Choices Bank takes advantage of readily available electronic technology and Internet access, as well as existing community institutions and systems, any community has the capacity to adopt and sustain this model.

Once the Choices Bank is developed and evaluated, it will offer an easily replicated, proven solution to communities across the country. By using simple, relatively inexpensive and commonly available

hardware and software, the Internet access of community health care providers and other organizations that serve the public, and existing community resources, others will be able to adapt versions of the Choices Bank with a limited financial investment.

The Missoula Demonstration Project is a recognized national leader in the end-of-life field and regularly provides technical assistance to communities nationwide. (See Appendix 3: MDP National Outreach Sites and Appendix 1: MDP Research and Publications ) We can help other communities develop their own “choices banks.” We will produce a replication manual to offer tested training tools, public education and promotional materials, protocols and a technical template to support this implementation. We will provide telephone, electronic, and onsite consultation. MDP staff regularly present at national conferences and will make presentations at a minimum of three conferences, such as those organized by the American Society on Aging and National Council on Aging, the American Academy of Hospice and Palliative Medicine, and the National Academy of Elder Law Attorneys.

MDP will also publicize our experience in developing the Choices Bank through Last Acts, a national alliance of over 600 end-of-life organizations nationwide. We will submit information and articles to the Last Acts online discussion group, online newsletter, and website. We will also share our experience in our quarterly newsletter, on our website<sup>7</sup>, and at our annual conference that shares MDP experience with professionals and community leaders from around the county. In addition, each of our community partners will actively share their experience via their own publications, websites, and national conference participation.

#### **4) Project Feasibility**

***Technical Approach:*** The Choices Bank system will pioneer the use of existing community resources and simple technology with minimal management structure. This information technology system easily interfaces with sophisticated information systems within organizations, as well as home users of computers or other Internet access devices. The Choices Bank structure and protocols will involve few steps. (See Appendix 4: Choices Bank Flowchart) First, the public and targeted populations will be encouraged to deposit their advance directives in any one of 22 portals within existing community organizations. Next, portal staff will review directives for completeness and transfer them to the contracted data entry site within St. Patrick Hospital. Third, a data entry clerk will scan the original advance directives, tie each to its corresponding record in an Oracle database, which will automatically update the [www.ChoicesBank.org](http://www.ChoicesBank.org) website. The clerk will use a laser printer to customize a pre-printed information sheet and wallet card. This information sheet, wallet card, and original advance directive will be returned to the depositor via USPS mail. The database will run on a Compaq ML 370, P1000 with 384Mb of RAM and mirrored 18Gb hard drives that will be backed up daily. A database administrator will monitor and maintain the system as well as install upgrades as necessary.

The fourth step represents a major advantage of this system. It allows anyone with a generic Internet browser access to the Choices Bank website for advance health care planning information and blank

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<sup>7</sup>The Missoula Demonstration Project website URL is: [www.missoulademonstration.org](http://www.missoulademonstration.org)

advance directive forms. In addition, anyone with the appropriate security information or a password will also be able to quickly and easily read and print an advance directive within days of its deposit. Audit trails within the system and brief user surveys will track who is using the website and how. Depositors will receive annual reminder postcards recommending they review their advance directives and deposit revised directives at a portal.

Security of the database and website from unauthorized access or modifications will be assured and maintained by an integrated multi-dimensional security and password authentication system. As the Choices Bank grows, additional portals can be added, the data entry capacity can be increased, and the server can be expanded up to a total of six 18Gb hard drives.

We have considered the use of existing hospital-based wide area network infrastructure, but noted access would be limited to those connected to the network. Further, a higher degree of security would be required to safeguard the network, each end user's computer would need additional software at additional expense, and the system could not be an independent, community-owned entity. Existing hospital computer systems were also ruled out for many of the same reasons. An automated FAX-back system was seen as too limited for individual access and use, and added unnecessary time between the request and the receipt of the advance directive. The system we have conceived uses widely available technology and other tools to accomplish our goals of fast, easy, inexpensive access to the lay public, professionals, and health care institutions alike at anytime from anywhere.

The Choices Bank marketing plan will be integral to our success. We have targeted seniors over 65 years old and adult children of aging parents, since 75 percent of those who die in Montana are over 65.<sup>8</sup> For each audience we will develop and test marketing strategies to determine the most effective messages and methods to reach them.

***Applicant Qualifications:*** Appendix 5 lists project staff and their qualifications.

***Budget and Implementation:*** We propose a three-year project, with a budget of \$923,520 including \$402,340 in kind and \$60,000 in cash match from community partners. The Budget Narrative details responsibilities of project staff and contractors. Appendix 6: Workplan and Timeline provides monthly activities for project development, implementation, and evaluation.

***Sustainability:*** The most resource-intensive phases of the Choices Bank will be its initial development and evaluation of its operation, of its efficacy, and of its promotional, educational and training materials. Its subsequent continued operation will be quite simple and relatively inexpensive. By the end of the grant period, MDP will establish for the Choices Bank a separate not-for-profit organization with a community-based board of directors. Portals will continue to provide service predominately to the particular populations their own missions already serve. Their costs will be part of their routine

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<sup>8</sup>Mortality. *Vital Statistics 1999 Report*. p. 28-32. Montana Department of Public Health and Human Services. 2000.

operations. Ownership of the hardware and software purchased through the grant will be transferred to the non-profit organization. The hospital providing space for the server and data entry functions anticipates continuing to do so on an in-kind basis. The contracted costs of entering data, maintaining and upgrading the system, postage, printing, and training support are projected to be less than \$75,000 per year. Several factors indicate the strong likelihood of securing these funds from within the community year after year. The amount is relatively small. The level of cash matching funds and other interest in this project is comparable to future cash requirements. Most importantly, the project meets a critical need identified, developed, and implemented by the institutions and professionals who are the end users and beneficiaries. Finally, the proven efficacy of the Choices Bank and community support developed through the grant period will encourage investment in its sustained operation.

### **5) Community Involvement**

MDP and its Advance Care Planning Task Force of health care, legal, and spiritual care professionals and aging and disabilities advocates have been working for nearly four years to ensure health care choices will be honored at the end of life. (See Appendix 7: Advance Care Planning Task Force) We identified access to advance directives as a significant barrier. As a result, its Choices Bank Steering Committee has been meeting monthly since late 1999 to develop a solution. (See Appendix 8: Choices Bank Steering Committee)

Seven of our task force partner organizations have signed memoranda of understanding committing staff time and other resources to a) develop the Choices Bank draft model into a working system, b) provide portals to receive completed advance directives from the public, c) provide data to MDP for evaluation, and d) substantiate the value of their donated services. Two of these partners have also agreed to provide cash donations. (See Appendix 9: Memoranda of Understanding and Attachments C - J: Worksheets) In addition, other task force members and partner organizations have committed to continue staff or volunteer time to develop and promote the Choices Bank. All of these partners will also be involved in establishing an independent not-for-profit organization to continue the Choices Bank prior to the close of the grant period.

The benefits we expect from this project include ready access to completed advance directives for those we serve and those individuals' loved ones, reduced staff time spent in locating and obtaining copies of previously signed advance directives, and time spent more effectively helping people complete or revise their directives. (See Appendix 10: Letters of Benefit)

MDP will direct the project including a) coordinate the planning and development of the system with our community partners, b) produce and distribute education, promotional and portal training materials, c) conduct training of trainers from portal organizations, d) purchase equipment, supplies, and printing, e) hire and supervise contractors, f) collect evaluation data, and g) comply with grant reporting and other requirements.

### **6) Evaluation**

The Choices Bank project is based on eight hypotheses that will be tested through our evaluation of project outputs and outcomes. We have developed our evaluation plan in collaboration with our *Independent Evaluator*. (See Appendix 11: Evaluation Plan) We will collect and analyze data four

times during the project: at the end of year one, the middle and end of year two, and the middle of year three. This data will be used to revise the system to better serve end users and beneficiaries during the project as well as to quantify project outcomes.

MDP will gather both qualitative and quantitative data through surveys of end users including baseline data from advance directive depositors and institutional staff such as social workers, chaplains, clinic receptionists, emergency room doctors, and critical care nurses. We will survey beneficiaries at the portals. We will also collect data on the use of the Choices Bank four times throughout the grant period from 1) a random sample of those depositors who consent to follow-up surveys and to our surveying their designated proxy decision makers, 2) a random sample of proxies where depositor consent has been given, 3) all portal staff, and 4) randomly selected health care providers who have used the system. All survey data will be coded for confidentiality. Our *Independent Evaluator* will continue to meet with the project team, monitor the progress of the evaluation, ensure the validity of the findings, and develop the final report.