

Volunteer advocacy program benefits the incapacitated with no family or friends

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A Regenstrief Institute and Eskenazi Health study reports on an innovative program that trains and supervises volunteers who act as advocates for adults and seniors who are unable to make their own decisions due to conditions like Alzheimer's disease or coma, but have no family or friends to help them. The study found that the program could serve as a national model to replace or complement the frequently overwhelmed guardianship services provided by state agencies from coast to coast.

Incapacitated [patients](#) who lack surrogates present a complex problem for [health care](#) providers as well as for the hospitals and [nursing facilities](#). A study of the design and first two years of the new program appears online in advance of publication in the *Journal of the American Geriatrics Society*.

Nationwide, public guardianship programs struggle with case overloads. They often are responsible for tens or even hundreds of at-risk individuals. As reported in the JAGS study, the volunteer advocates are responsible for one or, at most, two individuals. Several advocates accepted multiple sequential cases. The program had no problem recruiting volunteer advocates.

The JAGS study followed the first 50 patients in the Wishard Volunteer Advocates Program. The volunteers protect the interests of the incapacitated patients they serve while they are in the hospital. The volunteers are supervised by the program director, who is an attorney,

and legal guardianship is formally assigned to the Volunteer Advocates Program. The program continues to serve patients after they have been transitioned to [health care facilities](#) or returned home. In the study, more than 90 percent of those who survived hospitalization were transferred to nursing facilities.

"Adults who cannot make decisions for themselves because of developmental problems, injury or dementia and who are without family or other surrogate decision-makers are among the most vulnerable individuals in any community," said Robin J. Bandy, J.D., M.A., the program's founding director.

"Many do not have family or are estranged from them, and may be neglected or abused. They are alone and at risk for receiving inappropriate medical treatment and not getting government benefits for which they qualify.

"The volunteer model provides patients with someone who has the same compassion and better training and support than that of most loving family members," she said. "I am in awe of how these volunteers who included law, medical and social work students as well as employed and retired individuals with a variety of backgrounds dug in and made genuine committed efforts to get to know the patient to whom they were assigned. They did their best to both understand them and to make the difficult decisions the patients couldn't make for themselves."

Volunteer advocates in the program made health care decisions, including end-of-life decisions; facilitated post-hospitalization placement to nursing facilities; were often the only person to follow care in the nursing home after hospital discharge; tracked down important but often elusive paperwork needed for Medicare and Medicaid eligibility; and made limited financial decisions.

The patients in the study ranged in age from 22 to 90, with an average age of 67. All but one of the patients had at least four medical conditions at the time of hospitalization, indicating the need for complex [medical care](#) and difficult decision-making.

Among those assigned volunteer advocates after hospitalization were:

- An 85-year-old woman with dementia who had been living alone with her dead cat in an uninhabitable apartment.
- A 65-year-old woman with dementia removed from her son's care after he broke her arm.
- A 90-year-old man removed from his home, malnourished and covered in urine, feces and bedbugs; "caregivers" were exploiting him and not allowing access to food, medicine or appropriate medical care.

"A growing number of adults are all alone. The need for surrogate decision-makers is increasing as our population ages, as divorce becomes more common, as families are geographically dispersed," said the study's senior author, Alexia Torke, M.D., a Regenstrief Institute and Indiana University Center for Aging Research investigator and an associate professor of medicine at the IU School of Medicine.

"The default of the American medical system is aggressive care with its high personal and health system costs. The volunteer advocate model promotes thoughtful consideration of what is best for the patient," said Dr. Torke, an internist and medical ethicist who has conducted a number of studies on surrogate decision-making. "Adults and especially older adults without surrogates are at risk for receiving medical overtreatment due to fears of legal consequences if interventions are withheld, or under-treatment, as interventions are delayed or not performed at all due to lack of consent. In previous studies we have shown that patients need and physicians welcome surrogate decision-makers and the volunteer

advocates perform this function admirably."

In addition to providing voices for these patients, the volunteer advocates afforded institutional value by completing Medicaid applications resulting in \$297,481.62 in reimbursement for hospital services. Securing Medicaid as a payer source also facilitated quicker placement in nursing facilities.

The Volunteer Advocates Program was developed at Wishard Health Services, now known as Eskenazi Health, an urban, public safety-net health care system that is among the busiest safety-net hospitals in the United States. The individuals followed in the study from 2010 to 2012 were patients of both Wishard and Indiana University Health. In May 2013, the volunteer advocates program moved to the nonprofit Center for At-Risk Elders and is expanding to serve other health care systems in Indiana.

Provided by Indiana University

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