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# Giving Voice to the Voiceless: The Colorado Response to Unrepresented Patients

*Deb Bennett-Woods, Jean Abbott, and Jacqueline J. Glover*

## ABSTRACT

Medical decision making on behalf of unrepresented patients is one of the most challenging ethical issues faced in clinical practice. The legal environment surrounding these patients is equally complex. This article describes the efforts of a small coalition of interested healthcare professionals to address the issue in Colorado. A brief history of the effort is presented, along with discussion of the legal, ethical, practical, and political dimensions that arose in Colorado's effort to address decision making for unrepresented patients through an extension of the existing Colorado Medical Treatment Decision Act (CRS 15-18).<sup>1</sup> A discussion of lessons learned in the process is included.

## INTRODUCTION

"Unrepresented patient" is one of many terms used to describe a class of persons for whom the capacity to make medical decisions is absent or substantially impaired. "Unbefriended," "adult orphan," and "patient alone" also refer to this singularly vulnerable group of people who lack power or voice in representing themselves when confronting

medical decisions requiring informed consent. The lack of family, friends, or other social connections to make medical decisions can lead to delays in diagnostic procedures or treatment, prolonged or overly aggressive treatment, or extended placement in an acute care setting or other highly restricted environment. Such conditions come with associated clinical risks and threats to patients' finances, housing, and psychological well-being. The patients are among the most at risk in the healthcare system.<sup>1</sup>

Statistics on the number of such patients in various settings of the healthcare system are scarce, yet there is general agreement that it is growing.<sup>2</sup> Both the elderly and the chronically ill populations are increasing in number, with many of these individuals having outlived or been estranged from family and friends. Added to this are homeless persons, the mentally ill, and intellectually or developmentally disabled persons who do not have a guardian or other representation.

Current statutory solutions vary widely across the United States. The fact that there is no widely agreed upon standard for addressing decisions for unrepresented patients further increases the overall vulnerability of this population. In 2016, the American Bar Association Commission on Law and Aging reported that slightly less than half of the U.S. states have a comprehensive healthcare decision act that allows a range of decision makers including relatives, close friends, and clergy. Hawaii, Illinois, Kentucky, and Montana are examples of states with a comprehensive act. A few other states address proxy decision makers in focused statutes such as those on do-not-resuscitate (DNR) orders (Georgia), living

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**Deb Bennett-Woods, EdD**, is Professor Emerita and Faculty at Regis University in Denver, Colorado. [dbennett@regis.edu](mailto:dbennett@regis.edu)

**Jean Abbott, MD, MH**, is Professor Emerita and Faculty at the Center for Bioethics and the Humanities, University of Colorado Anschutz Medical Campus, in Aurora, Colorado. [jabbott49@gmail.com](mailto:jabbott49@gmail.com)

**Jacqueline J. Glover, PhD**, is a Professor at the Center for Bioethics and the Humanities, University of Colorado Anschutz Medical Campus. [Jackie.Glover@ucdenver.edu](mailto:Jackie.Glover@ucdenver.edu)

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wills (Iowa) or informed consent (North Dakota). South Dakota is an example of a state with a separate surrogate consent act. In most cases, these acts and statutes are silent beyond providing a common list or hierarchy of surrogates and assume someone will be found. West Virginia and the District of Columbia explicitly prohibit healthcare providers or facility employees from acting as a surrogate decision maker. Florida's statute allows the appointment of a licensed clinical social worker by a bioethics committee. However, most states with a comprehensive healthcare decision act that goes beyond the standard list of surrogate candidates have utilized physicians in the role of proxy decision maker. The most common approach authorizes the attending physician in consultation with an ethics committee or second physician (Alabama, Alaska, Arizona, New York, Oregon, Tennessee, and Texas).<sup>3</sup>

### PROXY DECISION MAKING IN COLORADO

Colorado has efficiently addressed a wide scope of issues related to medical decisions in the Colorado Medical Treatment Decision Act.<sup>4</sup> Section 18.5 of this act, entitled "Proxy decision makers for medical treatment authorized," specifically addresses surrogate decision making for incapacitated patients who lack a medical durable power of attorney or relevant advance directive. Developed during the 1980s in response to social changes that included the HIV epidemic and an aging population, the Colorado law accurately anticipated the need to create a flexible framework from which to draw potential surrogate decision makers. Rather than default to a specified hierarchy of familial surrogate candidates, the Colorado statute allows a broad range of interested parties (including not only family but close friends) to agree on a decision maker best able to represent the values and interests of the patient. In most cases, this approach is very helpful in identifying an appropriate decision maker.

Unfortunately, the Colorado statute failed to address the possibility that no interested party could be found, leaving facilities and healthcare providers with few options for timely medical decision making. In addition, Colorado lacks a guardianship system that can accommodate the nature and timing of medical decision making. In Colorado, the most common source of volunteer guardians has a waiting list of several months to a year or more. There is no system of public guardianship. The general guardianship process in the courts ranges from weeks at minimum to months or even well over a year. In addition, this process assumes that a willing candidate for a permanent guardian can be found

and is comfortable making medical decisions. Adult Protective Services is statutorily limited in applying as an interested person and, in most counties, will rarely act as a medical proxy.

### Colorado Collaborative for Unrepresented Patients

After a decade or more of general discussion among the Colorado healthcare ethics community, a coalition formed, calling itself the Colorado Collaborative for Unrepresented Patients (CCUP). The CCUP consisted of a small and loosely affiliated group of interested healthcare professionals, led primarily by representatives of two university ethics centers in the greater Denver area and the Colorado Healthcare Ethics Forum (CHEF). CHEF is a unique volunteer organization composed of a diverse membership of Colorado's ethics community, whose mission is to provide a forum for discussion and education for ethics committee members and other interested professionals. The formation of the CCUP launched a five-year odyssey that ultimately resulted in passage of a state statute addressing unrepresented patients. However, the path itself was not at all direct and reflects the complexity of the issue.

The initial intent of members of the CCUP was to research and write a white paper that explored existing approaches to the issue of unrepresented patients with the hope to eventually enable the creation of a network of qualified, volunteer proxy medical decision makers in Colorado. Known barriers included the lack of an ongoing supply of willing volunteers and no reliable or sustainable means of creating a community-based infrastructure to support the recruitment, training, and appointment of volunteers. The general options explored included private guardians, public guardians, attending physicians, other clinicians/individuals, and members of institutional and external committees.

As the white paper began to take shape, the CCUP team became aware of an initiative by a Denver probate judge to address the general issue of public guardianship. The team approached the judge with the specific problem of short-term medical decision making as a unique dimension of the larger issue of public guardianship. A member of the CCUP was invited to serve on a judicial task force charged with investigating and proposing a workable approach to public guardianship in Colorado. The Public Guardian Advisory Committee (PGAC) produced two well-researched reports in 2014.<sup>5</sup> The first report recommended establishment of an office of public guardianship and the second report proposed a pilot project to better define the necessary scope and likely costs. Given the problems of prior volunteer approaches, the CCUP's draft white paper was

eventually revised to support the PGAC's recommendation to establish an office of public guardianship with special provisions for medical proxy decision makers. The white paper was released in July 2014 and appended to the PGAC's second report to emphasize the unique challenge of medical decision making in the absence of a proxy.<sup>6</sup> Unfortunately, the political landscape in Colorado was such that the PGAC's recommendations did not go forward.

### A LEGISLATIVE APPROACH

With no workable community-based options and no promise of public guardianship in the near future, the CCUP went back to the drawing board and began considering legislative options. With the help and advice of an extraordinary lobbyist, who assisted our efforts on a *pro bono* basis throughout the process, we approached a member of the Colorado House of Representatives who had a known interest in both healthcare and guardianship. Having obtained his support, and with the help of a healthcare attorney familiar with the existing statutes involving both medical decision making and guardianship, HB 16-1011: Concerning Medical Decisions for Unrepresented Patients began to take shape in the fall of 2015. The goals of the proposed legislation were to:

- Address the oversight in the existing Colorado proxy statute that did not make allowance for situations in which no willing proxy can be found.
- Improve the timeliness and quality of medical decision making and placement for unrepresented patients.
- Provide transparency and a legal framework that limits professional liability and reduces the risk of unilateral decision making by physicians.
- Raise the community standard for decision making through the appropriate involvement of an ethics committee.
- Reduce moral distress among members of care teams as they experience care delays for these patients.

### Stakeholder Process

The stakeholder process began well before the legislation was drafted, with presentations and feedback sessions starting in early 2015 that proposed using physicians as proxies of last resort. Presentations were made at the annual CHEF conference and at invited sessions to an array of interested stakeholder groups. By December, a stakeholder list had been developed that included representatives of the state medical society and hospital association, indi-

vidual healthcare providers and facilities, the long-term care community, the disability community, state government (including adult protective services), the legal community, liability carriers, other professional associations, the senior lobby, and various miscellaneous other parties. Representatives of the legal community included the state bar association, with specific engagement by sections involved in elder law and guardianship, the state's association of trial attorneys, and a number of individual attorneys who specialize in health law. Professional associations included several medical specialties, nursing, social work, and chaplaincy.

The initial draft of the legislation proposed a basic modification to the existing proxy statute that allowed healthcare facilities to create a process by which an attending physician, on a voluntary basis, could serve as an interim proxy decision maker of last resort with mandatory ethics committee involvement. This draft was initially distributed to stakeholders in late November and December 2015. All the work with stakeholders up to this point suggested there was general support for legislative action, including formal support from the state medical society, and very little in the way of stated opposition. The primary concerns expressed up to that point involved dual professional roles and conflicts of interest, and the potential that the bill would become caught up in negative press and push back from advocates who opposed other legislative initiatives involving assisted death, personhood, and abortion.

Once the draft bill was circulated and formally introduced, the CCUP team did not expect the sudden level of stakeholders' opposition that arose. The first surprise was the strength of the response by the disability community; their concerns ranged from a perceived lack of due process to the historical experience of bias and devaluation of their lives by healthcare providers. Also not anticipated was strong opposition from the state's largest physician liability carrier, which directly led to an initial reversal of the medical society's position and opposition from the state hospital association. Active support from individual healthcare providers and facilities did not materialize to a meaningful extent and, in fact, resistance was encountered from the legal departments of several hospital systems. Finally, the CCUP team quickly found themselves caught in the middle of long-standing tensions between the liability carrier and Colorado's trial attorneys.

Thus, stakeholder negotiations continued throughout the legislative session and beyond. The challenges that arose in both the stakeholder process and the subsequent legislative process were

variously legal, ethical, political, and practical in nature. Given the complexity of the issues, it was not surprising to find a great deal of crossover between these four dimensions.

### **The Legal Dimensions**

The legal dimensions of HB 16-1101 were largely focused on deep-seated and opposing views between the Colorado Trial Lawyers Association (CTLA) and the primary medical professional liability insurance carrier for Colorado physicians regarding liability language in the proposed statute. This dispute then extended to many of the acute care facilities and hospital systems. Representatives of CTLA were concerned that the statute went too far in limiting the liability of healthcare providers and the rights of patients to file suit. The liability carrier insisted that facilities and healthcare providers willing to act on behalf of patients should be protected, so long as decisions are made in accordance with the statute.

The position of the CCUP team was that nothing in the proposed statute protected either physicians or facilities from legal action based on medical negligence or malpractice. Furthermore, the team argued that the current situation, in which physicians either delayed treatment decisions or made them unilaterally, was already fraught with potential liability. Nonetheless, attempting to garner agreement on the specific language within one brief section of the bill proved to be perhaps the greatest challenge faced. It resulted in numerous behind-the-scenes negotiations, competing versions of language, and specific clarifications of intent.

The other legal concerns raised by a variety of stakeholders involved the issues of dual roles and potential conflicts of interest in having the attending physician also act as the proxy decision maker. Inconsistencies in current Colorado statute served to confuse the issue. For example, while paid caregivers, including long-term care administrators, are specifically prohibited from petitioning to also be a patient's or resident's guardian, the proxy decision maker section of the Colorado Medical Treatment Decision Act was silent on the potential role of healthcare providers as proxy medical decision makers.<sup>7</sup> On the other hand, the proxy statute did appear to explicitly prohibit Adult Protective Services from petitioning as an interested person for purposes of becoming a proxy medical decision maker despite the fact that Adult Protective Services could accept appointment as a guardian.<sup>8</sup> In addition, the guardianship statutes restricted the ability of direct service healthcare providers, including long-term care administrators, from applying as guardians. Competing interpretations of existing law there-

fore raised questions about the legal status of any healthcare provider willing to serve in the role of proxy decision maker.

Colorado's primary medical professional liability insurance carrier also argued against the bill based on dual roles. The initial bill allowed for appointment of the attending physician as a proxy, and the early debate over both liability language and conflicts of interest was resolved, in part, by agreeing to use a different willing physician, who is not clinically involved in the treatment of the unrepresented patient, as the physician proxy. This change initially satisfied not just the trial attorneys, but also helped address the concerns of other stakeholders, including disabilities advocates.

However, the liability carrier eventually took issue with the use of a second physician, claiming that it created additional confusion with respect to liability standards and dual roles. The carrier argued that a physician providing a medical opinion as a consultant is held to the higher standard of a medical expert, or what a reasonable physician would recommend under the same circumstances. Under normal circumstances, a proxy decision maker would be held to the lower standard of ordinary negligence, which simply requires acting with the same degree of care as any other prudent person. In the case of HB 16-1101, the carrier argued that a physician acting as an interested person in the role of proxy might still be held to the higher standard even though, in that role, the physician would not be covered under a professional liability policy. Therefore, the conclusion of the carrier, as stated in its testimony during the first committee hearing, was that it would actively discourage physicians from acting in this capacity.

Related concerns over dual roles and conflicts of interest involved the imposition of a physician's values on the patient and potential pressure from the facility to make decisions based on financial factors. Although several parties shared this concern, the liability carrier was particularly strident in its insistence that a physician could not reasonably wear both hats. Throughout the process, the position of the CCUP team was that the potential for conflict of interest was already inevitable, and that the present situation, in which no proxy is appointed, carried a greater potential for unchecked conflicts of interest, given the lack of formal oversight and transparency. The team argued that safeguards in the bill, including an independent capacity assessment, mandatory ethics committee involvement, and a second medical opinion in end-of-life decisions, lent transparency and provided assurance that a multidisciplinary viewpoint, already accustomed to ne-

gotiating values-driven decisions, is in place. The team claimed that there are substantially more protections in this process than the average proxy process involving a distant or estranged relative who may have little insight into the patient's wishes. The CCUP team made the case that the current hesitation to make decisions (in order to limit liability) represented as great a conflict of interest as decisions made on the basis of direct financial factors.

### **The Ethical Dimensions**

The proposed legislation attempted to address a number of ethical dimensions relevant to this patient population. The primary challenge for medical decision making when a patient lacks a voice is how best to discern and honor the patient's values and those choices the patient would make if capable of fully informed and autonomous decision making. However, this is not the only ethical challenge. Unrepresented patients raise issues of preventing needless or avoidable harm, determining best interests, and achieving social justice, all of which were addressed at some level by the proposed legislation.

Respecting patients' autonomy, even when using a patient-appointed proxy, is challenging, since there is evidence that proxy choices do not reflect patients' preferences as much as 30 percent of the time.<sup>9</sup> No process can completely guarantee that the decisions made will be consistent with what an unrepresented patient might want; however, the participation of a multidisciplinary ethics committee can support the process by ensuring that patients are involved to the extent that they can be, that any existing collateral evidence of values is considered, and that bias is minimized by providing diverse perspectives to advocate for the patient.

The high potential for overtreatment, undertreatment, delayed treatment, and the risks associated with extended and inappropriate placement raise complex questions of patients' best interests and avoidable harm. For all practical purposes, delaying medically indicated urgent or elective procedures due to the lack of a proxy *is* a medical decision, as is continued aggressive treatment that the care team might not otherwise recommend to a capacitated patient or a proxy. Both situations offer the potential for increased suffering and for actions not fully in line with a patient's best interests or even optimal standards of care. When a patient's best interests are not evident, or it is difficult to weigh potential harms, shared decision making using an ethics committee can facilitate thoughtful deliberation and representation of a range of viewpoints.

Perhaps the most pressing ethical aspect of caring for unrepresented patients is their sheer vulner-

ability. Patients who lack capacity or who suffer from diminished capacity and who do not have representation are totally powerless and dependent on the care team for their medical well-being.<sup>10</sup> Many of these patients are the targets of negative assumptions and social biases regarding the elderly, the physically disabled, the intellectually or developmentally disabled, the mentally ill, the homeless, undocumented immigrants, and others. They often lack the means or opportunity to assure fair and equitable treatment or to appeal decisions made on their behalf. By mandating the involvement of an ethics committee, the legislation introduced a new level of protection based on the transparency of the decision-making process and a multidisciplinary effort to seek the patient's voice.

### **The Practical Dimensions**

A number of practical concerns were raised by individuals and institutions during the process of negotiating the legislation. While most of the stakeholders' and legislators' questions were logistical in nature (and too detailed to address in the statute), the conversation itself was instrumental in developing shared understanding, support for the legislation, and then, later, a process to develop implementation guidelines. These issues included, among others, due diligence in attempting to locate a proxy, the qualifications and education of a physician proxy, the termination of a physician proxy's responsibility, decision-making capacity assessments, an ethics committee's role and the extent of its involvement, and the possible lack of availability of an ethics committee in rural hospitals or other non-hospital facilities.

A good example of the practical issues encountered was the question of whether advance practice nurses could also serve as medical proxy decision makers under the statute. As a stakeholder in our process, the Colorado Nurses Association was supportive of an expanded definition of medical proxy, particularly in rural areas where there is a serious shortage of healthcare providers. While the CCUP team had no objection to the addition of advance practice nurses for practical purposes, it was strongly advised not to amend the bill in this direction due to current political realities related to other legislation and debate regarding scope of practice.

Of primary importance in addressing the many practical dimensions was the recognition that different settings were going to have different resources and different needs, so there was a strong effort to keep the statute itself as broad as possible in terms of specific requirements. The intent was to allow facilities to develop policies and procedures that met

the intent of the statute that were suited to each facility's unique context. The CCUP team's stated commitment to assist in the development of more specific implementation guidelines following passage of the bill was particularly helpful in preventing the process from getting bogged down with these issues.

### **The Political Dimensions**

The political dimensions reflected a combination of the legal, ethical, and practical aspects earlier. In particular, the legal concerns and subsequent lobbying efforts of both CTLA and the liability carrier became a primary political barrier to passage of the statute. In addition, there were challenges associated with competing priorities during this specific legislative session. There were a number of health-care related bills with significant fiscal implications that diverted attention from the efforts on behalf of the unrepresented. As mentioned earlier, political dynamics around scope of practice prevented the addition of advance practice nurses as proxy decision makers. In addition, and of particular concern, was HB 16-1054: "Concerning end of life options for individuals with a terminal illness," which we recognized could easily become negatively conflated with our bill by opponents of the assisted death initiative, including our stakeholders in the disabilities community.

More generally, the legislative effort was hampered by the relative obscurity of the issue. Although their numbers are increasing, these patients make up a small percentage of inpatient admissions. Aside from anecdotal case summaries, there are no systematic data documenting the number of patients and the relative costs or clinical outcomes of these patients as a class. There are no family members or friends to raise alarms, and many of our stakeholders proved unwilling to publicly advocate for these patients. On the positive side, the bill addressed an obvious shortcoming in existing statute, and did so in a manner that involved no fiscal impact. In addition, its use remained voluntary and at the discretion of both healthcare facilities and physicians.

### **THE LEGISLATIVE PROCESS**

As HB 16-1101 was altered to accommodate stakeholders' concerns, the CCUP team, the lobbyist, and our sponsors prepared for hearings in the Colorado House of Representatives. Prior to the first hearing in the house, and based on intensive meetings with stakeholders, the bill was revised to add an independent medical capacity assessment. In addition, language around the role of ethics commit-

tees was strengthened to require their agreement with significant medical decisions on behalf of a patient. Later in the process, the term "agreement" was changed to "consensus." Efforts to negotiate liability language that was acceptable to both the trial lawyers and the liability carrier failed.

The initial hearing of the bill in the Colorado House Committee on Health, Insurance, and Environment was unexpectedly contentious. We had been advised that the house would be the easier of the two state legislative bodies to approach, yet that proved not to be the case. In a hearing lasting nearly three hours, representatives of the trial attorneys and the liability carrier were called upon and challenged to defend their opposition to the bill. In addition, several amendments offered by committee members, relating mostly to end-of-life decisions, were introduced, debated, and defeated. One amendment, requiring facilities without an ethics committee to obtain an ethics consultation from another facility did pass. The bill eventually passed the committee on a vote of seven to six, along party lines.

The initial passage of the bill through committee brought the stakeholders back to the table. The primary issue remained liability, with stakeholders' efforts to include liability protections for physicians, facilities, and even members of ethics committees. Detailed requests for revision were received from several stakeholders, and a compromise version of the bill was crafted based on what we and our sponsor were willing to take forward. The most significant revision, proposed by CTLA, was to change the proxy-of-last-resort from the attending physician to a physician who is not involved in the treatment of the patient and appointed by the attending physician, with ethics committee approval. At the request of the liability carrier, a detailed list of the points at which a proxy's responsibilities terminated was added. In response to the concerns expressed by house committee members, language protecting against euthanasia that was consistent with other Colorado statute was added. Also, consistent with other existing Colorado statute, a second clinical opinion in end-of-life decisions was added. Finally, new liability language specifying a good faith standard for the physician acting as a proxy, specifying that the attending physician remains responsible for negligent acts or omissions in rendering care, was adopted. Through continued work with representatives of the disabilities community, we were able to make the above changes that enabled them to fully support the bill.

The substantially amended bill was introduced on the floor of the house, passed on a second and third reading, with a single technical amendment

on a vote of 40 to 25, with 18 cosponsors, and was referred to the Colorado Senate. Passage into the senate garnered yet another round of meetings with stakeholders. In particular, the liability carrier remained generally opposed to the bill, requesting that we return to having the attending physician serve as proxy and expressing continued concerns regarding untested liability, legal standards, and conflict of interest. Its position continued to be that it would instruct clients not to use the statute if it passed, rendering it virtually useless. The ensuing discussion was substantive and valuable, but a decision was made not to change the bill at that point and further requested amendments were not accepted.

Upon arrival in the senate, it was discovered that the bill was slated to be “killed” without an initial hearing. However, our lobbyist succeeded in turning the ship and located a senate sponsor on the Health and Human Services Committee. Despite testimony against the bill by the liability carrier, the bill received a favorable initial hearing and was passed unanimously, with one minor technical amendment to the floor. Here, it should be noted, further conversation with the liability carrier and the state hospital association did eventually result in support for the bill. The bill went on to pass the senate on third reading by a 33 to one bipartisan vote, and a successful concurrence vote back in the Colorado House of Representatives. The governor signed it into law on 18 May 2016.<sup>11</sup>

### IMPLEMENTATION

The statutory language of HB 16-1101 became law on 5 August 2016, and healthcare providers across the state began the process of implementation. To effect our goal of ensuring a more standardized and consistent approach to unrepresented patients, the CCUP engaged stakeholders to facilitate the development of a guidelines document to assist facilities in developing internal policies and procedures consistent with the statute. Active participation by numerous stakeholders, including the liability carrier and state hospital association, was of great value. The first version of the guidelines was released in November of 2016, and, as of this writing, the statute is in active use by at least a subset of healthcare providers and facilities.

### LESSONS LEARNED

The importance of a strong and broadly targeted stakeholder process cannot be understated. Earlier engagement with several key stakeholders could have avoided some of the initial opposition. For

example, we did not adequately include patient advocacy organizations, such as those in the disabilities community, until an early draft of the bill was circulated in late November 2015. Although key representatives from the disabilities community did ultimately support the bill, the initial response was negative, and we belatedly discovered that the entire process would have benefitted from their active engagement and advice during the initial drafting of the bill. Likewise, efforts earlier in the year to engage the state’s medical society and the state’s hospital association, among other key stakeholders, were not successful, with both organizations advising us to come back in the fall once the bill was drafted. However, it was not until the bill was introduced that serious objections were raised by these and other organizations. Key stakeholders then insisted that another full year was needed to work out the details, although it was unclear how another year would guarantee compromise once the immediate pressure of the legislative session was removed. While successful in our response to work very hard to keep bringing stakeholders back to a sense of urgency on the issue by emphasizing the negative impacts of further delay on patients and healthcare providers, it was clear that we had missed an opportunity to create momentum with specific stakeholders earlier in the process.

Another key lesson was the power of lawyers and liability carriers to dominate opinions. The CCUP team underestimated the extent and speed with which the liability carrier and the trial lawyers’ association could shift the positions of other stakeholders. Because we focused initially on the healthcare provider community, who we felt had a stake in the issue second only to the patients themselves, we neglected to fully consider nonhealthcare provider stakeholders such as the liability carriers and other members of the legal community, who exerted great influence over both healthcare providers and legislators.

Finally, the team’s perspective came from our experience at the bedside with direct healthcare providers, social workers, chaplains, and others from the Colorado healthcare ethics community who experienced firsthand the problems of “doing right” for this vulnerable group of patients. While ethics committees are often the venue in which these cases play out, the committees were not necessarily effective in communicating the issue and our legislative efforts to the top of their organizations. Therefore, there was little engagement from healthcare leaders, particularly from the hospitals, who deferred to their legal departments and the state hospital association. As noted previously, the extent to which

hospital legal departments took issue with the proposed statute was something that perhaps should have been anticipated, but was not.

On the positive side, our team learned very quickly the importance of patients' stories and proactive efforts to educate stakeholders and legislators. As is common with legislation, the issues are complex, and many of the decision makers will be marginally (if at all) familiar with the context and details of an issue. We created three documents that proved invaluable as the process unfolded. The first was a two-page (front and back) document entitled *Stories from the Bedside*, that presented eight actual patient cases to illustrate the range of potential circumstances and consequences of under treatment, over treatment, and improper placement for these patients. The second was a single page fact sheet presenting two brief cases, the definition of an unrepresented patient, an outline of the scope of the problem, and a request for legislative action. The third document, entitled *Questions and Response*, was more lengthy, and posed 25 questions, based largely on existing feedback from stakeholders, that anticipated legal, ethical, and practical concerns. The document detailed answers that addressed each concern in relation to the proposed statute. This last document also provided our team with consistent language to use when addressing stakeholders and providing testimony. Taken together, these documents provided stakeholders and, most importantly, legislators with information and detailed answers to relevant questions that may or may not have been addressed via testimony.

The final lesson was clearly the importance of collaboration and compromise. Although some of the compromises made the statute more cumbersome, the final legislation absolutely benefitted from most of the revisions negotiated throughout the process. Likewise, the process itself generated a community of stakeholders, both individual and institutional, that had previously not worked together on such an issue. It is easy to foresee these groups more easily coming together on similar issues in the future. For example, our team efforts contributed to a renewed legislative focus on the issue of public guardianship, which is now being addressed in the in the 2017 legislative session, and has brought many of the former stakeholders back together.

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