



Bill No. 6
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HB 742

MONTANA ADVOCACY PROGRAM, INC.

The Civil Rights Protection & Advocacy System for the State of Montana

Main Office

400 North Park Avenue
P.O. Box 1681
Helena, Montana 59624
406-449-2344 Voice/TDD
406-449-2418 FAX
E-mail:
advocate@mtadv.org

Visit us on the web at:
www.mtadv.org

Missoula Office

1280 S. 3rd Street West
Suite 4
Missoula, Montana 59801
406-541-4357 Voice/TDD
406-541-4360 FAX

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Esquire

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April 4, 2005

Senate Judiciary Committee
Senator Mike Wheat, Chairman

RE: SB 742, Healthcare declarations registry

Dear Mr. Chairman and Members of the Committee:

MAP is a private, nonprofit legal advocacy organization that serves people with disabilities.

We would like to share a story to explain why we think this bill is so important.

Lenore Manning was an advocate for the Mental Disabilities Board of Visitors at the Montana State Hospital for many years. She was asked to become the agent for health care decisions for a middle-aged man with mental retardation who had become medically fragile since breaking his hip. He had been hospitalized for pneumonia on a couple of occasions and his physician asked that a medical decision-maker be appointed.

Lenore talked to her client at length in order to find out what his wishes were with respect to end-of-life decisions. When she felt he understood the issues, she asked him what she should do if he ever needed hospitalization or surgery or other intrusive medical care. He said, "I pick the heartbeat."

So when Lenore got the call from her client's provider that he had been diagnosed with pneumonia and required hospitalization, she authorized it. The physician complained to the group home where the man lived that it was inhumane to let the man suffer through repeated hospitalizations. The man became non-verbal and seemed to be in pain and frightened. But when Lenore revisited the issue with her client afterwards, he continued to "pick the heartbeat."

The day came when Lenore was out of town and an out-of-state relative was visiting the man when he again became ill with pneumonia. The relative was approached for a decision about whether to hospitalize Lenore's client. On the advice of staff at the group home, he withheld permission and the man died.

People with disabilities often have complex medical conditions and many have extensive experience with the health care system. People with disabilities also tend to have a greater appreciation for health care directives because they have a well-founded fear that medical providers may place a lower value on their lives.

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People with disabilities know they are widely assumed to have a poor quality of life. They are even considered by some to have lives not worth living.

For a person with a disability, a health care directive may be a life saver. However, unless the person always carries the directive with him and remembers to show it to providers, there is no assurance it will be available when critical decisions have to be made.

This registry will provide the vitally important assurance that the health care directive will be available wherever the person is hospitalized in this state.

This is a well-written, much-needed bill and MAP hopes that you will support it.

Yours truly,



Anita Roessmann
Staff Attorney