

Advocating for the Unbefriended Elderly

An Informational Brief

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Issue

Rough estimates show that three to four percent of the nursing home population are older adults without capacity to give informed consent for treatment and who have no advance directive for the treatment nor any family, friends or legally authorized surrogate to be involved in medical decision-making. These older adults are often known as unbefriended elders or adult orphans. Unbefriended elders are vulnerable to under or over-treatment or treatment that does not reflect their values and preferences. As the U.S. population ages, individuals with developmental disabilities and mental retardation age and dementia becomes increasingly widespread, the issue of decision-making for unbefriended elders becomes even more pertinent for long-term care advocates, including state and local long-term care ombudsman programs. There is considerable variation in how states' assist unbefriended elders and approach the challenges posed by an individual's inability to give informed consent for treatment, and the lack of an advance directive or an authorized surrogate to make important medical decisions.

This brief, using data collected largely from the National Ombudsman Resource Center's (NORC) 2010 outreach to state long-term care ombudsmen and information from the July 2003 American Bar Association Commission on Law and Aging report *Incapacitated and Alone: Health Care Decision-Making for the Unbefriended Elderly*,¹ reviews existing mechanisms and practice for decision-making on behalf of unbefriended elders, including hierarchy laws and changes to state laws that address previous weaknesses in the law. This brief also highlights promising practices, puts forth strategies and ideas for long-term care ombudsmen to address the unbefriended elder issue, reviews policy suggestions and provides links to additional resources and sample forms and documents.

Existing Mechanisms and Practice

The American Bar Association report identified existing legislative mechanisms and institutional practice related to health-care decision-making for unbefriended adults. Mechanisms and practice, and corresponding examples are outlined below.

Legislative mechanisms to health care decision-making

The examples of legislative mechanisms listed below are not inclusive of all states; they reflect the information NORC received from ombudsmen who responded to the request for information. Further, several states have laws addressing the hierarchy of individuals authorized to provide consent. Select state information on this topic is provided in the section of this brief addressing hierarchy laws.

- *State health care consent laws or consent statutes granting authorization*

Definition: State statute authorizing health care consent in situations when a surrogate decision-maker is unavailable.²

Example:

- In Georgia, SB 367 expands the list of people authorized to make the decision about surgical or medical treatment for an incapacitated individual.³ Additionally, Georgia's Temporary Health Care Placement Decision Maker for an Adult Act provides assistance to family members or others who need to provide placement for adults who cannot give consent and have not authorized consent regarding admission, transfer or discharge from a health care facility.⁴ Further information can be found in the Hierarchy Laws section of

1 Naomi Karp and Erica Wood, *Incapacitated and Alone: Health Care Decision Making for Unbefriended Elderly* (American Bar Association Commission on Law and Aging, Jul. 2003).

2 Ibid., viii, 19-22.

3 Georgia General Assembly, "Senate Bill 367." 9 Aug. 2010 <http://www.legis.state.ga.us/legis/2009_10/fulltext/sb367.htm>.

4 Natalie K. Thomas, "Temporary Health Care Placement Decision Maker for an Adult Act." 30

this brief.

- West Virginia uses health care surrogacy. In this situation, a doctor appoints a health care decision representative after it has been determined that the individual in question lacks capacity to make such decisions and does not have a medical power of attorney representative or a court-appointed guardian. The West Virginia Department of Health and Human Resources serves as the representative of last resort.⁵

- *Surrogate decision-making committees existing by statute*

Definition: Laws exist in some states allowing external committees authorization to make health care decisions for an unbefriended elder.⁶

Example:

- California's Health and Safety Code includes a law allowing nursing homes to establish interdisciplinary teams (IDTs) of facility staff and a patient representative (a family member or an ombudsman) to make decisions about treatment for incapacitated elders.⁷

- *Public guardianship*

Definition: When a court rules that an individual has the authority to make decisions for another individual related to personal or property issues.⁸

Examples:

- Colorado's Proxy Medical Decision Maker statute (CRS 15.18.5-101) does not establish a hierarchy for appointing a proxy. Instead, the statute allows interested individuals to determine who should serve as proxy. The proxy has the same decision-making authority of a guardian appointed by court, excluding situations pertaining to withdrawal of artificial nourishment and hydration.⁹
- Georgia has a law in place that authorizes volunteers to act as public guardians if appointed by a probate judge, but the training and registration project to implement the program no longer has funding. The Georgia Department of Human Services, with Adult Protective Services (APS) serving as the case worker, is the guardian of last resort. APS does not usually provide case worker services to individuals living in long-term care facilities at the time that they are determined to need a guardian.¹⁰
- Kentucky uses guardianship when the decisions fall beyond the scope of an Emergency Protective Services Order.¹¹
- There is a guardianship system in place in Massachusetts, and the Massachusetts Uniform Probate Code (MUPC) brought about major changes to the law. The new standard for determining an individual to be incapacitated is based on a clinical diagnosis of a condition which prevents them from being able to take care of their basic personal needs. Information about the ways in which the individual cannot care for themselves must be included in any petition for guardianship and the medical certificate. A guardian cannot be appointed unless the court makes specific findings of the individual's incapacity, and if guardianship is granted, the guardian's powers do not extend beyond the incapacitated individual's needs. The incapacitated individual is usually able to attend the hearing and can be appointed counsel. Additionally, the individual is encouraged to be part of decisions and to regain the capacity to manage their affairs. The law places several constraints on guardians: a potential guardian must be found by the court to be qualified;

Sept. 2009, 9 Aug. 2010 <<http://www.georgiaombudsman.org/docs/TemporaryPlacementAct.doc>>.

5 Suzanne Messenger, West Virginia State Long-Term Care Ombudsman, E-mail, 29 Apr. 2010.

6 Karp & Wood, viii, 22-27.

7 Joseph Rodrigues, California State Long-Term Care Ombudsman, E-mail, 28 Apr. 2010.

8 Karp & Wood, viii, 27-29.

9 M. Carl Glatstein, Glatstein & O'Brien LLP, E-mail, 28 Apr. 2010.

10 Becky Kurtz, Georgia State Long-Term Care Ombudsman, E-mail, 24 May 2010.

11 Kimberly Baker, Kentucky State Long-Term Care Ombudsman, E-mail, 29 Apr. 2010.

a guardian does not have authority to admit their ward to a nursing home without court approval; and guardians are required to submit annual reports about the mental, physical and social conditions of their ward.¹²

- Rhode Island has a public guardianship program.¹³
- West Virginia uses guardianship in cases where the decisions are beyond the scope of health care. The West Virginia Department of Health and Human Resources serves as the representative of last resort.¹⁴

- *Court authorization for treatment or guardians for limited temporary medical treatment*

Definition: Consent, or the appointment of an individual to provide consent for health care, sought through a state court process.¹⁵

Examples:

- In Georgia, under SB 367, if no one on the list of authorized persons exists or is willing to give consent to surgical or medical treatment, any interested person or health care facility can initiate an expedited judicial intervention by filing a petition for the appointment of a temporary medical consent guardian.¹⁶

Under Georgia's Temporary Health Care Placement Decision Maker for an Adult Act, individuals or the current facility can petition the probate court for a health care placement transfer, admission or discharge order if no

one on the list of authorized persons exists to give consent to admission, discharge or transfer to another facility. The court orders are sent to the state ombudsman who notifies local ombudsmen to check on long-term care residents who have no decision makers. Ombudsmen are made aware of the presence and vulnerability of these individuals through this notification process.¹⁷

- In Kentucky, Adult Protective Services (APS) can seek a court order for a procedure under an Emergency Protective Services Order. In this case, a physician has to provide a statement about the "imminent need of the procedure" along with documentation about why the individual cannot provide informed consent themselves.¹⁸
- Rhode Island petitions the Mental Health Court for a Petition to Instruct, thereby asking the court for permission on a one time only basis, permission to have surgery or permission for medical tests.¹⁹
- In Utah, decision-making issues go through the Office of Public Guardian where the petitioner seeks a court order for Emergency Guardianship, and a physician has to provide a statement regarding the imminent need for guardianship.²⁰

Institutional Practice

In states where there are no existing provisions for legislative mechanisms to make decisions on behalf of incapacitated, unbefriended elders and where there are no health care consent laws with decision-maker hierarchy, advance directives and guardianship are often "the only statutorily authorized mechanisms".²¹ In some instances, communities and institutions have taken different approaches to

12 Wynn Gerhard, Massachusetts Guardianship Task Force, Greater Boston Legal Services, "Fact Sheet, S. 2622, An Act Protecting Persons Under Disability and their Property."

13 Kathy Heren, Rhode Island State Long-Term Care Ombudsman, E-mail, 29 Apr. 2010.

14 Messenger.

15 Karp & Wood, viii, 29-32.

16 Georgia General Assembly.

17 Thomas.

18 Baker.

19 Heren.

20 Daniel Musto, Utah State Long-Term Care Ombudsman, E-mail, 3 May 2010.

21 Karp & Wood, viii, 32-33.

decision-making on behalf of unbefriended elders.²²

- *Ethics Committees*
These committees help to address ethical dilemmas in acute and long-term care facilities. For the most part, ethics committees provide assistance, education, consultation, etc., rather than making health care decisions for unbefriended elders.²³
- *Informal Surrogate Systems*
One variation for a surrogate system is for the ethics committee to assign a member of the committee to an unbefriended individual as an informal surrogate. The surrogate relationship generally begins while the elder has some capacity to make decisions so that they can consent to the relationship and the surrogate can get to know the resident and their preferences and values; such conversations occur on a regular basis and are documented.²⁴
- *Ad Hoc Procedures*
Institutions and providers often develop internal procedures for obtaining consent for treatment, such as the facility administrator or physician giving consent on behalf of the unbefriended elder.²⁵

Hierarchy Laws

Below is information about state decision-maker hierarchy laws that NORC collected from its 2010 outreach to state long-term care ombudsmen. It is not inclusive of all states; it reflects the information NORC received from ombudsmen who responded to the request for information.

Georgia

Georgia Law SB 367 expands the list of people who can make the decision about surgical or medical treatment for an incapacitated individual. The law addresses consent for surgical or medical treatment or procedures for individuals across the age-span. However, the portions pertaining to adults and elders state that in addition to anyone who is authorized, any adult can consent for themselves. Further, anyone who is authorized to give consent under an advance directive for health care or durable power of attorney for health care can provide consent. If neither of the above options exists or is available, a married individual can give consent for their spouse or a guardian can consent for their ward. If an adult cannot consent for themselves and there is no authorized person from the above list, the order of priority for those authorized to consent to medical treatment are: (1) an adult for their parents; (2) a parent for their adult child; (3) an adult for their sibling; (4) a grandparent for their grandchild; (5) an adult grandchild for their grandparent; (6) an adult niece, nephew, aunt, or uncle of the person in question “who is related to the patient in the first degree;” or (7) an adult friend.²⁶ To learn more about the law in instances where there is no one willing or authorized to provide consent, see the “Court authorization for treatment or guardians for limited temporary medical treatment” subsection of the Existing Mechanisms and Practice section of this document.

Georgia’s Temporary Health Care Placement Decision Maker for an Adult Act, as mentioned above, provides assistance to family members or others who need to provide placement for

22 Ibid.
23 Karp & Wood, viii, 33-37.
24 Karp & Wood, 37-38.
25 Ibid., viii, 38-40.
26 Georgia General Assembly.

adults who cannot give consent and have not authorized consent regarding admission, transfer or discharge from a health care facility. The order of priority for individuals who can make the decision about transfer, admission or discharge, is as follows: (1) an adult for themselves; (2) anyone named in a Durable Power of Attorney for Health Care Act; (3) a guardian for their ward; (4) a spouse for their spouse; (5) an adult child for their parent; (6) a parent for their adult child; (7) an adult for their adult sibling; (8) a grandparent for their adult grandchild; (9) an adult grandchild for their grandparent; (10) an adult uncle or aunt for their adult nephew or niece; or (11) an adult nephew or niece for their adult uncle or aunt. Under the law, the current health care facility's social worker, discharge planner or other designated person must help the authorized individual "with identifying the most appropriate, least restrictive level of care available, including home and community based services and available placements" that is as close as possible to where the individual in question currently resides. For information about the law in the absence of an individual who is authorized to consent, see the "Court authorization for treatment or guardians for limited temporary medical treatment" subsection of the Existing Mechanisms and Practice section of this document.²⁷

New Mexico

The Uniform Health-Care Decisions Act (NMSA 1978) allows an individual to complete an Advance Health-Care Directive. An individual with capacity can also designate someone to act as surrogate.²⁸

A surrogate can make a health care decision for an individual if it has been determined that the individual lacks capacity (according to the provisions of New Mexico law) and there is either no designee or guardian or the designee or guardian is not available. If there is no designated surrogate or if the surrogate is not available, the state identifies and prioritizes surrogate decision-makers based on their relationship to the individual, even if they are not named in the Advance Health-Care Directive. The priority list for potential surrogates is as follows: "(1) the spouse, unless legally separated or unless there is a pending petition for annulment, divorce, dissolution of marriage or legal separation; (2) an individual in a long-term relationship of indefinite duration with the patient in which the individual has demonstrated an actual commitment to the patient similar to the commitment of a spouse and in which the individual and the patient consider themselves to be responsible for each other's well-being; (3) an adult child; (4) a parent; (5) an adult brother or sister; or (6) a grandparent." If none of the potential surrogates listed above are available, "an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values and who is reasonably available may act as surrogate."²⁹

Promising Practices

The following programs and practices are those that are potentially promising based on our research; we have not conducted thorough interviews with others in the state to gather their feedback.

Volunteers of America - Minnesota's Unbefriended Elders: Matching Values with Decisions Project

This project is located in Minneapolis and "supports the rights and choices of unbefriended elders/adult orphans who are at risk of incapacity." The project, supported in part by a

²⁷ Thomas.

²⁸ "Advance Health-Care Directives," Senior Supplement, An Education Service of Lawyer Referral for the Elderly Program, Apr. 1999 <http://www.nmaging.state.nm.us/PDF_files/AHCDQA.pdf>.

²⁹ Justia.com, US Laws, "New Mexico Article 7A – Uniform Health-Care Decisions, 24-7A-1 through 24-7A-18." 9 Aug. 2010 <http://law.justia.com/newmexico/codes/nmrc/jd_ch24art7a-acff.html>.

Community Service/Community Services Development grant from the Minnesota Department of Human Services and a grant from the Stevens Square Foundation, began in 2008 and will continue through October 2010. An unbefriended elder is defined as an older adult with no identifiable family or friends to help with medical decisions. The project, which is free to participants, seeks to create proactive involvement with at-risk individuals before a medical crisis occurs or they become incapacitated. To be eligible, participants must live in specific areas of Minnesota, be 65 years of age or older and have no known emergency contact or responsible person. Additionally, participants must have no written Health Care Directive and/or no verbal health care instructions and/or be at risk of guardianship. Project staff assist unbefriended elder participants by working to locate their family members to seek reconnection; making sure that medical wishes are known, discussed and documented by facilitating communication between elders and their primary care practitioners; working with the elder to identify a surrogate decision-maker when possible; and facilitating and distributing completed health care directives to appropriate professionals.³⁰ Since 2008, the program has worked with 75 individuals. The rate of completion for a health care directive is approximately 60%. Of that 60%, approximately 80% of elders named a health care agent. Many of the approximately 40% of participants who did not complete a health care directive simply refused service (as compared to them being incapacitated).³¹

Contact: Mary Bornong, 612.617.7815, mbornong@voamn.org

SAFE, Special Advocates for Elders

This program in Washoe County, Nevada “recruits, trains and supports volunteer advocates to form one-on-one relationships with their assigned elder.” Guardianship judges in Nevada may appoint a SAFE advocate to an individual who is under or facing guardianship. SAFE advocates offer support, assess the participants’ needs, investigate care received and speak for the participants.³²

Contact: SAFE Executive Director Scott Trevithick: 775.325.6717

Guardianship Alliance of Colorado

The Guardianship Alliance of Colorado (GAC) is part of Cerebral Palsy of Colorado’s Statewide Family Support Services, and provides information and guidance about adult guardianship. GAC also provides the following programs and services: Volunteer Guardian Program; Guardian Training classes; Guardianship Petition Assistance classes; Information and Referral Services; Presentations and In-Service Training. GAC sometimes provides volunteer guardians for unbefriended elders when county Adult Protective Service departments decline involvement.³³

Regular Review of Values and Preferences

Regularly review individuals’ values and preferences, and make sure their advance directive or other written documentation expressing their preferences is up to date. Colorado’s Medical Orders for Scope of Treatment (MOST) law (HB 1122) follows Oregon’s Physician Orders for Life Sustaining Treatment (POLST). Under MOST, health care professionals are authorized to work to prepare advance directives with the individual or surrogate; the directives then become medical orders. MOST has been adopted in seven states outside of Colorado, and is being considered in additional states as well.³⁴

30 Volunteers of America, Minnesota, “Unbefriended Elders: Matching Values with Decisions.” 2009, 9 Aug. 2010. <<http://www.voamn.org/Services/SeniorServices/UnbefriendedEldersProject/tabid/7425/Default.aspx>>.

31 Mary Bornong, Geriatric Care Manager and Program Director, Access Advisors, Volunteers of America - Minnesota, Phone conversation, 9 Aug. 2010.

32 “RSVP Station Highlight, Become A Legal Advocate,” *RSVP of Washoe County Newsletter*, Mar 2010: 2.

33 Guardianship Alliance of Colorado, “Guardianship Alliance of Colorado.” 9 Aug. 2010 <<http://www.guardianshipallianceofcolorado.org/>>.

34 Glatstein.

As law allows, involve interested persons (family, friends and neighbors) in assessing resident values and preferences.

Strategies and Ideas for Ombudsmen

- Promote, hold and encourage educational events
 - In-service trainings on advance directives for ombudsmen, facility staff, or others
 - Work with organizations including citizen advocacy groups (CAGs) in your state to bring attention to the issue of unbefriended elders and assess next steps and advocacy needs
 - I.e. creating an office of public guardian, promoting the use of advance directives, guardianship certification, determination and assessment of capacity
- Work with state organizations, including your state CAG for advocacy around various issues in your state
 - I.e. decision-maker hierarchy, advance directive changes, guardianship certification requirements, limits on guardianship powers, how capacity is determined and re-assessed
- Learn about institutional practices in the long-term care facilities in your state
 - I.e. surrogate systems, ethics committees, etc.

Policy Suggestions

The policy suggestions below are excerpted from the American Bar Association Commission on Law and Aging report, *Incapacitated and Alone: Health Care Decision-Making for Unbefriended Elderly*, and “seek to ensure that patients with no advocate and no track record of values and life history are the focus of a deliberative process of both medical and ethical scrutiny.

1. Research should analyze federal data on long-term care residents to shed light on the unbefriended population.
2. Further study should include a focus on cultural diversity and health care decision-making.
3. Long-term care staff should play a greater role in investigating and conveying resident values and preferences.
4. Long-term care facilities should develop procedures for collecting and using resident histories and values information.
5. Health care professionals should improve techniques for assessing and enhancing patient decisional capacity; and medical institutions should provide training for health care professionals in assessment of capacity for informed consent.
6. In developing decision-making mechanisms for unbefriended elderly patients, policymakers should seek to incorporate hallmark characteristics that will best serve this vulnerable population.
7. Facilities should develop and/or strengthen internal decision-making mechanisms; and states and communities should develop external bodies to make health care decisions for patients lacking surrogates.
8. Facilities should develop, and funders should support, demonstration projects involving ethics committee decision-making on behalf of unbefriended patients.
9. States with existing surrogate decision-making systems should test their use for the unbefriended elderly population.
10. State health care consent laws and their practical application to the unbefriended population merit further study.
11. States and localities should develop temporary medical treatment guardianship programs.
12. States should support public guardianship programs that are adequately funded and staffed; and research should explore key questions about the quality of care and decision-making in public guardianship programs.”

Additional Resources and Sample Forms and Documents

- Advance Directives and State-Specific Resources
 - Caring Connections: <http://www.caringinfo.org/stateaddownload>
 - National Healthcare Decisions Day: <http://www.nationalhealthcaredecisionsday.org/>
- Aging with Dignity – Five Wishes
 - <http://www.agingwithdignity.org/five-wishes.php>
- My Personal Directions for Quality Living (sample and blank forms)
 - <http://www.theconsumervoice.org/sites/default/files/advocate/My-Personal-Directions-Blank-Format.pdf>
 - <http://www.theconsumervoice.org/sites/default/files/advocate/My-Personal-Directions-Sample.pdf>

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