

In the May 15, 2018 issue of *Catholic Health World*, CHA's Julie Minda published a piece detailing a recent initiative on end-of-life education for clergy members – “Clergy gain insights in end-of-life choices.” Fr. Charlie Bouchard and I spent a day with priests, deacons, and the bishop of Victoria, Texas reviewing the church’s teaching on end-of-life ethical issues to prepare them to advise their parishioners about advance care planning. The following week, I spent an evening with a group of Stephen’s Ministers, parishioners trained to accompany others in difficult times, overviewing the same topic. What became clear at these events was that both the laity and the ordained are yearning for answers and advice.

One topic each group raised regarded the role of a durable or medical power of attorney (POA). As ethicists reading this publication, you are all very familiar with this subject. However, the public continues to question the need for and the role of a POA. One member of the Stephen’s Ministers stated the difficulty in naming one member of their family as the decision maker for fear of offending the others. Another individual assumed that should no family member be available, the hospital staff will make the proper medical decisions. These are not isolated questions; they reaffirm CHA’s initiative to educate more of the faithful and church leaders on our tradition’s end-of-life teachings.

With these two events, and the planning for more in the near future, my eye has been keen on topics related to surrogate decision making. So, I was immediately alert when one Sunday John Oliver on his HBO series *Last Week Tonight* raised the topic of guardianship in the United States. Using the story of a couple in Nevada, Mr. Oliver began to outline a series of abuses within the court-appointed guardianship system. In fact,

the use of the word “system” gives too much credit to the disparate rules and procedures among the states. With my interest piqued, I began to research for more information.

Last year, *The New Yorker* contained a piece outlining a few cases and the need for more oversight. The publication revealed that, “according to an auditor for the guardianship fraud program in Palm Beach County...a million and a half adults are under the care of guardians, either family or professionals, who control some two hundred and seventy-three billion dollars in assets.”<sup>1</sup> This is a very large group of people dependent upon others for decisions regarding their health, finances, and living situation.

According to the Missouri Developmental Disability Resource Center, when an individual is deemed to lack capacity and is assigned a guardian, he/she “may lose many rights that are often taken for granted such as the right to vote, obtain a driver’s license, consent or object to medical care, or enter into contracts like marriage or home ownership. Individuals with a guardian may not get to decide where they live, with whom they live, where they go in the community or how their money is spent.”<sup>2</sup> In an article for *Forbes*, Emily Gurnon sums up this extreme intervention: “With as little as a single document – and in some cases, not even a court hearing – older adults can see their most basic rights stripped away.”<sup>3</sup> With the potential elimination of such fundamental rights, one would hope that the system of becoming and assigning a guardian was well regulated and overseen. Unfortunately, that is not the situation.

States do not need to keep records on the outcomes of court-appointed guardians. In 2010, a Government Accountability report said, “We could not locate a single Web site, federal agency, state or local entity, or any

other organization that compiles comprehensive information on the issue.”<sup>4</sup> Pamela Teaser, of the Center for Gerontology at Virginia Tech, summed up the situation as “a morass, a total mess. It is unconscionable that we don’t have any data, when you think about the vast power given to a guardian. It is one of society’s most drastic interventions.”<sup>5</sup> In 2014, a survey on state guardianship laws found that “40 percent of the 1,000 respondents said that criminal background checks were not required of non-professional guardians of an estate” and that “sixty percent of the court respondents said they did not require a credit or financial background check on a prospective guardian.”<sup>6</sup> As Teaser tells *HuffPost*, “In most states around the country, it is easier to qualify as a guardian than it is to become a hairdresser...”<sup>7</sup>

What is the effect of this lack of oversight? The GAO, in a different 2010 report, “found hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010.”<sup>8</sup> The financial exploitation totaled nearly \$5.4 million in assets stolen by the very people entrusted to manage it.<sup>9</sup> If the patient, or their family uncovers the abuse or exploitation, the system makes it almost impossible to exit. A patient is unable to testify in court, or to hire an attorney. As Bredna Uekert, principal court research consultant with the National Center for State Courts, tells *Forbes* “Go ahead and see what you can do, because you have been deemed incapacitated, so everything you say or do is meaningless.”<sup>10</sup>

Clearly this is a tragic and unjust situation. It ought to raise our awareness when we encounter a patient who is on the course towards incapacitation. How many times have you been called to a consult in which the individual does not have an assigned

POA, whose family members are never present (yet known), and whose decision making is waning? I am sure this a very common occurrence for our readership. When a care team meeting is called to decide next steps, often someone raises the idea of seeking a guardian. Their intentions are good; they know a person is needed to assist in decision making. I wonder now how much about the guardianship program these healthcare workers truly understand.

Within our church tradition we have a view of the person that extends beyond their decisional capabilities. Unfortunately, society equates one’s value with one’s performative function. Court appointed guardianship relies upon this latter anthropology. It sometimes excessively strips away one’s rights because they cannot make certain decisions. Yet, we are called as Catholics to respect one’s *dignity*, not just one’s decision-making ability. This demands that we keep the person in proper relationship with the world and with those actions that affect his/her own life.

Human dignity also underlines Part Three of the *Ethical and Religious Directives*. It is in this section that the bishops recognize the obligation that we have towards the vulnerable in our midst. Most importantly we must ensure “mutual respect, trust, honesty, and appropriate confidentiality.” The directives extend from these values to outline the right of a patient to “identify in advance a representative to make health care decisions” and “their rights...to make an advance directive...”<sup>11</sup> These directives lead me to provide some recommendations.

The first is simple and many are trying to already increase the numbers – encourage patients to assign a trusted POA. Along with the official paperwork, the person ought to have many conversations about their values, fears, and preferences to ensure that any

future decisions align with their wishes. The ERDs describes a good surrogate as “those who are in a position to know best the patient’s wishes.” This is the surest way to prevent the need for a court-appointed guardian.

A second avenue is to know the alternatives for a guardian. Just because someone has been declared to lack capacity in medical decisions, does not necessarily mean that they lack capacity for all decisions. The Missouri Developmental Disability Resource Center outlines a few such paths:

- General Supports – natural, unpaid, and community resources and may include family, friends, and advocacy organizations.
- Money Management Supports – help manage financial obligations and avoid exploitation. These supports include such things as joint bank accounts and trusts.
- Personal Safety Supports – are useful for individuals at risk for being abused/neglected by an intimate partner, spouse, family member, personal assistant or caregiver.<sup>12</sup>

The third recommendation is to be alert should a court-appointed guardian be assigned to one of your patients. Knowing the power a guardian has over every facet of the person’s life, we should keep an eye out for potential abuse happening outside the hospital. Be wary should the guardian suddenly inform you of an address change; they may have just sold the patient’s house. No family or friends visiting the patient? This could be a sign of exploitation and isolation. We have a duty to protect the vulnerable in our midst beyond curing their illness. This duty is outlined in Directive 35 of the ERDs: “Health care professionals should be educated to recognize the symptoms of abuse and violence and are obliged to report cases

of abuse to proper authorities...” Developing awareness about and procedures for when a co-worker suspects abuse by a guardian is a starting point for the protection of these potential victims.

<https://www.forbes.com/sites/nextavenue/2016/05/23/guardianship-in-the-u-s-protection-or-exploitation/#7acbdb4e3b49>

<https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>

[https://www.huffingtonpost.com/entry/court-appointed-guardian-system-failing-elderly\\_us\\_59d3f70be4b06226e3f44d4e](https://www.huffingtonpost.com/entry/court-appointed-guardian-system-failing-elderly_us_59d3f70be4b06226e3f44d4e)

<https://health.mo.gov/shcn/CSHCN/docs/GuardianshipInfoPack.pdf>

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<sup>1</sup> “How the Elderly Lose Their Rights,” *The New Yorker*, 10.9.2017

<sup>2</sup> A New Way to Support Families, Missouri Developmental Disability Resource Center

<sup>3</sup> “Guardianship in the US: Protection or Exploitation,” *Forbes*, 05.23.2016

<sup>4</sup> “How the Elderly Lose Their Rights,” *The New Yorker*, 10.9.2017

<sup>5</sup> “How the Elderly Lose Their Rights,” *The New Yorker*, 10.9.2017

<sup>6</sup> “Guardianship in the US: Protection or Exploitation,” *Forbes*, 05.23.2016

<sup>7</sup> “Court Appointed Guardian System Failing Elderly,” *HuffingtonPost*, 10.10.17

<sup>8</sup> “Guardianship in the US: Protection or Exploitation,” *Forbes*, 05.23.2016

<sup>9</sup> “Guardianship in the US: Protection or Exploitation,” *Forbes*, 05.23.2016

<sup>10</sup> “Guardianship in the US: Protection or Exploitation,” *Forbes*, 05.23.2016

<sup>11</sup> USCCB, *Ethical and Religious Directives for Health Care Services: 5<sup>th</sup> Edition*, #24, 25.

<sup>12</sup> A New Way to Support Families, Missouri Developmental Disability Resource Center

N.H.

## Health Care Reform Should Not Be Compassionate

*Justice comes first, but it's a hard sell*

Health care reform in the U.S. is like a swinging bridge high above a wild river. It is shaky and the stakes are high, but at least it's still there. Things are calm for the moment. It is hard to say whether there will be further attempts to weaken the Affordable Care Act (ACA) before the fall mid-terms. This is a good time to step back and reflect, especially in light of what we have learned about attitudes toward health care financing since the ACA became law.

Americans remain deeply divided about health care reform. Across all groups except young millennials, support for it is only slightly above half of those polled. Among some groups (e.g., older whites who identify as Republican) only about 15% support it. In December of 2017 a *Kaiser Health News* survey tried to find out, "Why do people hate Obamacare, anyway?" They summarized the responses in four categories: ideology (too expensive, too much government involvement); lack of knowledge about what the bill actually does; confusing the law with the health care system generally; and the fact that the ACA actually made things worse for some people.<sup>1</sup>

At first many of these objections puzzled me. Recently, I have come to understand them better. One problem is the language we use to frame the case for reform. Many times during the debates I heard critics denounce reform proposals as cruel or lacking in compassion. I don't think that kind of language is appropriate to the political process. To say that a health care bill should be compassionate implies that there are some people who own or control health care (the government, health care providers, insurance companies?) and that they should kindly

share more of it with those who are less fortunate. This view makes allocation of health care an act of charity – a handout from the haves to the have nots. This might be appropriate if the donor were a private employer who chooses to give a large, unearned bonus to employees at Christmas, but it is not the way politicians should think. Charity should infuse our lives as Christians, and ultimately it is union with God. But we're not there yet. Our very imperfect world, and its even less perfect political system, must be ruled by justice and not charity.

Moral theologian Stephen Pope makes a similar point in his review of Paul Bloom's book *Against Empathy: The Case for Rational Compassion*.<sup>2</sup> Compassion and empathy are not the same, but their similarity as affective responses to evil warrant their comparison here. Pope recognizes empathy as an emotion and agrees with Bloom that emotion has weaknesses as a basis for morality. "Empathy is a human capacity that can serve good or evil, and that can be exercised wisely or foolishly, so it has to be properly developed, trained and ordered by reason." Its proper moral significance, he says, is only apparent if you put it "into the context of an overarching commitment to justice, the virtue that requires us to consider the goods and harms done to individuals in light of the common good." He does not deny the importance of empathy or other feelings, but he denies their "ethical primacy."

Justice is the will that "each receives his or her due." This is a hard sell in part because it depends on the idea of rights. My "due" is what I am owed. But we run into problems as soon as we introduce rights language because "right" is a highly analogous term. It means different things to different people. In the Catholic tradition, a right is a moral power, that is, the ability to lay claim on

something. A right may be positive or negative. I can lay claim to something, or to be free of something but rights are only meaningful if there is a corresponding obligation. This works in a cohesive, tightly-woven community like a family and sometimes in much larger entities where there is a shared value and story about what is good. This may have been true in the U.S. in the 1940s and 50s. However, starting in the 1960s, our relatively cohesive culture began to unravel, individualism took on a new prominence, and the idea of a manifesto right began to arise.<sup>3</sup> A right became a “moral trump card.” People demanded power, equality, solidarity, health care, health, and life itself, but it was not clear who had the corresponding obligation. This led many people, especially in the United States, to see a right as code language for entitlement, or giving lots of free stuff to people who presumably don’t deserve it.

Atul Gawande, the well-known physician-author, recently tried to understand what the problem was with the right to health care coverage that was part of the Affordable Care Act.<sup>4</sup> He went back to Athens, Ohio, the working-class town where he grew up and where the recession hit hard and lack of health care coverage is still a major problem (now exacerbated by the opiate addiction crisis).

Gawande asked people what they thought about the ACA and especially about a “right” to health care. It is clear from the answers he got that many of his friends were suspicious of rights language because it appeared unjust. “One person’s right to health care becomes another person’s burden to pay for it,” one friend said. “Everybody has a right to access health care,” he continued, “but they should be contributing to the cost.” Another childhood friend was bothered by the fact that rights make no distinction between the

deserving and underserving. Some even felt rights were undermining work and responsibility. Their views were all articulations of a classic theory of rights which requires more than a manifesto.

The most interesting thing about the interviews was the careful distinction Gawande’s interlocutors drew between Medicaid and Medicare. Most of them disliked the right that undergirds Medicaid, because it seemed to reward eligible people who they felt were underserving, people who didn’t pay in and who didn’t work. This is a popular misconception since many Medicaid recipients are employed but don’t have adequate medical coverage.

Medicare, however, was an entirely different story. Almost everyone supported it because they had all paid into it. “To them,” Gawande said, “Medicare was less about a universal right than about a universal agreement on how much we give and how much we get.” They had an intuitive sense that rights were more complicated than a claim. They understood that rights are rooted in a complex web of relationships that require both give and take.

So, part of the problem is that we need to acknowledge legitimate anger about perceived injustice. It is pretty hard to see the big picture of health economics if you’re barely making it yourself and feel like you’re also paying for someone else. We need to do a better job of explaining what rights and justice mean or find other language altogether.

Another issue is to be clear about self-interest. If a right to health care is not a big giveaway, then what’s in it for me? ACA proponents did an inadequate job of presenting the case for better coverage. Self-interest plays a role because all of us are

vulnerable and rights are one way that we limit or at least account for vulnerability. Even if I am healthy right now, I could get sick tomorrow. More to the point, my health is connected to the health of others, a fact that becomes painfully obvious in the case of an epidemic. We haven't even had a bad flu season in the last few years, so we tend to forget about this possibility. Even if I don't worry about catching the flu, do I really want to live in a society full of sick people?

Self-interest has an economic aspect as well. There are plenty of academic studies to prove it, but even an amateur can understand that lack of primary care, especially for chronic illnesses, is going to increase health care costs down the line. Providing inexpensive drugs and regular checkups for diabetes and hypertension lowers health care costs for heart attack, stroke, kidney disease and other complications that inevitably occur if these manageable diseases are left untreated. Society (not just government) will pay the long-term costs through charity care, welfare or higher insurance premiums. It is the same principle that sends us to the mechanic for regular oil changes before the engine blows up.

The insurance mandate was a feature of the Affordable Care Act that required everyone to buy a certain level of insurance coverage. It was the obligation that corresponds to the right to health care. Yet opponents of the mandate, like Senate Majority Leader Mitch McConnell (R-KY) see it as incompatible with self-interest because it infringes on individual liberty. He says citizens should not be forced to buy something that they "don't want, don't need and can't afford." Citizens should be free to buy any kind of insurance, or no insurance at all.

This is appealing to many Americans who like to think of freedom negatively, as the

absence of obligation. We regard anything that involves a mandate with suspicion. Yet there are many things that are essential to our lives which would be impossible without broad public support. Requiring me to buy a certain minimum level of insurance is not like making me buy a lawnmower or a certain model car. Health care is not a commodity. It's a public service that, like the fire department or the police department involves complex logistics, expertise and sophisticated training. Maintaining them requires a stream of revenue and broad participation by citizens. One of Dr. Gawande's friends, Mark, came to this realization after he had a serious heart attack. He said he thanked his whole medical team not just for taking care of him, but for "when I was smoking drinking and eating chicken wings. They were all here working and studying and I appreciated it." They were getting ready for Mark, Gawande said, "regardless of who he would turn out to be - rich or poor, spendthrift or provident, wise or foolish."

It is certainly possible to argue that we don't want health care to be a government handout or even that we don't want the government to control health care. But you can't make that argument and also say that citizens have no responsibility for their own health care or to contribute to a health care system they will eventually need.

No one wants to live in a world without compassion, but a world without justice is even worse. Let's work toward justice first, even if the first step is enlightened self-interest. Let's also work harder to put the Gospel mandate for justice and the common good into language that is clear and persuasive.

C.B.

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<sup>1</sup>Julie Rovner, “Why do People Hate Obamacare, Anyway?” *Kaiser Health News* (December 13, 2017). Nate Silver’s website FiveThirtyEight did an overview polling on the same questions in 2014 and 2015 and came to similar conclusions. They said the top five reasons were a) personal costs/unaffordable; b) infringes on rights/unconstitutional; c) not proper role of government; d) constrains choice and e) is unfair. See Dan Hopkins, “What Americans Don’t Like About Obamacare,” *FiveThirtyEight* (June 27, 2017).

<sup>2</sup>HarperCollins, 2017. Pope’s review is found in *Commonweal* (June 16, 2017) 33-34m “I Don’t Feel Your Pain.”

<sup>3</sup>See Andrew Latham and John Bowlin, “Is the Common Good Obsolete?” *Commonweal* (November 17, 2016). Latham maintains that the lack of a common idea of human fulfillment has made the common good an impossible goal.

<sup>4</sup>“Is Health Care a Right?” *The New Yorker* (October 2, 2017): 48-55.