

Office of Public Guardianship
Advisory Committee Recommendations for a Pilot Program

THE PUBLIC GUARDIANSHIP ADVISORY COMMITTEE’S REPORT
TO THE CHIEF JUSTICE OF THE COLORADO SUPREME COURT

Advisory Committee members:

Hon. Elizabeth Leith (Chair)
Hon. Mark MacDonnell
Hon. Mary Deganhart

Affiliation

Denver Probate Court
16th Judicial District
7th Judicial District

Representative

Peggy Rogers
Nancy Sharpe
M. Carl Glatstein
Sarah Solano
Dr. Debra Bennett-Woods
Darla Stuart
Mary Catherine Rabbitt

Policy Advisor, Office of the Governor
Colorado Department of Human Services
Arapahoe County Commissioner
Elder Law Section Colorado Bar Assoc.
Guardianship Alliance of Colorado
Colorado Collaborative for Unrepresented Patients
The Arc of Aurora
Legal Center for People with Disabilities
and Older People
Colorado Health Care Association
Acting Director/Deputy Director of Clinical
Services, Colorado Department of Human Services,
Office of Behavioral Health

Arlene Miles
Patrick K. Fox, M.D.

Date of Recommendation:

July 31st, 2014

Acknowledgements

List of assisting persons or organizations

Affiliation

Joseph McMahon
Staff

Collaborative Processes®, (LLC)
State Court Administrator's Office

TABLE OF CONTENTS

	PAGE
Charge to the Committee	5 - 6
Executive Summary	7
Introduction	8 – 9
Scope of Work	10
Process	11
Recommendations	12 – 24
Appendices	25 - 53

APPENDICES

	PAGE
Attachment A – Definitions and Acronyms	25
Attachment B – Narrative Examples of Persons in Need of Public Guardianship Services	26 - 29
Attachment C – White Paper, Colorado Collaborative for Unrepresented Patients	30 – 49
Attachment D – Proposed Budget	50
Attachment E – Program Timeline	51
Attachment F – Other State Experiences	52 - 53



Chief Justice Charge
Establishing the
Public Guardian Advisory
Committee

Purpose and Authority

Colorado lacks sufficient systems to protect indigent, incapacitated adults who do not have appropriate family or friends available to act as guardian. For high-risk, low-income persons there is no money to hire a professional guardian. Additionally, the State of Colorado does not have a public guardianship program or other resources that could address the needs of these vulnerable people.

Committee Charge

In its final report to the General Assembly, the Elder Abuse Task Force, created by Senate Bill 12-078, recommended further study of the need for and implementation of a public guardianship system in Colorado. In order to better understand the approaches to public guardianship that may work best in Colorado, the Public Guardian Advisory Committee was originally charged on July 3, 2013 to review these issues and filed its final report on February 7, 2014. The committee is charged anew with the following tasks:

- Design a pilot project for the purpose of testing the benefit of public guardian services for indigent, incapacitated, isolated adults.
- Recommend the counties to be included in the pilot project and the number of cases to be provided pilot services.
- Recommend the target populations for these services, including the distinct characteristics of groups that are most in need of these services.
- Recommend an oversight and compensation model for these services.
- Recommend standards of practice and a code of ethics for public guardianship services and to ensure equal access and protection for all individuals in need of public guardianship services.
- Provide for an evaluation plan to describe the costs and benefits of public guardianship services. This plan should be aimed at providing information to policy makers regarding the feasibility and benefit of adopting a publicly funded guardianship model on a statewide basis.
- Define the scope of guardianship services to the extent possible.
- Recommend a data and case management system to track public guardian services provided.

- Identify stakeholder agencies to be involved with the pilot project
- Other pertinent recommendations as identified by the task force.

The Public Guardian Advisory Committee shall report back to the Chief Justice with their recommendations on or before **August 31, 2014**.

Membership

The following persons are appointed to serve as members of the Public Guardian Advisory Committee:

<u>Advisory Committee members:</u>	<u>Affiliation</u>
Hon. Elizabeth Leith (Chair)	Denver Probate Court
Hon. Mark MacDonnell	16th Judicial District
Hon. Mary Deganhart	7th Judicial District
Representative Peggy Rogers	Policy Advisor, Office of the Governor
Nancy Sharpe	Colorado Department of Human Services
M. Carl Glatstein	Arapahoe County Commissioner
Sarah Solano	Elder Law Section Colorado Bar Assoc.
Dr. Debra Bennett-Woods	Guardianship Alliance of Colorado
Darla Stuart	Colorado Collaborative for Unrepresented Patients
Mary Catherine Rabbitt	The Arc of Aurora
Arlene Miles	Legal Center for People with Disabilities and Older People
Patrick K. Fox, M.D.	Colorado Health Care Association
	Acting Director/Deputy Director of Clinical Services, Colorado Department of Human Services, Office of Behavioral Health

Additional persons may be asked to serve as sub-committee members when deemed appropriate by this advisory committee as related to the goals and objectives assigned in this charge.

Effective this 14 day of July, 2014.

Nancy E. Rice
Nancy E. Rice, Chief Justice

Executive Summary

Colorado courts struggle to address the needs of incapacitated adults who do not have the resources or family to provide for their own guardianship needs. Without a system of providing legal guardianship services to indigent persons, the courts are left with few options for addressing these person's needs. The Public Guardian Advisory Committee (PGAC) was charged by the Chief Justice of the Colorado Supreme Court to study these needs, after review of the final report of the Elder Abuse Task Force created by Senate Bill 12-078 to the 2013 General Assembly. The broad PGAC membership has allowed an expansive review of the issues including many different points of view. The PGAC unanimously supports a pilot project. The overall goal of the pilot project is to test the viability of implementing public guardianship services for incapacitated, indigent and isolated adults and to provide data to support a legislative request for funding such an office.

The Committee recommends:

- The Judicial Department initiate a pilot project to **quantify** Colorado's unmet need for public guardian services for incapacitated, indigent and isolated individuals, to assess the average cost associated with these services, and to evaluate the net cost and benefits to the individual and the State of Colorado;
- Three judicial districts participate in the pilot project: 2nd (Denver), 7th (Montrose) and 16th (Otero). The study includes an assessment of whether an independent office, such as the current Office of the Child's Representative (OCR), is preferable and feasible statewide. Alternatively, the study should include a determination as to whether an office such as OCR could, or should, be expanded to include public guardian services.
- Professional standards of practice be adopted for public guardian-designees; and
- The case management system newly developed for the Colorado Department of Human Services Adult Protection Services (CDHSAPS) be purchased, modified and incorporated into the pilot project, if possible.

Introduction

Incapacity is a legal term that describes when someone cannot understand relevant information or cannot appreciate what may happen as a result of decisions they make or do not make about their finances, health or personal care. This may present as an inability to meet their own personal needs for medical care, nutrition, clothing, shelter, or safety, even with appropriate and reasonably available technological assistance.

If an adult in the community appears to exhibit incapacity issues, a person interested in the individual's welfare may initiate a petition for a guardianship proceeding to determine if the person satisfies the legal standard of incapacity. If proven, the court will appoint a guardian that has the legal authority and duty to care for the incapacitated person, who is then called a ward.

Any interested person age 21 or older may be appointed as a guardian in Colorado. For a majority of incapacitated persons, a family member or friend assumes the role of guardian and performs the decision-making responsibilities. Other wards are able to pay for a certified professional guardian. However, some persons do not have family, friends, or the financial resources necessary to obtain guardianship services or someone to petition the court on their behalf.

Colorado Statutes provide for protective services for at-risk adults both with and without consent, §26-3.1-104, C.R.S. If a county director determines an at-risk adult is self-neglecting and the at-risk adult consents to protective services, the county director is directed to immediately provide or arrange for the provision of protective services. If the at-risk adult appears to lack capacity to make decisions and does not consent to services, the county department of human/social services (County Department) director is *urged*, if no other appropriate person is able or willing, to petition the court for an order authorizing the provision of specific protective services and for the appointment of a guardian. Currently, there are not enough guardians and there is inadequate funding for guardianship services to be provided by County Departments. Therefore, counties restrict the number of cases they can accept due to limited resources, and may opt not to provide guardianship services at all. This creates a disparity state-wide regarding where guardianship services by Adult Protective Services are provided.

These limitations were exemplified by the Colorado Court of Appeals case *In re Estate of Sarah Morgan*, 160 P.3d 356 (Colo.App. 2007). The guardian *ad litem* for Sarah Morgan petitioned the court for the appointment of a guardian for Sarah and no one could be found. In a last move, the court appointed the county department of human services (DHS) as guardian. DHS objected to the appointment as guardian, because an acceptance of office was not submitted to indicate DHS agreed to the appointment. The court of appeals agreed and reversed the lower court's decision by holding the decision whether to provide services to, or seek a guardian for, an at-risk adult rests within the discretion of the director of the County Department and not with the court. The Colorado Court of Appeals also acknowledged the difficulty this situation creates, by stating:

“Yet, for persons like Morgan, who have been “wards of the State” for much of their lives and whose disabilities render them incapacitated as

defined by law, guardianship through a public agency may be the last resort before they fall through the cracks of our society. See Commonwealth v. Cabinet for Human Res., 686 S.W.2d 465, 468 (Ky.Ct.App.1984)(“Without either guardian or conservator, the [ward] is in a desperate situation. Given the provisions of [Kentucky's statutory framework], it is clear that the legislature intended to see that mentally retarded individuals are cared for by the state.”).

Despite a court’s finding of incapacity, a court does not have statutory authority to require a public agency to assist a ward. *Morgan, supra*. As a result, wards are left to their own devices and may linger in institutional settings such as a jail or hospital without a guardian or may become homeless.

Other states have similarly grappled with this issue and adopted various forms of public guardianship services over the years. The most recent State that passed a public guardianship program was Nebraska in 2014.

“We tried to do it on a volunteer basis, but it didn’t work out as everybody would have liked,” said Governor Dave Heineman.

Though Senator Colby Coash, who introduced the bill, said it has been years in the making, a very public scandal last fall showing flaws in Nebraska’s volunteer guardianship program provided the motivation to get this done.

The PGAC has determined Colorado’s experience is similar to Nebraska, in that volunteer guardian programs, while available on a limited basis, are insufficient to address Colorado’s statewide needs. This paper discusses formation of a pilot project to serve as the basis for state funding of a public guardianship program. Narrative examples of persons in need of public guardianship services drawn from PGAC committee member case experiences are contained in the Appendix, Attachment B.

Scope of Work:

In its final report to the 2013 General Assembly the Elder Abuse Task Force, created by Senate Bill 12-078, recommended further study regarding the need for the implementation of a public guardianship system in Colorado. In order to better understand the approaches to public guardianship that may work best in Colorado, the Public Guardian Advisory Committee was established by the Chief Justice of the Colorado Supreme Court and charged anew with the following tasks:

- **Design a pilot project for the purpose of testing the benefit of public guardian services for indigent, incapacitated, isolated adults.**
- **Recommend the counties to be included in the pilot project and the number of cases to be provided pilot services.**
- **Recommend the target populations for these services, including the distinct characteristics of groups that are most in need of these services.**
- **Recommend an oversight and compensation model for these services.**
- **Recommend standards of practice and a code of ethics for public guardianship services and to ensure equal access and protection for all individuals in need of public guardianship services.**
- **Provide for an evaluation plan to describe the costs and benefits of public guardianship services. This plan should be aimed at providing information to policy makers regarding the feasibility and benefit of adopting a publicly funded guardianship model on a statewide basis.**
- **Define the scope of guardianship services to the extent possible.**
- **Recommend a data and case management system to track public guardian services provided.**
- **Identify stakeholder agencies to be involved with the pilot project**

Process:

The Public Guardian Advisory Committee (PGAC) published its first recommendation for establishing an Office of Public Guardianship within the State of Colorado coupled with additional need for studies. (*The PGAC's report to the Chief Justice of the Colorado Supreme Court, dated February 2014*). *The group anticipated asking for an interim committee study. However, in light of the election year, it was determined that this issue might not rise as a top priority for interim committee designation.*)

Consequently, it was decided to pursue the possibility of a public guardianship pilot within the Judicial Branch and to attempt funding of the pilot project through a judicial budget request. Through the pilot project, necessary factual information will be collected to approach the legislature to request the creation of a public guardianship office and funding for such an office.

To that end the Chief Justice formulated a new charge (June 2014) directing the PGAC to develop a pilot public guardian office to provide services to the identified target population and collect data necessary to determine the cost of providing such services statewide. Through extensive discussion, review of concerns from various interest groups and analysis of the existing limitations, the PGAC developed a pilot office proposal that will answer these primary questions: a method to quantify Colorado's unmet need for public guardianship services for incapacitated, indigent and isolated individuals, an assessment of the average cost associated with these services, and an evaluation of the net cost and benefits to the individual. The information gathered is intended to support a possible legislative proposal.

Members of the PGAC are united in their determination that a definite need exists in Colorado for a public guardian, that the unmet need remains to be quantified and qualified, as well as to determine where such an office would be housed. Viable options discussed include creation of a new and separate office modeled after the Office of the Child's Representative (OCR) within the Judicial Branch, an expansion of the OCR, or an agency within the Department of Human Service in the Executive Branch. (*The PGAC's report to the Chief Justice of the Colorado Supreme Court, dated February 2014*).

- **1. Recommended target populations for these services, including the distinct characteristics of groups that are most in need of these services.**

The target population for these services is characterized by Colorado's lack of sufficient systems to protect *incapacitated* adults who are *isolated* and do not have appropriate family or friends available to act as guardian, and who are indigent and do not have the financial resources to hire a professional fiduciary.

The need for a guardian arises when a qualified local source identifies a person who may be in need of guardianship services. This local source may include but not be limited to an adult care facility, Adult Protective Services, a hospital or any other organization that supports individuals who work with indigent and incapacitated people. A person's incapacity may have different causes, such as a primary diagnosis of mental illness, intellectual or developmental disabilities, complications from Alzheimer's disease, dementia or traumatic brain injury. Once a local source has identified a person in need of adult guardianship services, the local source may submit a certified referral that includes factual information about the individual. Certified referrals must include an explanation of any and all lesser intrusive interventions that have been unsuccessfully applied. It is believed that many individuals who are incapacitated, isolated, indigent and without a guardian are maintained in inappropriate settings which are not the least restrictive, such as a hospital intensive care unit or other inpatient acute care setting, a care facility rather than a community setting or in a county jail. Some incapacitated, isolated and indigent individuals are homeless as they are unable to successfully apply for services which would assist them to obtain housing, food and medical services.

- **2. Define the scope of guardianship services to the extent possible.**

The Committee recommends no additional filters be added for adult public guardianship services beyond the *isolated*, *incapacitated* and *indigent* status. Therefore, all new adult guardianship cases that satisfy these constraints within one of the pilot districts are eligible to apply for participation in the proposed pilot, subject to available funding.

Guardianship services to be provided include, at a minimum, the following:

- review of an individual's supporting documentation provided by the local source
- preparation of petitions, documents, notices and provision of legal services for all phases of proceedings before the court to establish guardianship
- legal support for modification or termination of guardianships
- recruitment, training and oversight for guardian-designees
- implementation and maintenance of a case monitoring system
- budgeting and payment to guardian-designees

- establishment of relationships with agencies, non-profit organizations, companies, individual care managers and direct-care providers to provide services within the financial constraints established for the office
- establishment of relationships with local, state and federal governmental agencies to provide funding and service support
- public education and outreach regarding the role of the office and guardian-designees

§ 15-14-314, C.R.S. defines the duties of a guardian. A guardian shall make decisions regarding the ward's *support, care, education, health and welfare* to the extent necessitated by the ward's limitations.

Service decisions may range from residential placement in the community or a facility to medical treatments, on-going casework, or locating the appropriate person to serve as guardian. For example, deciding where the ward will live is a decision based on the ward's preferences, needs and resources. It may mean deciding the community the ward will live in, whether the ward will live at home, in a group home, nursing home or other living arrangement based on the least restrictive environment consistent with the individual's needs. Based on the current information available to the Committee, it is believed many individuals may be moved from a current facility-based living arrangement to a community placement with support services. A guardian-designee would be responsible for ensuring the ward receives good care, arrange for any appropriate training, education, employment, habilitation or rehabilitation the ward may need, giving consent or approval for the ward to receive any needed services (medical, dental, legal, psychological, etc.), taking reasonable care of the ward's personal belongings and to inform the court if the ward's condition has changed so that the ward is capable of exercising rights previously removed.

There are limitations to a guardian's duties. For example, a guardian may not revoke a medical durable power of attorney and also may not initiate the commitment of a ward to a mental health-care institution, except in accordance with the state's procedure for involuntary civil commitment and no guardian shall have the authority to consent to any mental health care or treatment against the will of the ward.

Guardianship services to be provided under the Pilot will include the appointment of temporary guardians for persons in need of short-term medical decision-making. The Colorado Collaborative for Unrepresented Patients has authored a White Paper which addresses gaps in healthcare decision making for unrepresented adults, defined as adult patients who lack decisional capacity to give informed consent for medical treatment, do not have an applicable advance directive, and for whom there is no legally authorized surrogate decision maker, family or friend who is available, competent and willing to assist with medical decision-making. Under current Colorado law for these individuals, there is a critical gap between clinical treatment authorized by statutory "emergency waiver" provisions and the ability to provide other medical treatment. A court-appointed guardian is necessary to make those decisions on behalf of the

unrepresented patient in a timely and appropriate manner. These issues are more fully described by the White Paper attached in the Appendix, Attachment C.

- **3. Recommend counties to be included in the pilot project and the number of cases to be provided services.**

The following three judicial districts were selected based upon their urban and rural population characteristics: 2nd (Denver), 7th (Montrose) and 16th (Otero). The three judicial districts show a total population of 731,501 residents, broken down by individual districts (Denver 600,158), (Montrose 100,190) and (Otero 31,153), or 17% of the entire Colorado population (731,501/5,029,196) and represent a large, a medium and a small county. ¹

P2: URBAN AND RURAL - Universe: Total population dola.colorado.gov							
Fip Code	Area	Total:	Urban:	Inside urbanized areas	Inside urban clusters	Rural	Pct Rural
TOTAL	Colorado	5,029,196	4,332,761	3,865,471	467,290	696,435	14%
8011	Bent County, Colorado	6,499	4,032	-	4,032	2,467	38%
8025	Crowley County, Colorado	5,823	-	-	-	5,823	100%
8029	Delta County, Colorado	30,952	11,399	-	11,399	19,553	63%
8031	Denver County, Colorado	600,158	600,158	600,158	-	-	0%
8051	Gunnison County, Colorado	15,324	6,343	-	6,343	8,981	59%
8053	Hinsdale County, Colorado	843	-	-	-	843	100%
8085	Montrose County, Colorado	41,276	22,706	-	22,706	18,570	45%
8089	Otero County, Colorado	18,831	12,352	-	12,352	6,479	34%
8091	Ouray County, Colorado	4,436	-	-	-	4,436	100%
8113	San Miguel County, Colorado	7,359	-	-	-	7,359	100%
		731,501					

¹ The demographics of the Denver population is comprised of (143,526 [82%]) younger than 20 years of age, (366,254 [84%]) between ages 20 and 60 and (90,378 [75%]) older than age 60. The Montrose population is comprised of (24,556 [14%]) younger than 20 years of age, (52,164 [12%]) between ages 20 and 60 and (23,470 [19%]) older than age 60. The Otero population is comprised of (7,307 [4%]) younger than 20 years of age, (17,051 [4%]) between ages 20 and 60 and (6,795 [6%]) older than age 60.

During the years 2000, 2010, and 2013 a total of 3,485 (1,208, 938, 1,339) new adult guardianship cases were filed in Colorado statewide: Denver, 560 (201, 158, 201) adult guardianship cases, Montrose, 85 (19, 32, 34); and Otero, 26 (10, 9, 7) respectively. Combined, a total of 242 adult guardianship cases were filed in 2013, or 18% of all Colorado adult guardianship cases were filed in the three pilot regions.²

	2000	2010	2013	
	GA (CG) cases filed			
2nd Judicial district	201	158	201	
7th Judicial district	19	32	34	
16th Judicial district	10	9	7	242
(rest)	978	739	1097	
TOTAL	1208	938	1339	

Therefore, a sample of 200 cases in these three pilot regions should satisfy a possible study. If for some reason, the sample size cannot be met by these three pilot regions, additional districts may be added to compensate for the gap. On the other hand, if the unmet need should exceed the pilot's budget or case load of 200, a waiting list will be created.³

² Using an extrapolation of Professor Schmidt's population extrapolation estimate method provides an anticipated need for adult guardianship cases in the three districts total 640 cases (526, 87, 27 respectively).

2nd Judicial district > 20 (456,632 * 0.00115) = 526

7th Judicial district > 20 (75,634 * 0.00115) = 87

16th Judicial district > 20 (23,846 * 0.00115) = 27

³ The margin of error with 200 pilot cases – with an underlying population of 1,339 new adult guardianship petitions filed in 2013 – would equate to 6,5%.

- **4. Recommend an oversight and compensation model for these services.**

The Committee recommended creation of an independent office modeled on the OCR or alternatively, the expansion of the present OCR to include not only Colorado's most vulnerable children but also Colorado's most vulnerable adults. This outline presumes the creation of an independent office modeled on the OCR. However the possibility of expanding the current OCR may still be explored, if feasible. (*See Office of Public Guardianship Advisory Committee Recommendations: The Public Guardian Advisory Committee's Report to the Chief Justice of the Colorado Supreme Court, dated February 2014*).

The OCR-LIKE model "Office" will be staffed with a director, an administrative assistant, a transition coordinator, a staff attorney, a programmer-analyst, and 10 public guardian-designees who will each handle up to 20 individuals, for a total of 200 new adult guardianship cases. There is a total need of 15 FTE. *See Appendix, Attachment D*.

The Committee recommends the public guardian-designees be hired based on a broad knowledge of human development, intellectual disabilities, sociology, and psychology with business acuity and experience in public education and volunteer recruitment.

The office shall provide equal access and protection for all eligible individuals in need of guardianship services and who meet the criteria established for OPG clients (isolated, incapacitated, indigent), shall have the ability to respond immediately when a guardian is needed in an emergency situation and to provide an option upon the resignation, removal or discharge of a guardian-designee without lapse in service to the ward. The office shall provide public education to increase the awareness of the duties of the public guardian. The office will serve as a resource to persons already serving as guardians for education, information and support. The office shall always work to safeguard the rights of individuals by exploring all options available to support individuals in the least restrictive manner possible (including placement in the community) and seek full guardianship only as a last resort. The public guardian-designees appointed through the state office shall model the highest standard of practice for guardians to improve the performance of all guardians.

The OCR was created by the General Assembly in 2000 to improve representation for Colorado's most vulnerable *children* by establishing minimum standards of practice and providing litigation support, accessible high-quality statewide training and oversight to guardians *ad litem*. The OCR oversees attorneys providing services as guardian *ad litem*, child's legal representative, and attorney child and family investigators. OCR provides timely services, is simple in application and avoids complexity. OCR maintains good community connections, aims toward the least intrusive measures, increases the number of qualified providers, and encourages volunteerism. OCR not only partners with volunteers, but it recruits and trains appropriate contractors, thereby creating an eligibility list for court appointments. The Committee has determined these same attributes are necessary for an Office of Public Guardian.

- **5. Design a pilot project for the purpose of testing the benefit of public guardian services for indigent, incapacitated, isolated adults.**

There are two distinct models to be considered within an OCR-like structure. Public guardian-designees may either be hired as state employees (FTE) or recruited through independent contracts.

The Committee had lengthy discussions about whether discretion should be given to the director to make these determinations following assessments in each of the three pilot regions. The pilot model may hinge upon the Office’s ability to attract qualified guardian-designees. However, staff counsel for the State Court Administrator’s Office researched the two options and determined that if the guardian-designees fall within the definition of “employees” of the judicial branch, they will enjoy the protection of the Colorado Governmental Immunity Act. They are “immunized” from legal actions, unless their actions are willful or wanton and fall outside the scope of their employment duties. If the guardian-designees are independent contractors they will not enjoy the protection of the Colorado Governmental Immunity Act, as they would not be directly supervised. Consequently, professional liability insurance may need to be secured by each individual. The Committee determined that public guardians should have the protections of the Colorado Governmental Immunity Act and so the Committee recommends the pilot office be staffed with up to 10 public guardian-designee FTE.

The pilot project is planned with a life-span of four years with an actual monitoring period of 12-15 months (4/2016 – 7/2017). Key dates are as follows:

8/2014	1 st Budget request (Fiscal year - starting 7/2015)
7/2015	Implementation of the Office with 2 nd Budget request (starting 7/2016)
7/2016	1 st interim report and 3 rd Budget request (starting 7/2017)
7/2017	2 nd interim report and Request for legislation (1/2017-11/2017)
7/2018	New office*

The process for appointment of guardian-designees through the proposed Office of Public Guardian (OPG) will use the process currently established under Colorado law. The actual design of the OPG itself will be developed after recruitment and hiring of the director and support staff. The Committee recommends the office be modeled upon the OCR with necessary adjustments to account for the differences relating to the appointments of guardian-designees as opposed to guardians *ad litem*. A more detailed time line is contained in Appendix, Attachment E.

*The Committee recommends a contingency exit strategy. Some wards may benefit from the original public guardian pilot project whether or not the final office is implemented. Therefore, a plan for long term commitment to these individuals may be needed beyond the year 2018.

- **6. Recommend standards of practice and a code of ethics for public guardian services to ensure equal access and protection for all individuals in need of services.**

After discussion, the Committee voted unanimously to adapt the National Guardianship Association's Standards of Practice (2013) as the guideline for use by the Office of the Public Guardian in Colorado. The Committee believes the NGA Standards contain the necessary components to guide the establishment of a comprehensive standard of practice and code of ethics for public guardianship services, and may be tailored for Colorado's specific needs. The NGA Standards may be found at:

http://www.guardianship.org/documents/Standards_of_Practice.pdf

- **7. Recommend a data and case management system to track public guardian services provided.**

It is the Committee's recommendation that a case management system newly developed for the Colorado Department of Human Services Adult Protection Services (CAPS) be purchased, modified and incorporated into the pilot project.

The system was designed on the Salesforce.com platform. The State has a price agreement with the contractor that built CAPS, Vertiba, Inc., and so an RFP process would not be required to engage Vertiba to re-design CAPS for use by the pilot. The CAPS case management system was built for a one-time cost of \$191,000, with a 7 year contract for maintenance and support at the cost of \$45,000 per year. The warranty includes breakdowns caused by the system or the user. There is a help desk support module within CAPS. For an additional \$55,000 per year the system can undergo external enhancements and improvements based upon identified needs and changes. Custom codes for specialized functions can be added to the system by Vertiba, either as part of the initial design of the system or as an enhancement later.

For no additional cost, the Salesforce.com platform allows state staff to become administrators with the ability to make minor changes to most areas of the system independently such as adding fields, adding windows and functions, changing pick list values, and developing additional reports and templates.

Licenses are required for each user. Administrator licenses (one for the contractor and 2-3 for the state office staff) are \$450 per year and regular user licenses are \$192.60 per year. Salesforce offers a powerful reporting package with no additional cost. An additional reporting tool, Conga, is recommended. Conga allows the user to create custom text-based reports and templates using the data in the system. Conga licenses are \$96 per user per year. The CAPS case management

system can provide the following functions: all of which would be pertinent to guardianship cases, with some minor changes:

- Intake for new reports which can include information on the client, (person in need of a guardian), reporting party, any collaterals/other people who might have knowledge of the situation, the allegations, any worker safety concerns, and any physical, medical, cognitive issues the client might have;
- Provides an area to document and manage the investigation, client assessment, and case/safety plan: gathers evidence related to the allegations, allows a quantitative assessment of the client's overall risk and safety in six major areas (physical, medical, environmental, mental/cognitive, resources/financial, and support network/supports in place), has an area to document all the services the client needs, an area to document all case notes and interviews, and a case closure function;
- Allows for all supporting documents (medical records, capacity evaluations) and photographic documentation to be uploaded and attached directly to the case so there is no need for a paper file. All records are accessible immediately to anyone assigned to the case;
- The ability to build modules to document other required activities, such as on-going worker training hours, activities of multi-disciplinary teams, worker FTE, county business hours, etc.
- The system has a reporting tool that allows the user to develop standard reports with up-to-the-second data. These reports can be made available on a worker's home page or can be downloaded or emailed to an established email list. The system also has an ad hoc reporting capability that allows the user to pull data on any field in the system so that more "obscure" reports can be developed.

The Colorado Department of Human Services implemented CAPS on July 1, 2014. County Department APS staff find the system to be intuitive, easy to use, and the implementation has gone extremely well. It is an exceptional platform for a data system with time-saving features. CAPS could be easily modified for the public guardianship office.

- **8. Identify stakeholder agencies to be involved with the pilot project**
 - Colorado Coalition for the Homeless
 - Silver Key (Senior Services)
 - Colorado Cross Disability Coalition
 - American Civil Liberties Union (ACLU)
 - The ARC of Aurora
 - Colorado Collaborative for Unrepresented Patients (CCUP)
 - Guardianship Alliance of Colorado
 - Colorado Coalition for the Homeless

- **9. Provide for an evaluation plan to describe the costs and benefits of public guardianship services, aimed at providing information to policy makers regarding the feasibility and benefit of adopting a publicly funded guardianship model on a statewide basis.**

The overall goal of the pilot project is to test the viability of implementing public guardianship services for incapacitated, indigent and isolated adults on a state-wide basis.

Unmet Need for Guardian Services - Quantity and Scope

The Committee recognizes a need for services provided by an Office of the Public Guardian in Colorado, even though it is presently unable to quantify the exact need for services with firm data. The pilot project will focus on the collection of information and data by local sources. A local source identifies a person who is in need of guardianship services. This local source may be an adult care facility, Adult Protective Services, a hospital or any other organization that works with indigent and/or incapacitated people. Once a local source has identified a person in need of adult guardianship services and who meets the criteria established for referral to the OPG, the local source will submit a certified referral to the OPG that includes factual information about the individual. Certified referrals must include an explanation of any and all lesser intrusive interventions that have been unsuccessfully applied, as well as supporting documentation such as physician statements or evaluations to support the alleged incapacity.

Other states have grappled with the same dilemma in attempting to identify or articulate an unmet need. In 1987, Schmidt and Peters studied the unmet need for guardians in Florida and developed a “population-based extrapolation model” to assess a projected total need for plenary public guardian services based upon the state’s population.⁴ The model extrapolates the need for public guardian services based upon a calculated proven percentage. Even though the extrapolation model has been successfully applied in other states, the Committee was not comfortable with relying solely on this methodology to identify the unmet need for guardianship services in Colorado. (*See Office of Public Guardianship Advisory Committee Recommendations: The Public Guardian Advisory Committee’s report to the Chief Justice of the Colorado Supreme Court, dated February 2014*).

Identifying low-income state residents who need guardianship services is a challenging undertaking for two reasons. First, not all individuals identified as in need of guardianship services may meet the statutory criteria for imposition of a guardianship. While state law defines incapacity, a definitive determination of whether a person is incapacitated cannot be made until a court determines this issue. Second, allegedly incapacitated persons who may need a guardian

⁴ Winsor Schmidt, Kent Miller, William Bell, & Elaine New, Public Guardianship and the Elderly, (Ballinger 1981).

are distributed across the state, are not routinely identified in any information system, and cannot be accessed using common survey techniques. Additionally, the type and extent of needs to be addressed by a guardianship vary by individual.

The intent of the pilot project is to capture the actual unmet need for guardianship services through the referrals to the Office of Public Guardianship and establishment of guardianships. There are three basic types of guardianships available under Colorado law:⁵

- Emergency (formerly temporary)
- Limited
- Unlimited

The case management system proposed for the pilot will track the types of guardianships established, services needed and provided, and provide the basis for detailed future queries. (*See recommendation 7 above*)

Person-centered services evaluation of individual guardianships

The delivery of person-centered services should result in the achievement of appropriate outcomes for individuals. When services and supports are targeted and customized around the needs and preferences of individuals, better outcomes are achieved and the statutory intent is fulfilled. Outcomes are affected by the services a system offers, the allocation of resources within the system, and the extent to which a system promotes the achievement of valued outcomes.

One component of the pilot project is to evaluate the well-being of the ward, taking into consideration culturally-defined values and how people experience the quality of their life both emotionally, volitionally and cognitively. To the extent possible, the incapacitated person may be asked to rate his or her personal experience before and after the guardianship services were initiated. Additional indicators will be used to evaluate the ward's support, care, education, health and welfare, consistent with statutory considerations and requirements.

The Pilot will attempt to identify for each guardianship whether the following statutory criteria were met §15-14-314(2), C.R.S.:

1. Did the guardian encourage the ward to participate in decision-making processes?

⁵ The court may appoint an emergency guardian when substantial harm to the respondent's health, safety, or welfare is likely to occur without intervention. Emergency guardianship is limited to 60 days. Appointment of an attorney for the respondent is mandatory and continues throughout the emergency guardianship. Appointment of an emergency guardian is not a determination of incapacity.

The appointment of a limited guardian grants only those powers to the guardian needed by the ward due to the ward's limitations. Limitations are included in the court order of appointment.

An unlimited guardianship grants all decision-making powers to the guardian. The court will require sufficient justification as to why a limited guardianship should not be granted.

2. When making decisions did the guardian consider the expressed desires and personal values of the ward to the extent knowable?
3. Did the guardian act in the ward's best interest and exercise reasonable care, diligence, and prudence?
4. Did the guardian become or remain personally acquainted with the ward and maintain sufficient contact with the ward to know of the ward's capacities, limitations, needs, opportunities, and physical and mental health?
5. Did the guardian take reasonable care of the ward's personal effects and bring protective proceedings if necessary to protect the property of the ward?
6. Did the guardian appropriately expend money of the ward and received by the guardian for the ward's current needs for support, care, education, health, and welfare?
7. The length of time taken for the appointment of a guardian after the need was identified by a local source.

The pilot will also evaluate whether timely provision of services, least intrusive measures and the ability to meet client needs in both urban and rural areas are achieved.

Net benefit (cost avoidance) to society

The Public Guardian Advisory Committee believes a public guardian could improve the quality of life for low-income, incapacitated, isolated persons. For example, individuals who currently reside in a long-term care facility setting could be moved into a community setting with appropriate support services. Those Adult Protective Services programs that do accept guardianship rarely will accept guardianship if the client is living in the community, as the County Department does not have staff resources to adequately monitor those clients. The Office of Public Guardianship could provide this level of monitoring to allow clients to live in the community with adequate supports in place.

The Committee has been provided information that identifies cost avoidance resulting from lower health care costs and recovery of financial assets or benefits, based on a move from facility placement to less restrictive and less costly residential settings with support services. In March 2013, the Department of Health Care Policy and Financing implemented Colorado Choice Transitions (CCT), which is a federal grant program designed to facilitate the transition of clients currently residing in nursing facilities into the community, utilizing home and community-based services (HCBS) and supports. Providing adequate levels of support in the community setting is critical to ensuring clients can live at home while receiving appropriate services and supports. For clients that transition out of institutions, the Department realizes savings by providing

services in the community, as community-based services are generally less costly than providing services in a nursing facility.⁶

Under CCT, clients receive intensive HCBS services for 365 days to ensure a successful transition. As a result, the Department does not expect to achieve cost avoidance during a client's transition year, but does expect savings in subsequent years as HCBS services return to non-intensive levels. As of February 2014, after the first year of transition, the Department expects to avoid \$10,958.38 in costs per client who is successfully transitioned from a long-term care facility to an HCBS waiver for persons receiving services through the Developmentally Disabled Individual/Dual Diagnosis waiver. The anticipated cost-avoidance for persons transitioning to HCBS services provided through the Elderly, Blind, and Disabled; Brain Injury; or Community Health Supports Waivers is \$33,980.67 per client.

A further net benefit analysis should be conducted during the pilot project, to focus upon these major areas:

- *Whether the average residential cost per client decreased and if so, by what amount.*
- *Whether the cost for personal care for each client under a public guardianship decreased and, if so, by how many hours per month as compared to an increase in care hours for similar clients.*
- *The number of clients showing improvement in self-sufficiency during the pilot study or who have regained individual liberty and autonomy.*

Organizational effectiveness and resources

The primary goal of the pilot project is to demonstrate the feasibility of establishing a permanent organizational structure with resources adequate to meet the identified need for public guardianship services. The pilot structure can be assessed according to the following measureable objectives:

- Demonstrated level of staffing appropriate to workload
- Standard operating policies and procedures in place
- Case management system adapted and implemented
- Standard of practice and code of ethics adapted and implemented with a tracking system for quality control
- Costs managed within established budget

⁶ Colorado Choice Transitions (CCT) is part of the federal Money Follows the Person (MFP) Rebalancing Demonstration, which is a five year grant program. The goal of CCT is to facilitate transitioning Medicaid clients from long term care facilities to the community utilizing home and community based services and supports (HCBS). The Department receives a 25% enhanced federal match on HCBS. This additional funding is intended to improve the long-term care system by promoting awareness, use, and/or access to transition services, and to enhance HCBS waiver programs.

- Sustainability of actual costs projected into the future with full implementation

Costs and benefits of public guardianship services are appropriately tracked through each individual who is a participant in the program. The automated system may be useful to track the public and private costs, such as cost of care, residence, services, Medicaid costs and the guardian-designee. Another alternative could be a contract with a private evaluation and cost-benefit analysis for the project. The experience of public guardianship programs in other states may be instructive and useful to determine the method of tracking the cost-benefit analysis. (*See Appendix, Attachment E*).

APPENDICES

Attachment A

Definitions and Acronyms

PUBLIC GUARDIANSHIP: The appointment and responsibility of a public official or publicly funded organization to serve as legal guardian in the absence of willing and responsible family members or friends to serve as, or in the absence of resources to employ, a private guardian.⁷

PUBLIC GUARDIAN: the Director of the Office of Public Guardian .

GUARDIANSHIP: a legal arrangement where a person or institution is appointed as a guardian to make decisions for an incapacitated person which may include decisions about housing, medical care, legal issues, and services. In Colorado, a guardian may also manage certain of the Ward's funds without the appointment of a conservator. §15-14-314, C.R.S.

GUARDIAN: an individual at least twenty-one years of age, resident or non-resident, who has qualified as a guardian of a minor or incapacitated person pursuant to appointment by a parent or by the court. The term includes a limited, emergency, and temporary substitute guardian but not a guardian ad litem. §15-14-102(4), C.R.S.

CONSERVATORSHIP: a legal arrangement where a person or institution is appointed to handle the financial affairs for another person. The conservator collects and deposits any income, pays any debts or bills, secures all assets, and handles taxes and insurance. A person appointed as guardian may also be appointed as conservator, or a separate conservator can be appointed.

CONSERVATOR: a person at least twenty-one years of age, resident or nonresident, who is appointed by a court to manage the estate of a protected person. The term includes a limited conservator. §15-14-102(2), C.R.S.

PROTECTED PERSON: an individual for whom a conservator has been appointed or other protective order has been made. §15-14-102(11), C.R.S.

WARD: an individual for whom a guardian has been appointed. §15-14-102(15), C.R.S.

OCR: The Office of the Child's representative (OCR) is the state agency mandated to provide competent and effective best interests legal representation to children involved in the Colorado court system. §§13-91-104 *et seq.*, C.R.S.

GUARDIAN- DESIGNEE: An individual who is appointed as a guardian by the Court through the Office of the Public Guardian.

⁷ Teaster, P., Wood, E., Karp, N., Lawrence, S, Schmidt, W., Mendiondo, M. *Wards of the State: A National Study of Public Guardianship*. The Retirement Research Foundation, (2005), p. 31.

Attachment B

Narrative Examples of Persons In Need Of Public Guardianship Services

A. Client Stories from Adult Protection Services (APS)

ML

ML was in her mid-30's when she came to APS's attention. Diagnosed with cerebral palsy, she was non-verbal and answered questions with eye movements. Her care providers reported that her mother, who was her guardian, was abusive and was isolating the client from friends, school, and other activities and forcing ML to be part of other activities against her will. ML had previously requested legal assistance to have mother removed as guardian but failed in getting the guardianship revoked. APS was able to document mother's abuse and petitioned the court on the client's behalf and was able to have the guardianship transferred to APS. The guardianship was a limited guardianship and APS worked with ML to find a more appropriate group home placement with a high technology home that allows ML to have enhanced communications and increased independence. ML's mother fought the county for several years to try and regain guardianship but the court found mother to be an inappropriate guardian. Had ML lived in a county where APS did not accept guardianships, she would have had no appropriate guardian.

CD

APS received a report on CD, a man in his early 20's, profoundly intellectually disabled. CD needed help with all ADLs and was non-communicative. CD's mother had never requested services for him as he transitioned from school support to adulthood. He had no guardian. CD's Mother was his caregiver; however, she was morbidly obese and bed-bound, and she herself had a HCBS services and a caregiver who came to the home. CD's Mother was using her son's SSI to pay bills and was not providing him services. CD's Mother declined comprehensive services that were offered through the CCB because she would have to turn over the client's SSI payments to cover some costs of the services. APS and law enforcement intervened on the client's behalf. CD's Mother was told that she would either need to consent to CCB services or be arrested for caretaker neglect. A second son, with a lesser intellectual disability, was also living in the home, also not receiving appropriate services. Both sons should have a guardian, other than their mother, but this county APS program does not accept guardianship.

GM

GM was an intellectually disabled woman (IQ of 50) in her late 40's when APS received a report. She lived in a trailer park with her sister and only living relative, who had been her caregiver her entire life. Her sister became very ill with cancer and GM was trying to care for her sister. A male neighbor was also sexually assaulting GM on a fairly regular basis. Sister was eventually moved to a nursing home and GM had been left on her own in the trailer, when a report was finally made to APS. She was first denied services through Medicaid but APS was able to appeal the decision and obtain services for her. APS was able to relocate GM into a group home to stabilize her and now she is in an independent living condo with a roommate, with supports through the CCB. GM's sister eventually died and GM is now a ward of the county APS program. Had she lived in one of the 35 counties that do not accept guardianship, she would have no appropriate guardian available.

These next two stories highlight clients who, even with a guardian, would remain at-risk due to a lack of appropriate placement options. These examples are included to showcase the need to try to quantify (through the pilot) the number of similar individuals throughout the state.

PL

APS was guardian of a male client with multiple risk factors including mental illness, traumatic brain injury (TBI), substance use disorder, and a history of seizures. The client also had a criminal record and has been incarcerated intermittently for assault. The caseworker-guardian worked with him extensively over several years to maintain him in a community-based setting. After multiple acute exacerbations of his medical conditions and contacts with law enforcement, the client was hospitalized for 10 months. The hospital reportedly contacted 150 facilities to request long-term care placement, but none of the facilities would admit him. APS also requested Medicaid approval for an out-of-state placement, but it was denied. HCPF issued an individual Request for Proposal (RFP) in an attempt to secure a facility placement but the RFP failed. Meanwhile, the client assaulted a nurse at the hospital and was incarcerated again.

AD

APS received a report on a male in his late 20's, diagnosed with bi-polar disorder, spina bifida, and frontal lobe dementia. Hospital was reporting that his needs were so great, both mentally and physically, it did not feel he was safe in his home and that his mother could not provide the level of care for his needs. No care providers would come to his home because of his sexual and aggressive behaviors, and false allegations of sexual assault against caregivers. Multiple professionals gave him different diagnoses with a

different treatment plan, causing instability in his behaviors and an inability to manage those behaviors. APS and other community providers and first responders have been trying to find a solution to meet his needs for more than a decade, without success. As he ages, his behaviors are worsening to the point that his only care provider, his mother and current guardian, is no longer safe in her home with him as he physically assaults her and threatens to kill her.

B. Stories from the Bedside

Ethics committees in each of our hospitals are frequently asked to help healthcare providers when patients remain in acute care settings without acute medical needs or are continuing to receive disproportionately burdensome treatments because they are unrepresented and unable to make decisions. Here are a few actual stories, from different healthcare providers in the Denver metro area, of vulnerable patients caught in this limbo. A theme of these stories is that patients are stuck in a restrictive environment because they are unrepresented and they often suffer consequences of being in that setting while awaiting authorization for transfer to a more appropriate environment or a decision regarding continuation of aggressive medical intervention.

□ A 59 year old man was admitted with stroke. He was long estranged from 4 siblings who were unwilling to be surrogates. Unable to speak, the patient could only nod and was unable move his right arm or leg. The providers were unclear whether they should treat him with long-term intubation and resuscitate if his heart stops.

□ A homeless patient lacking capacity or representation was admitted for acute care and received initial treatments under the “emergency exception”. There was an incidental finding of dry gangrene of foot that was not currently causing sepsis but would proceed to sepsis if an “elective” amputation was not performed.

□ A man with developmental disabilities came into the emergency department with pneumonia. He lived in a group home and his parents, who were his guardians, had just recently passed away tragically in a car accident. There was no other designated guardian and he had no siblings to help with medical decisions or support him through the process of understanding the various medical procedures that might be needed.

□ A 66 year old man with chronic lung disease and alcoholism, but without decision-making capacity (DMC), presented with a hip infection and received emergent surgery and IV antibiotics under the “emergency exception” because it was in his best interest. No surrogate decision-maker could be found, and the patient needed a supervised setting due to his confusion. It took 5 months for a guardian to be appointed, a condition necessary for transfer to a long term care facility, and he remained in the acute facility (hospital) throughout.

□ An elderly patient with dementia from syphilis presented to an emergency department with a bloodstream infection. He was stabilized with 6 weeks of intravenous antibiotics; however, he remained in the hospital, pleasant but without insight or ability to care for himself, for 2 more months until a guardianship hearing could occur and allow him to go to a long-term care facility.

□ A young woman sustained permanent brain damage from the rupture of a brain aneurysm. Her kidneys also failed as part of her medical catastrophe and she required kidney dialysis 3 times a week. Her family refused responsibility and would not authorize her treatment, due to legal concerns and behavior that they could not control. She remains in an acute-care hospital after more than a year due to the inability to obtain a guardian because of the complexities of her medical, behavioral and social situation.

□ An elderly man who had not sought healthcare in over 20 years collapsed with a blood stream infection on his way to the grocery store. He was treated in an acute care hospital and found to have dementia as well as require supervised treatment for tuberculosis. In addition, the healthcare team suspected he had bladder cancer. The patient's family had not been in touch for several decades, and refused to participate in healthcare decisions due to his past history of abusing them. The patient refused all evaluation or treatments, so he was kept in the acute care setting, without access to the outside environment, to receive supervised TB treatment mandated by public health officials. He eventually developed hospital-related infections and died in the hospital, 3 months after admission, on the day his guardianship hearing was finally scheduled.

□ A man in his 60's was admitted to an area hospital with alcohol and substance abuse-induced dementia and received 2 weeks of medical treatment. Eight weeks after clearance of acute medical problems, the patient remained in the hospital without a guardian or safe place for discharge. Two security guards are required to keep him in his room and his primary concern is that he is unable to see his companion dog. Guardianship Alliance had a 2-3 month waiting list for a volunteer guardian.

Colorado Revised Statutes lack clarity about the process for medical decision making when patients lack capacity and are unrepresented. In order to avoid a conflict of interest resulting from dual roles, health care facility personnel, physicians and social workers are prohibited by Colorado Statute to petition to be "interested parties" for patients [For example, see C.R.S. 15-14-310 regarding guardianship and prohibition of dual roles].

Attachment C

A White Paper

by the

Colorado Collaborative for Unrepresented Patients

Addressing Gaps in Healthcare Decision Making for
Unrepresented Adults:

A Proposal for the Inclusion of a Public Healthcare
Guardian in the Office of Public Guardianship

© 2013 Colorado Collaborative for Unrepresented Patients
Revised: July 2014

Colorado Collaborative for Unrepresented Patients consists of the following institutions and individuals:

Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus

Jean Abbott, MD, MH

Professor Emeritus, Emergency Medicine; Clinical Faculty Associate

Jacqueline J. Glover, PhD

Professor, Department of Pediatrics; Director of Clinical Ethics

Center for Ethics and Leadership in the Health Professions, Regis University

Deb Bennett-Woods, EdD, FACHE

Chair & Professor, Department of Health Care Ethics

Director, Center for Ethics and Leadership in the Health Professions

Children's Hospital Colorado

Jacqueline J. Glover, PhD

Ethics Committee Member

Stefan Mokrohisky, MD

Clinical Professor of Pediatrics; Ethics Committee Chair

Tracy Price-Johnson

Ethics Committee Member

Colorado Healthcare Ethics Forum

Jean Abbott, MD, MH

Deb Bennett-Woods, EdD, FACHE

Aaron Snyder, MD, Retired geriatrician and clinical ethics consultant

Kayte Fulton, BA, Clinical Patient Communications consultant

Denver Health and Hospital Authority

Kathryn Witzeman, MD

Assistant Professor, Department of OB/GYN; Ethics Committee Chair

JFK Partners, University of Colorado School of Medicine

Tracy Price-Johnson

University of Colorado Hospital Authority

Jean Abbott, MD, MH

Ethics Committee Chair

Jacqueline J. Glover, PhD

Ethics Committee Member

Acknowledgements:

Sharon E. Caulfield, Esq. and Kristofer M. Simms, Esq.; Caplan and Earnest, LCC; Boulder, CO

Gail Finley, Vice President, Rural Health and Hospitals, Colorado Hospital Association

Carolyn H. Welsh, MD, Ethics Committee Chair, Veterans Administration Medical Center and Professor of Medicine, Division of Pulmonary Sciences and Critical Care Medicine, University of Colorado School of Medicine

Overview

The Elder Abuse Task Force, who were mandated to conduct a review of existing research related to S.B. 12-078 (Colorado State, 2012), recommended that the Colorado General Assembly study the need for and implementation of a public guardianship and conservatorship program, in addition to the mandatory reporting of abuse of at-risk adults (Elder Abuse Task Force, 2012). The Colorado Judiciary responded with the appointment of the Public Guardianship Advisory Committee, who is charged with examining options for creating an Office of Public Guardianship to assure protection for vulnerable adults who need legal guardians but who lack willing and responsible family members or friends to make legal decisions.

County Adult Protective Services (APS) agencies are frequently asked to provide guardianship for the purpose of healthcare decision-making, when patients or residents lack the capacity to make their own decisions and also lack family, friends or other legally authorized representatives to make decisions on their behalf. However, such requests are prohibited by statute and not part of the defined role of APS. Healthcare decisions may be required in the context of acute illness, significant chronic disease or disability, end-of-life decisions, and placement for ongoing treatment. The lack of a decision maker for health care can leave Colorado adults without decisional capacity inappropriately institutionalized and can leave health care providers without authorization to make important clinical decisions.

In this white paper, the Colorado Collaborative for Unrepresented Patients (CCUP) seeks to define the problem of “unrepresented” adults in the healthcare system, review Colorado law pertinent to healthcare decision-making, and describe some solutions that have been enacted in other states or systems. The Colorado Collaborative for Unrepresented Patients recommends adding to the public guardianship system a “public healthcare guardian”, with the accompanying training, funding and public support.

I. Definitions (in alphabetical order)

Advance directive: A written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual lacks decisional capacity or elects to delegate decision making to another.

Best interest standard: A decision-making standard used when it cannot be determined with certainty what the patient would have chosen regarding treatment or setting if he or she had decisional capacity. The standard requires the decision maker to consider the patient’s preferences and values to the extent they are known or discoverable, and the likelihood that benefits will outweigh foreseeable risks and burdens to the patient. Factors that should be considered by a legally authorized representative (LAR) in determining whether treatment decisions are in the best interests of the incapacitated individual include:

- the patient's present level of physical, sensory, emotional, and cognitive functioning;

- the various treatment options and the risks, side effects, and benefits of each of the options;
- the life expectancy and prognosis for recovery with and without treatment;
- the degree of pain and discomfort resulting from the medical condition, treatment, or termination of treatment;
- the degree of dependency and loss of dignity resulting from the medical condition and treatment (adapted from Washington State Hospital Association, 2010).

Decision-making capacity (DMC): A patient’s ability to (a) recognize the need for a decision, (b) understand the nature and consequences of the decision; (c) weigh the relative benefits, burdens and risks of available treatment options, (d) and communicate a decision consistent with his or her values. Also referred to as decisional capacity.

Emergency waiver of consent: The rendering of medical care to an incapacitated person without the patient’s consent in an emergency situation, using the standard of what a “reasonable person” would want. Emergent surgeries, antibiotic treatments and invasive testing and treatment can be initiated under the “emergency waiver”.

Health care agent: Person authorized, verbally or in writing, by a patient at a time when he/she had DMC to be his/her agent in making healthcare decisions when he or she lacks capacity, generally under a medical durable power of attorney (MDPOA) or other document.

Public healthcare guardian (proposed): A person appointed via the Office of Public Guardianship and authorized narrowly to make healthcare decisions on behalf of an unrepresented patient who either temporarily or permanently has lost the capacity to make such decisions on his or her own behalf.

Legally authorized representative (LAR): An adult authorized (by statute or by common law) to make decisions on behalf of another person. Also referred to as a surrogate decision maker. This adult can either be authorized as a health care agent by the patient or a proxy decision maker according to Colorado statutes.

Scope of treatment decisions:

- Routine treatment – medical interventions that do not pose significant risk to the patient’s health or life, and about which major differences in personal, social or religious values are unusual. This generally includes interventions and procedures for which signed informed consent is normally not required or for which signed informed consent is normally required but are considered low risk. Examples of routine treatment may include, but are not limited to: administration of parenteral medications, transfusion of blood products, routine laboratory and radiographic diagnostics, radiographic procedures involving contrast dye, placement of intravenous access, biopsies that do not invade a body cavity, and some invasive diagnostic procedures (paracentesis, spinal tap, etc.).
- Major invasive treatment – medical interventions for which there is substantial risk to the patient for serious injury, significant suffering, or death, or for which there is a reasonable likelihood of major differences in personal, social or religious values. This includes most, but not all, individual interventions for which signed informed consent is normally required. Examples of major invasive treatment may include, but are not limited to: most surgery, most invasive diagnostic and therapeutic procedures, interventions that carry substantial morbidity or mortality

risk (such as cancer chemotherapy), or lower risk interventions that imply large decisions about overall treatment goals (dialysis, feeding gastrostomy, tracheostomy, etc.).

- Life-sustaining treatment – medical intervention without which there is reasonable medical expectation the patient will die within a brief time period.
- End-of-life treatment – medical interventions intended to provide comfort during the dying process. This includes comfort care, palliative care or hospice.

Unrepresented patient: An adult patient who lacks decisional capacity to give informed consent for medical treatment, does not have an applicable advance directive, and for whom there is no legally authorized surrogate decision maker, family, or friend available, competent and willing to assist with medical decision-making. Also referred to as “unbefriended patient”, “adult orphan”, and “patient without proxy”.

II. Scope of the Problem

The problem of unrepresented patients is increasing. Growing numbers of the elderly and/or chronically ill adults suffer from dementia and have abandoned or been abandoned by family, outlived family and friends, or have lost contact with their community. In addition, homeless persons and the mentally disabled may not have guardians, representation, or a stable community. Several studies have tried to estimate the current scope of the problem. In one study, 3-4% of nursing home residents were unrepresented (Pope, 2012, Part 1) and in another study more than 16% of patients admitted to intensive care units of hospitals were unrepresented (White, 2006). By 2030, it is estimated that more than 2 million adults over the age of 70 will have outlived all of their friends and family members (Weiss, 2012).

In the current legal system, there is a critical gap between clinical treatment that is authorized by the “emergency waiver” and other medical treatment that requires the appointment of a guardian by the courts. While the Probate Court’s public guardianship proposal seeks to eliminate the current time gap of 4-8 weeks, further issues remain. There are also knowledge gaps for guardians when they are called upon to act beyond their standard legal representational role. They must be capable of making difficult healthcare decisions regarding both clinical treatment and treatment setting. Yet, guardians

- are often unprepared or unwilling to make difficult health care decisions;
- may be unfamiliar with the special aspects of decision making in the medical context or of the patient’s values and wishes regarding health care;
- tend to have limited interactions with the medical team or with persons they represent (Bandy, 2010).

III. Risks and Problems for Unrepresented Patients:

Unrepresented patients, often called “unbefriended,” are vulnerable and often socially isolated. Some may be elderly persons who have outlived all of their friends and families, while others may be homeless or estranged from family or friends. Sometimes, friends or family are unable or unwilling to act as guardian (Bandy, 2010). Medical treatment and disposition decisions are often paralyzed by this lack of a

proxy decision maker. The medical care team often does not know the patient's values, how he or she has lived life, or what he or she would prefer in the current circumstances.

As a result, unrepresented patients may suffer from either overtreatment or undertreatment. Prolonged life-supporting measures may be continued without a process to decide whether such interventions are in the "best interest" of the patient. Providers feel safer continuing treatment than withdrawing it. There are financial incentives to do more interventions, as well as legal fears if treatments are withdrawn. And there is often a bias towards the "status quo" of continuing those interventions that have been started. It has been estimated that patients without representation spend an average of 50% more time in intensive care units than those whose wishes are known. This difference is thought to be due to reluctance of physicians to revert to comfort care or stop treatments of marginal benefit without a representative of the patient with whom to share those difficult but important decisions (White, 2006).

Undertreatment is also a risk, since providers may hesitate to initiate new treatments without knowing the patient's wishes or in the absence of a consenting party, and they may postpone surgeries or other more elective interventions until they become emergencies. Such delay can increase the risks of these interventions, prolong suffering and pain, as well as compromise the quality of care in an already vulnerable patient.

Unrepresented patients are also at risk from prolonged placements in settings that threaten their well-being and cause suffering. Delayed discharge from acute care hospitals increases the risk of hospital-acquired infections and complications. Institutionalization can jeopardize a person's financial situation or long-term housing. Transfer to a less restrictive setting reduces suffering and encourages people to live the fullest life that they can, creating opportunities for social contact, experiencing the outdoors, and pursuing activities that make their life meaningful.

IV. The Need in Colorado:

The Colorado Collaborative for Unrepresented Patients came together because ethics committees in each of our hospitals are frequently asked to help healthcare providers when patients remain in acute care settings without acute medical needs or when they continue to receive disproportionately burdensome treatments because they are unrepresented and unable to make decisions. Here are a few actual stories of vulnerable patients caught in this limbo from different healthcare providers in the Denver metro area,. A theme of these stories is that patients get stuck in a restrictive environment because they are unrepresented. As a result, they often suffer negative consequences from being in a medically inappropriate setting while awaiting authorization for transfer to a more suitable environment or a decision regarding the continuation of aggressive medical interventions.

- A 59-year-old man was admitted with stroke. He was long estranged from four siblings who were unwilling to be surrogate decision makers. Unable to speak, the patient could only nod, was unable move his right arm or leg and was deemed to lack decisional capacity. The providers were unclear whether they should treat him with long-term intubation and resuscitate him if his heart stopped.

- A man with developmental disabilities came into the emergency department with pneumonia. He lived in a group home and his parents, who were his guardians, had just recently passed away tragically in a car accident. There was no other designated guardian, and he had no siblings to help with medical decisions or to support him through the process of understanding the various medical procedures that might be needed.
- A 66-year-old man with chronic lung disease and alcoholism, but without DMC, presented with a hip infection and received emergent surgery and IV antibiotics under the “emergency exception.” No surrogate decision maker could be found, and the patient needed a supervised setting due to his confusion. It took five months for a guardian to be appointed, a condition necessary for transfer to a long-term care facility, and he remained in the acute care facility (hospital) throughout.
- An elderly patient with dementia from syphilis presented to an emergency department with a bloodstream infection. He was stabilized with six weeks of intravenous antibiotics; however, he remained in the hospital, pleasant but without insight or ability to care for himself, for two more months until a guardianship hearing occurred, a guardian was appointed, and he was transferred to a long-term care facility.
- A young woman sustained permanent brain damage from the rupture of a brain aneurysm. Her kidneys also failed as part of her medical catastrophe and she required kidney dialysis three times a week. Her family refused responsibility and would not authorize her treatment, due to legal concerns and post-stroke behavior that they could not control. She remained in an acute-care hospital for more than a year due to the inability to obtain a guardian because of the complexities of her medical, behavioral and social situation.
- An elderly man, who had not sought healthcare in over 20 years, collapsed with a blood stream infection on his way to the grocery store. During his treatment in an acute care hospital, he was found to have dementia as well as a need for supervised treatment for tuberculosis. In addition, the healthcare team suspected he had bladder cancer. The patient’s family had not been in touch for several decades and refused to participate in health care decisions due to his past history of abusing them. The patient refused all evaluation or treatments, so he was kept in the acute care setting, without access to the outside environment, in order to receive supervised TB treatment that was mandated by public health officials. He eventually developed hospital-related infections and died in the hospital three months after admission, on the day his guardianship hearing was finally scheduled.

Colorado Revised Statutes have not established a clear and effective process for medical decision making when patients lack capacity and are unrepresented, yet these statutes impose serious restrictions on who may speak on behalf of such patient. In order to avoid a conflict of interest resulting from dual roles, health care facility personnel, physicians and social workers are prohibited by Colorado Statute to petition to be “interested parties” for patients [For example, see C.R.S. 15-14-310 regarding guardianship and prohibition of dual roles].

Figure 1, below, illustrates a typical process for medical decision making for an unrepresented patient who either does not have decisional capacity at the time of admission, or loses capacity following admission, or whose preferences cannot be ascertained by health care facility staff. Social workers or case managers attempt to track down relatives or other interested parties, as required by the Colorado statutes (CRS 15-18.5-103), while the patient is treated appropriately for emergent conditions under the “emergency exception” provision while a surrogate is sought.

Protocols for the search for somebody to speak on behalf of an unrepresented patient without decisional capacity vary among hospitals, but include: searches in old medical records, evidence from prescriptions, names solicited from the patient's primary physician, evidence from the patient's personal effects, etc. The search process may continue for several days or weeks. If a surrogate cannot be located, a judicially appointed guardian is sought. While Colorado does have a statute allowing appointment of an "emergency guardian" (CRS 15-14-312), this process is not uniformly available when needed. Most adult guardianship petitions related to medical treatment entail a 4-6 week gap. In the interim, significant medical decisions may need to be made (e.g. more elective surgery, such as the placement of kidney dialysis catheters, feeding tubes or tracheostomies), and many of these decisions will not fall within the emergency waiver of consent, as interpreted by the current standard of care and community practice.

Given the high workload of case managers, the labor intensive nature of the search process, and the time required to establish a formal guardianship, patients often endure substantial delays in receiving medically beneficial elective treatments or discharge to a medically more appropriate environment. Critical decisions regarding highly invasive end-of-life treatments are also delayed, often resulting in potentially avoidable suffering and an unnecessarily prolonged dying process.

V. Alternatives – A Review of the Literature

Through most of history, physicians made choices about medical care and treatments for patients under the principles of acting in a patient's best interest (beneficence) and the assumption that the physician "knows best" (paternalism). Recently, patients have asked for and received more independence in participating in decision-making. The federal 1991 Patient Self-Determination Act (42 USC §§1395cc, 1396a, 1994) promotes the use of advance directives to empower patients by placing them at the center of making decisions about what interventions they do or do not wish to have or who they wish to have represent them if they are incapacitated. Colorado's medical decision-making law has an expanded list of potential proxy decision makers that includes friends as well as family as potential "interested parties," which has been very helpful.

Unfortunately, when a patient is not able to speak for him/herself and has no surrogate to express his/her values or wishes, the legal framework for decision-making in medical situations is unclear. Currently, in most published studies, a large number of critical health care decisions fall to the medical treatment team alone because they lack the opportunity to consult with a representative of the patient. Such decisions encompass the full scope of treatments—from routine to life extending. (White, 2007; Bandy, 2010).

Across the country, there are five main processes by which spokespersons can be obtained:

- 1) Appointing legal guardians: private, volunteer or public to act as decision makers;
- 2) Authorizing attending physicians caring for individual patients to act as decision makers;

- 3) Authorizing other clinicians, individuals and entities within the healthcare setting to act as decision makers;
- 4) Empowering institutional committees, like the ethics committee of the institution, to act as decision makers;
- 5) Creating and/or empowering external state-authorized committees, beyond the institution, to act as decision makers (Pope, 2012, Part 2).

Table 1, below, lists various solutions that institutions, organization and states have set up to address this legal gap, as well as the pros and cons of the various solutions.

As noted previously, current statutes in Colorado prohibit any process that gives full decision-making authority to the clinician or health care organization, and the current guardianship process is often too lengthy and unwieldy. While there have been attempts in Colorado to create entities external to the health care institutions to assist in decision making (e.g. Guardianship Alliance and others), these entities have struggled to remain sustainable due to a lack of funding and infrastructure. With the creation of an Office of Public Guardianship comes the potential to create an alternative process that addresses these issues, as well as other barriers to appropriate decision making by guardians as noted in Section II. This alternative is the public healthcare guardian.

VI. Role and Responsibilities of a Public Healthcare Guardian

The role and responsibilities of a public healthcare guardian would be limited to making health care decisions. Clinical decision-making for a patient with impaired decisional capacity by a proxy decision-maker can involve decisions ranging from routine treatment or treatment placement, to major invasive treatment, to life sustaining treatment or end-of-life care. These decisions require working closely with health care providers and, in some cases, an ethics committee. Clinical decision-making differs from other types of proxy decisions that might be made by a court-appointed general guardian. The former are much narrower and include specific issues of timing, complexity, and the necessary clinical knowledge and skills.

Timing

The need for medical decisions can evolve rapidly. A delay of days or even hours in making a decision can result in gaps in appropriate treatment that may cause the patient significant and avoidable suffering

or harm, either from delays in initiating treatment or appropriate transfer, or from extended periods of overly aggressive treatment.

Complexity

Decisions involving medical treatment or placement can involve challenging ethical considerations including assessing the potential benefits and harms of each course of action in light of likely clinical outcomes and what is known of the patient's preferences and values. Such decisions may involve clinical uncertainty, conflicting viewpoints within the clinical care team, religious or cultural dimensions that require interpretation, and/or a lack of clarity regarding patient values and preferences. A public healthcare guardian must be able to understand and objectively analyze treatment options and potential ethical conflicts with the assistance of health care providers and, if needed, members of the facility ethics committee in order to make decisions that reflect the best interests of the patient in light of the patient's values and preferences to the extent they are known.

Knowledge, Skills and Abilities

In order to ensure the best possible representation for the patient, a public healthcare guardian must:

- Stay informed of the patient's current medical condition and prognosis including requesting medical information, asking questions, and discussing treatment options
- Understand any prior advance medical directives the patient may have in place
- Be available to members of the care team by phone or in person to discuss the patient's condition and treatment options and participate in scheduled care team meetings when requested
- Consult with anyone who might offer insight into the patient's interests, goals, values and preferences.
- Coordinate medical decision-making with other decisions being made by a public guardian or other interested party acting on behalf of the patient.

In terms of knowledge, the public healthcare guardian ideally has:

- Basic medical knowledge adequate to understanding the clinical issues, asking questions and weighing alternatives.
- Basic working knowledge of the health care system with respect to appropriate care settings
- Familiarity with common bioethical issues, concepts and guidelines.

Healthcare guardianship requires the following skills and abilities:

- Gather relevant clinical, social, cultural, religious and other personal information appropriate to treatment and transfer decisions;

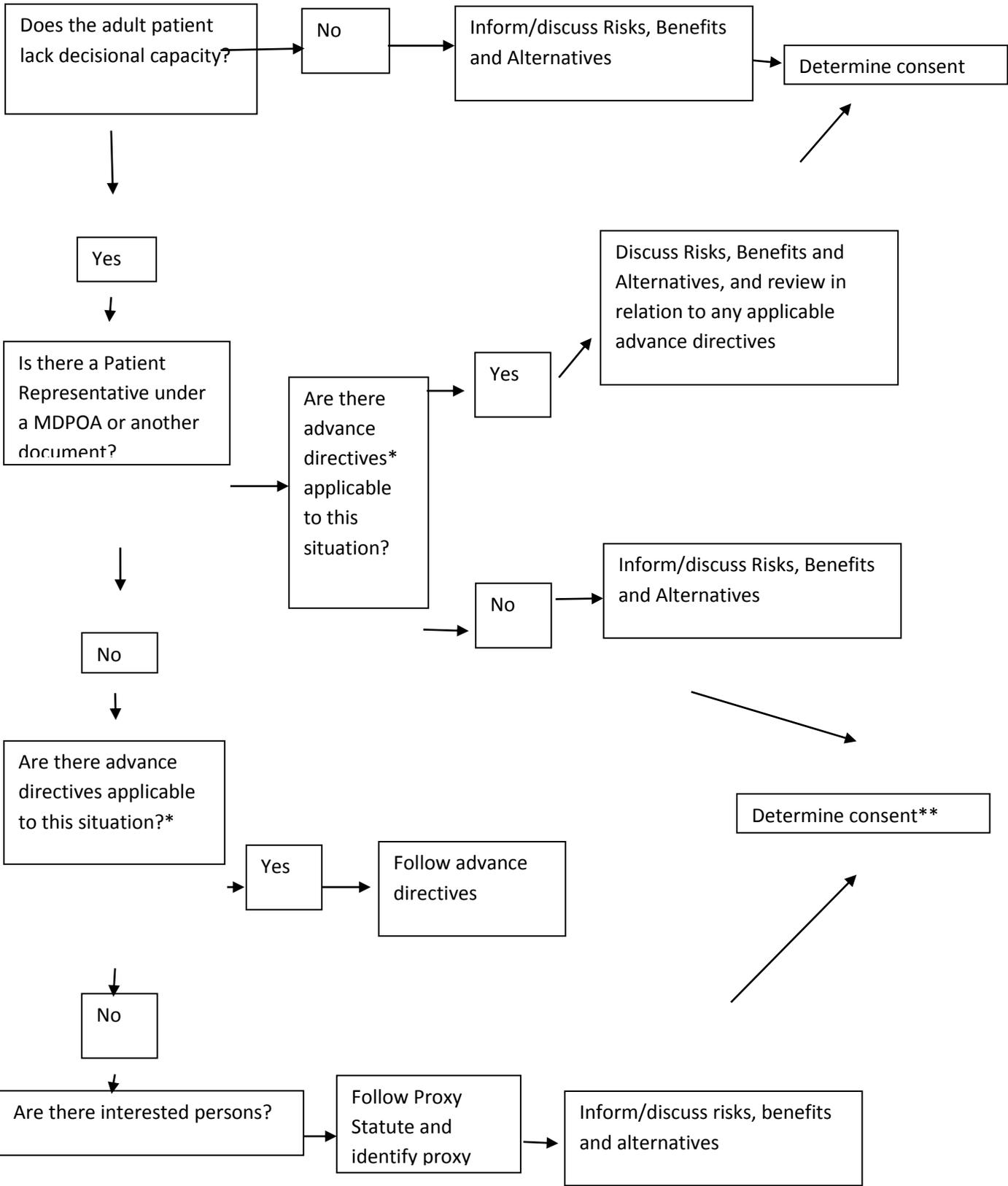
- Communicate effectively with health care providers, social workers, chaplains, ethics committee members and others involved in the patient’s care;
- Differentiate between types of medical advance directives and observe other legal constraints on proxy decision-making;
- Recognize and apply basic bioethical concepts when ethical issues arise;
- Set aside personal bias and preference, especially when dealing with conflicting cultural or religious values;
- Make difficult decisions including those involving end-of-life choices.

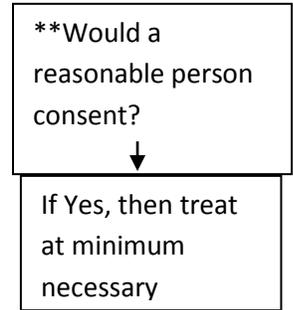
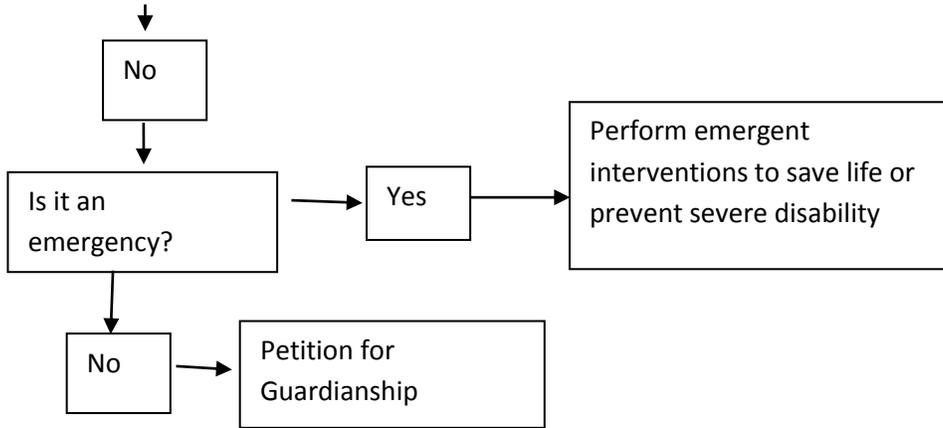
VII. Recommendations

The CCUP makes the following recommendations regarding medical decision-making for unrepresented patients.

1. Establish and fund the role of “public healthcare guardian”, as defined in Section I, granting persons in this role the explicit authority to make decisions regarding medical treatment options and appropriate setting choice for unrepresented patients.
2. Establish the required training and preparation needed to support the role and responsibilities of a healthcare guardian, as defined in Section VI, and develop a mechanism for ensuring that appointees meet the minimum requirements for the role.
3. Define a process by which a public healthcare guardian can be appointed by the Office of Public Guardianship within 24 hours of a request by a healthcare provider.
4. Provide education to health care providers regarding the availability and process for requesting a public healthcare guardian on behalf of a patient.

Figure 1: CURRENT DECISION TREE ALGORITHM
 MEDICAL DECISIONS FOR ADULTS IN COLORADO





* Types of Advanced Directives in Colorado:

MDPOA: C.R.S. §15-14-503 – 509

Living Will: C.R.S. §15-18-101 *et. seq.*

CPR Directive: C.R.S. §15-18.6-101 *et. seq.*

MOST Form: C.R.S. §15-18.7-101 *et. seq.*

Table 1: HOW TO MAKE DECISIONS FOR UNREPRESENTED PATIENTS: CURRENT SOLUTIONS

TYPE OF AUTHORIZATION	EXAMPLES	PROS	CONS	COMMENTS
PRIVATE GUARDIANS	Colorado and most other state court laws	Comprehensive – includes property, finances, overall wellbeing	Slow speed, Cost, Competence, Availability	Leaves gap of 4-6 weeks minimum from “emergency exception”. Doesn’t allow for limited-scope or time-limited medical decisions
	Denver Health Hospital Authority	Accelerated assignment of guardian by Probate Court	Need for court cooperation, staffing	Court Assigned Guardian: Affidavit prepared with SW, Petition for Guardianship prepared by hospital counsel.
PUBLIC GUARDIANS	Guardianship alliance (intermittently in Colorado. Indiana)	More agile, trained for medical decision making,	Requires volunteers; requires sustained funding.	Has not been sustainable in Colorado.
	Morgan County Colorado; Australia, Ontario, Canada	Public funding and employees	From experience, underfunded, overburdened and understaffed. Requires licensing, training	
ATTENDING PHYSICIANS	12 states: MO, SC, OR, CT;	Medical expertise,	Perceived conflict of	Can be unilateral (6

	with concurrence: TN, TX, NC, AZ, NY, NJ, AL, GA	speed of assistance	interest, concern about personal bias.	states) or with second opinion via 2nd physician, institutional or external committee.
	Veterans Administration Medical Center	Medical expertise, speed of assistance; separates into types of decisions		Routine: physician Major: physician + Chief of Service Life-sustaining: physician plus multidisciplinary committee serving as patient's advocate
	San Francisco General	Most knowledgeable about best medical interest of patient	Not authorized by State of California Statute	Attending, Ethics Committee encouraged
OTHER CLINICIANS, INDIVIDUALS AND ENTITIES	Florida: social worker	Medical expertise		"clinical social worker...selected by provider's bioethics committee and not employed by provider"
	Texas: clergy	Surrogate outside of medical system	Unchurched persons excluded	Member of clergy "surrogate of last resort" – required to know patient
	Oregon: health care provider trained in bioethics	Appointment by hospital		
INSTITUTIONAL COMMITTEE	AMA: Consult Ethics Committee	Avoids ad hoc decision-making; Committee protects	Outside the consultant role for ethics committees	Safeguards often increase with more grave decisions. Sometimes

		against individual biases. More speedy response, more personalized.		ethics committee has informal advisory role.
	Kaiser Permanente, Santa Clara (only), CA – multidisciplinary ;	Timely and transparent; Procedure rather than outcome; consistent with community standards		Multidisciplinary subcommittee of ethics committee appointed by EC Chair, includes “non-medical” member, community member, patient’s community; consensus required for WH/WD
	Santa Clara County Medical Association (California)	Process; presentation by physician, decision separate from treating team.		Ethics committee chair convenes 3+ subcommittee to review proposals and act as decision maker(one non-HC and not with organization)
EXTERNAL COMMITTEES	New York (and TX): Surrogate Decision Making Committee	Patient-centered; faster than courts	Mental disability patients without DMC only	Volunteer panel of 4 (medical, advocates for disability, attorney, individual with expertise)
	IA: local substitute medical decision-making boards	All unrepresented patients		Have been hard to set up and sustain locally.

Based on the references found in the reference list.

References

- Bandy RJ, Helft PR, Bandy RW, et al. Medical decision-making during the guardianship process for incapacitated, hospitalized adults: a descriptive cohort study. *J Gen Intern Med* 2010; 25: 1003-8.
- California Hospital Association. Health care decisions for unrepresented patients. Appendix 2-D, March 2008, with new versions previewed for 2011 at:
<http://www.calhospital.org/publication/principles-consent-and-advance-directives>.
- Colorado State. Senate Bill 12-078 Concerning protections for at-risk adults. (2012).
- Denver Health Policy. Proxy Decision-Maker. P-1.507, and Guardianship Procedures for Adult Patient. P-1.508, most recently reviewed by the institution 8/30/2011.
- Department of Veterans Affairs. Informed consent for clinical treatments and procedures. VHA Handbook 1004.01, 2009, p. 14.
- Elder Abuse Task Force. Elder Abuse Task Force Policy Decisions. (November 30, 2012). Available at <http://www.colorado.gov/cs/Satellite/CDHS-ExecDir/CBON/1251624797615>.
- Hyun I, et al. When patients do not have a proxy: a procedure for medical decision making when there is no one to speak for the patient. *J Clin Ethics* 2006; 17: 323-330.
- Isaacs ED, Brody RV. The unbefriended adult patient: the SFGH approach. *San Francisco Medicine*. 2010; 83(6).
- Kolan, K. Surrogate healthcare decisions. The Washington State Developmental Disabilities Council, The University Center for Excellence at the University of Washington, and Disability Rights Washington, 2010. Available at:
http://www.ddc.wa.gov/Publications/110110_Summary_of_Consent_Issue_with_Appendices.pdf.
- MacKenzie TD, Kukolja T, House R, Loehr AA, Hirsh JM, Boyle KA, Sabel AI, Mehler PS. A discharge panel at Denver Health, focused on complex patients, may have influenced decline in length-of-stay. *Health Aff.* 2012 Aug;31(8):1786-95. *Denver Health experience – a “best practices” model*.
- Moye J, Naik AD. Preserving rights for individuals facing guardianship. *JAMA*. 2011; 305: 936-7.
- Patient Self-Determination Act, 42 USC §§1395cc, 1396a (1994).
- Pope TM, Seller T. Legal briefing: the unbefriended: making healthcare decisions for patients without surrogates (Part 1). *J Clinical Ethics*, Spring 2012; 23: 84-96.
- Pope TM, Seller T. Legal briefing: the unbefriended: making healthcare decisions for patients without surrogates (Part 2). *J Clinical Ethics*, Summer 2012; 23: 177-192.
- Roberts S. Nowhere to go, patients linger in hospitals, at a high cost. *New York Times*, January 2, 2012.

- Sabatino CP. Advance directives and advance care planning: legal and policy issues. US Department of Health and Human Services, October 2007. Available at <http://aspe.hhs.gov/daltcp/reports/2007/adacplpi.pdf>.
- Southern California Consortium of Ethics Committees. Hospital guidelines for reviewing healthcare treatment recommendations for patients who lack decision-making capacity and have no surrogates and no advance directives. 2005. Available at: http://www.socalbioethics.org/Files/Documents/Final-Guidelines_for_Healthcare_Decision-makingforincap_SCBCC_rev50405.pdf
- Weiss BD, Berman EA, Howe DL. Medical decision-making for older adults without family. J Am Geriatr Soc 2012; 60: 2144-50.
- White DB, Curtis JR, Lo B, Luce JM. Decision to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. Crit Care Med 2006; 34: 2053-9.
- White DB, et al. Life support for patients without a surrogate decision maker: who decides? Ann Intern Med 2007; 147: 34-40.

Attachment D

Proposed Budget

Pilot Full

Staff Costs:

Personal Services	1,016,279	5,283,440
<i>FTE</i>	14.00	81.00
Benefits	150,088	829,626
Operating	28,300	76,950
Capital Outlay	74,242	429,543

Program Costs

Training	10,000	30,000
Case Mgmt System	300,000	100,000

Facilities

Reception Area	1,500	
Filing Cabinets/Bookcases	1,500	
Copy/Fax Scanning Machines	2,400	
Space build out	560,000	
Leased Space	102,690	729,000
	2,246,999	7,478,559

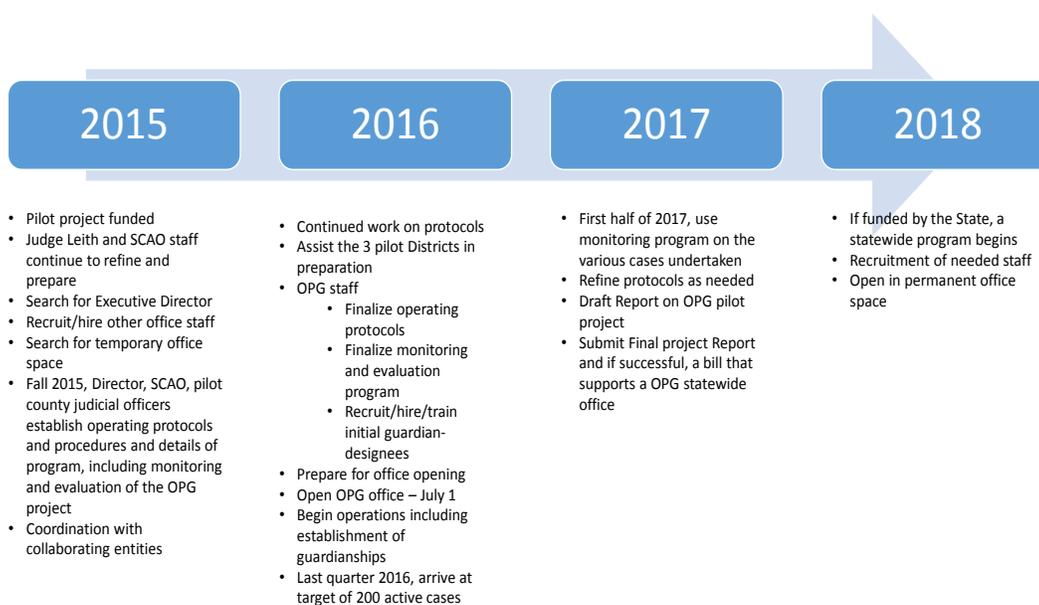
Cost/case (excludes 1 time costs)	\$7,814	\$4,666
# cases	200	1,500

FTE Detail

Exec Dir	1.0	1.0
Deputy		1.0
Staff Assistant	1.0	1.0
Staff Attorney	1.0	2.0
Transition Coordinator	1.0	1.0
Public Guardian*	10.0	75.0
Bill Payer		

Attachment E

Program Flowchart



Attachment F

Other State Experiences

The Washington State Institute for Public Policy published *Costs and Benefits* (2011).

Virginia Public Guardian and Conservator Programs. A 2003 study conducted by the Center for Gerontology at Virginia Polytechnic Institute and State University looked at outcomes for 158 incapacitated persons served by public guardians.⁸ The study period took place between 2001 and 2002. During this time, the average annual cost to provide services to incapacitated individuals was \$2,995 per person.

In each period, the study reported on the following types of discharges:

- State psychiatric hospital to assisted living facility
- State psychiatric hospital to nursing home
- Medical hospital to assisted living facility
- Medical hospital to skilled nursing facility
- Skilled nursing facility to assisted living facility

In total, 85 incapacitated persons moved to a less restrictive residential setting, resulting in a reported cost savings of \$5.6 million. Nearly two-thirds of the reported cost savings were attributed to discharging incapacitated persons from psychiatric wards. The final evaluation report concluded that, “such a cost savings indicates that the programs not only pay for themselves, but they pay for themselves over three times their funding amount in a single fiscal year, and relatively early in the life of the programs.”⁹

Florida Public Guardian Programs. The Florida statewide Public Guardianship Office was established in 1999. A 2009 evaluation of this program used methodology similar to the study conducted in Virginia.¹⁰ The evaluation followed 2,208 incapacitated persons served by public guardians during 2008. During this period, 958 incapacitated persons were discharged to a less restrictive residential environment, resulting in a reported cost savings to the state of over \$1.8 million. The average cost savings were estimated after accounting for \$2,648 for guardianship services per client per year. These findings led the authors to conclude that the public guardian programs in Florida would recover public costs within a year.¹¹

The Guardianship Project Demonstration. The Guardianship Project is a foundation-supported demonstration started in 2005 by the Vera Institute of Justice. The program provides guardianship services in New York City to elderly and disabled individuals. The program

⁸ Teaster, P., & Roberto, K. Virginia public guardian and conservator programs: Evaluation of program status and outcomes. Blacksburg, VA: The Center for Gerontology, Virginia Polytechnic Institute and State University (2003).

⁹ Ibid., p. 67

¹⁰ Teaster, P., Mendiondo, M., Schmidt, W., Marcum, J., & Wangmo, T. (2009). The Florida public guardian programs: An Evaluation of program status and outcomes. Lexington: University of Kentucky Graduate Center for Gerontology.

¹¹ Ibid, p. 23

includes both clients with assets to pay for services and those without financial resources. The Project employs not only attorneys for legal representation, but also staff such as bookkeepers and social workers.

Over 100 clients were served by the Guardianship Project in 2010; the program budget was \$1,2 million. After calculating costs for both living and deceased clients, the program estimated that the annual average cost per living client was approximately \$8,600. Researchers at the Vera Institute analyzed the cases of the 111 clients served during 2010, and examined cost savings in the following areas:¹²

- Nursing home, hospital, and mental health facility avoidance among Medicaid clients
- Private-pay clients who avoided or delayed Medicaid receipt by staying in the community
- Medicaid liens paid by the Guardianship Project out of client assets

Based on these cost areas, the projects saved a reported \$2,5 million in Medicaid costs for these clients in 2010. Like the results from other studies mentioned, a substantial portion (over half) of the cost savings reported in the Vera study came from a reeducation in the time clients spent in a mental health/psychiatric facility.

The Washington State Public Guardianship program.

Washington State implemented a pilot program in 2007 to provide public (state-paid) guardianship services for individuals whose family members were unable to serve as a guardian, or the individual did not have financial resources to pay for a guardian. The average residential costs per client decreased by \$8,131 over the 30-month study period. The average cost for providing a public guardian was \$7,907 per client during that time. Personal care decreased by an average of 29 hours per month for public guardianship clients, compared with an increase in care hours for similar clients. One in five public guardianship clients showed improvements in self-sufficiency during the study.

¹² Unpublished manuscript on file with the Vera Institute of Justice, Inc. Guardianship Project. www.vera.org/project/guardianship.