

Ethics of Autonomy and Protection

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The ethical component autonomy and protection, pushes us to look beyond ourselves in decision making. Asking first who are we protecting from what real or feared harm. Living in a civilized society places reasonable limits on choices, the danger in setting limits on choices is setting unreasonable limits that in an effort to protect from harm the person whose rights are being limited, while offering limited or no protection to society.

Adults are allowed to make choices. Choice is a fundamental part of being human, even deciding not to make a choice, is a choice. Not all choices we make are good choices. As adults we enjoy the right to make bad choices. Some choices place us in harm's way. Yet, we allowed to make those choices as long as we understand the choice we are making. This is not an unlimited right. Society will intervene on personal choice if the person is unable to understand the choice the person is making, or if the behavior presents an unreasonable risk of harm to other persons or property.

In the United States it is legally difficult to interfere with bad choices made by an adult unless the adult has been found by a Court to be a "person in need of protection"¹ or if the risks to others are so high that the choice becomes a criminal.

A first step is asking, who are we protecting from what risk? When you dig into this, there are a lot of surprises, we are more concerned about protecting others and society than we are about protecting the individual making the choice. We don't stop a person from walking in traffic on an expressway because it presents a risk to the pedestrian, we prohibit pedestrians in freeway traffic because allowing it runs a high risk of property damage to cars trying to avoid hitting the person or cars that hit the person. Arguably walking in traffic on an expressway could be done safely, but the risks to others are too great resulting the behavior being criminalized.

As a civil society we have a duty to others, to limit as criminal behavior that presents an unreasonable risk to other persons or property. When a guardian or conservator is helping a person found to be in need of protection, it is important to try to prevent the person from making choices that would result in an unreasonable risk of harm to other persons or property.

What is a reasonable risk, what is an unreasonable risk? A reasonable risk is some risk of a bad outcome, but not a certainty or even likely hood of a risk of harm to others. It is also important to look at the potential harm to others, is it a harm that is great enough to limit the freedoms of others? Take second hand smoke. For decades it was normal to see smoking in restaurants, offices, and even airliners. Non-smokers complained, but restricting smoking in public places didn't start to gain traction until medical evidence of the risk of exposure to second hand smoke moved the perception of risk for reasonable to unreasonable.

Traditionally guardianship appointed a person to protect the person and conservatorship appointed a person to protect money and property of a person found to be "incompetent" or "incapacitated²." Modern usage has blurred the lines between guardianship and conservatorship, with some state statutes still following the distinction, but many using guardianship for both person and property and one notable exception, that uses conservatorship to cover both person and property. For

¹ Guardianship, Conservatorship, and Other Protective Arrangements Act, Uniform Law Commission (2017.)

Available at

<http://www.uniformlaws.org/Act.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act>

² Incompetent and incapacitated are outdated terms, that promote misunderstanding and stereotypes that are still found in use.

simplicity, I will use guardianship for all arrangements where a Court has found a person to be in need of protection and appointed a fiduciary to serve this role.

Guardianship or Conservatorship is the process by which Courts are most likely to determine that a “person is in need of protection.” (States generally have separate laws for involuntary hospitalization for persons needing mental health treatment.) The basis for appointment of a guardian is that the person lacks “the ability to meet essential requirements for physical health, safety, or self-care because the respondent is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance, or supported decision making.”³ It is important to note that under modern law, a person subject to guardianship is a person in need of protection, not a person whose rights have been terminated or taken away. The role of the guardian is to the extent possible, to help the person make decisions and choices.⁴

The latest update to the Uniform Guardianship and Protective Arrangements Act, specifically incorporate the person centered and person driven decision making model of supported decision making into the decision making process for persons in need of protection.⁵ Section 313 (b) specifically says that a guardian must promote self-determination and participation in decision making to the extent possible.⁶ This passage means nothing unless it means that the guardian should allow a person in need of protection to make choices, within the scope of the persons’ ability (also known as capacity), even if those choices are considered by others to be “bad choices.”

We really can’t look at autonomy and choice without talking about Capacity. Capacity is the ability to make an informed choice. An informed choice is a decision that the person makes, understanding there are options and the choice has consequences. Capacity is not an on/off switch. Capacity falls on a spectrum from fully independent, to fully unable to make informed choices. As long as a person is able to express a preference in a meaningful way, the person may have some measure of capacity. Capacity is situational, the capacity or ability needed depends on the question or issue and the person’s ability and life experience with that issue or question. Capacity may be transient, capacity can increase or decrease.

We all have limited capacity – there are issues or decisions that are beyond our ability to understand and comprehend. The list of issues that fall outside of our capacity will vary depending on our native abilities, our education and our life experiences. When I was in my late teens I took flying lessons. I was quite good at getting an airplane in the air safely and flying around, but I never learned how to land the plane. Just because I could take off and fly around, didn’t mean I could land, and the inability to land, didn’t mean I was unable to take off or move around in the sky. When thinking about capacity and ability we have to constantly ask, “what are we asking the person to do?” The only capacity that counts is the capacity to do the essential act we are focusing on. The inability to do other tasks or make other decisions shouldn’t impact our judgement on the question at hand. All of us have times when our judgement is at its best, and times when our judgement is impaired. Capacity or ability are impacted by sleep, illness, medication, mental health, stress, distraction, or pain. A few years ago, I had a spinal fusion, about 8 inches of my spine are held together with titanium plates and about a dozen screws. As expected the post-operative pain was significant, significant enough to impair my judgement. The good

³ Id note 1 at 71

⁴ Id note 1 at 105

⁵ Id note 1 at 105

⁶ Id note 1 at 1-5

news is that the pain control medication did a wonderful job of managing the pain and also impacted my judgement for a week or so. I know this because; and the bad news is, they gave me my smart phone on the second day after surgery. When I look back at the text messages and Facebook postings from that first week, it is obvious that my capacity was diminished (and Facebook postings live on forever.) When the pain became tolerable, and the drugs went away, my capacity came back.

Capacity is one of the most complex issues in human interaction. A decision without capacity won't reflect the true wishes of the person. This is balanced against denying a person choice based on a perceived lack of capacity, and in the process denying the person basic human rights.

We have a long history of overprotecting persons that are perceived as lacking capacity by making their choices for them. We do this for a variety of reasons, wanting to protect the person, wanting protect society and wanting to protect ourselves.

What are we protecting the person from? Choice carries with it a risk of making a bad choice. Everyone makes bad choices. When I was learning to delegate work responsibilities my mentor told me, "don't worry about your colleagues making a bad choice, it won't be any worse than some of the choices you have made!"

We want to protect people from failure. Failure hurts emotionally, sometimes physically or economically. Failure is a part of life. While we want to prevent emotional injury, we need to be careful to not prevent emotional growth. We want to prevent economic loss. We all make bad financial decisions. The summer between my junior and senior years of High School I helped my grandmother care for my grandfather who had advanced dementia. I was helping her in the kitchen one morning and he walked in and said, "its Friday Emmi" and held out his hand. She dug in her purse and handed him \$50 in cash. When he scurried off into the bedroom I asked her, "why did you do that, he can't find his way up the driveway without help, he can't manage money?" Her response stays with me to this day, "for 50 years I have managed the finances, on Friday I give him his allowance. If he asks for it, I still give it to him. I don't care what he does with it, it makes him feel normal. We can afford it, I don't care if he buries it behind the barn. I have never asked him what he does with his allowance, why should I start now?" Her simple analysis was that the worst case was they could afford it if he wasted it, and it made him feel good. At times we have to ask, what is the worst that can happen? If everyone can survive the worst that can happen, why interfere with a person's right to make a decision? Now it is worth noting, she was not asking him to make choices about investing their lifesavings (though she did tell him what she was doing.) The greater the impact of the decision, the more control she took.

We want to protect society from danger, inconvenience, discomfort or embarrassment. Protecting society from danger makes sense. We don't hand loaded firearms to persons unable to understand the concept of a loaded gun, or unable to control their actions. We don't permit people to drive cars until they have reached a reasonable level of maturity and have proven that they possess a minimum of knowledge and skill. There needs to be a weighing of the risk of physical harm to others in deciding how much autonomy to give.

We are worried about inconveniencing others. Waiting for a person to count out change when boarding a bus or paying in a store can be frustrating, but it is part of empowering that person. If we place ourselves in the shoes of the person, what would we want? What can we do to streamline the process (pre-paid debit cards – stored value transit cards speed things up for everyone.) Other persons can be uncomfortable being around a person with differing abilities. Why should this be the basis for limiting the freedoms a member of our society? People sometimes say or do things that are embarrassing, violating social norms. Who is truly harmed by this? Isn't it better to recognize that this

is part of the human condition than to restrict the humanity of the person to protect ourselves from embarrassment?

When helping persons in need of support, what are we protecting ourselves from when we limit the person's participation in decision making or limit the activities they can do? We want avoid feeling responsible if something goes wrong. Our feeling should be weighed against the feelings of the person who is denied opportunity. Life is not perfect or without risk. We hurt people by trying to overprotect them. This is not to say we should be reckless or careless, but a calculated risk is a part of every person's life. We want to avoid needing to rescue the person. Rescuing can be inconvenient, but it also a part of being involved in the life of other persons. We need to ask, what can we do to reduce risk, and to make rescue easier. Caregivers / supporters want to avoid hurt feelings or needing to apologize. Apologies are a part of life. A sincere, I am so sorry, we will try to be more careful the next time goes a long way.

From a lawyer's standpoint there are two issues of concern we want to look at. I have left them until last, because they really should be the last concerns.

We need to protect ourselves and the person we are helping from civil liability. Civil liability would come from two places, an injury or damage to another person or property that was reasonably foreseeable, or from a breach of contract such as a debt.

Liability for injury or damage is known in the legal world as tort liability. The basics for a claim for tort damages is that something happened, that was within the control of a person, that was reasonably foreseeable and resulting in an injury or damage or injury to a person or property. There are two people who might have tort liability, the person committing the act or omission, and the person who is responsible for the supervision of that person (i.e. the guardian.) The person subject to guardianship could be held responsible if a reasonable person would know that the behavior created a risk for others. Care should be taken to supervise behavior to limit foreseeable risks of injury to to other persons or property. Liability for the guardian in their role as guardian, would be based on negligent supervision. A failure to take reasonable steps to supervise or limit the activities of another person, resulting in a foreseeable risk of injury or damage.

Protecting a person subject to guardianship from breach of contract is helped by the law placing the right to contract on behalf of the person in the hands of the guardian. The existence of the guardianship can be raised as a defense to an action to enforce a contract or collect a debt, incurred after the guardianship was in place. Making others aware of the existence of the guardianship can be helpful (I once sent copies of a guardianship order to every car dealer in town – the person had already taken a taxi to the Cadillac dealer once.) Prevention is easier than cure, it is important to get an agreement with the person that they will never sign anything until you have seen it. The guardian or agent under a power of attorney would not have personal liability on contracts as long as it was clear that they were acting in the capacity as agent for the person. The obligation for payment would be limited to the assets of the person.

I was court appointed to represent an 18-year-old man, in responding to a guardianship filing. He was a very pleasant young man and had a functional age of about 6 or 7. Shortly after his 18th birthday he went to the mall with friends. He became excited by some electronic games and the store signed him up for a credit card, incurring over \$1,000 in debt. The debt triggered his family to file for guardianship. With a court order, his family put a "freeze" on his credit, preventing further debt. (They probably could have put a freeze on his credit with his permission, without the guardianship order.)

Many supporters or guardians fear criminal responsibility for the acts of the person they are trying to help. Criminal liability is hard to attach for the acts of another person, you have to help that person in the furtherance of the commission of a crime to be responsible. If the person commits an act

of vandalism, the supporter or guardian would only have criminal responsibility if they knew the person was going to commit the crime and failed to stop it, or if they made it easier for the person to commit the act of vandalism. For example, if a person you are helping breaks a window you would not normally have criminal liability unless you knew they were going to do it and failed to try to stop them, or if you helped them, by handing them rocks to throw at the window. The duty to prevent a crime, does not require locking the person up and supervising their every move.

The Person can commit a crime. Most modern criminal codes look for the persons intent at the time the crime is committed. Some persons are found to be unable to form consent, and hence not held responsible. Some crimes are “status” offenses, such as the mere possession of a controlled substance. The modern rule on “insanity” is that the person must be unable to understand the nature of the act. That is a very high standard of diminished capacity to meet. Really the best protection for the person from criminal responsibility is to be helped by dedicated supporters who will guide the person away from criminal acts.

Supporters and guardians can be held responsible for criminal acts committed against the person in need of protection. Theft of money or property, assault, and criminal neglect by caregivers, family members, friends, and supporters are increasingly being reported and prosecuted. Anyone can and should report the abuse, exploitation or neglect of a person in need of protection, many persons involved in providing services to persons at risk, are required to report a reasonable suspicion of abuse, exploitation or neglect.

- ❖ David wants to drink diet cola.
 - Risks – caffeine – extra sodium – carbonation – unknown impact of exposure to artificial sweeteners His sleep is not disturbed by the caffeine and he seems calm and comfortable. He has no known risk factors for sodium intake. The carbonation makes him burp, but he seems to enjoy that. He seems indifferent to the possible health risks of artificial sweeteners and struggles to control his weight. He likes the flavor and gains pleasure from consuming.
 - Is it ethical to allow David to drink diet cola?
- ❖ Rebecca wants to smoke. She is 52 and has smoked since she was a teenager. Over the years there have been several attempts to get her to stop. When cigarettes are taken away, she becomes agitated, upset, and within a couple of days her family and caregivers relent and provide her with cigarettes. When asked about the health risks, she responds with “smoking makes me calmer, I feel better.”
 - What if she starts smoking in bed?
 - What if she starts falling asleep while smoking in bed?
 - Prohibit or agree to restrictions for safety?
- ❖ Falls prevention - if no one walks, no one falls
 - If we want to reduce the risks of falls by adults in health care facilities, we can prevent them from trying to walk. Placing wheel chairs, walking sticks and walkers out of reach, raising bedrails, requiring them to call for help to get out of bed. Force them to use wheelchairs. The result is that the patients will become increasing bedridden, less able to ambulate.
 - Is restricting movement the best way to reduce the risk of falls?

- ❖ Michael is legally blind. He has very limited vision in a narrow vertical window.
 - Michael wants to play golf. There is a risk that he could not see other players ahead on the course and hit the ball, risking hitting them. He could hit the ball off the course and injure person or property. He could play poorly and be upset by doing so.
 - Mitigation: He could play with a partner who would tell him when the course was clear ahead.
 - He gains joy from playing
 - He benefits from the exercise and socialization
 - Michael wants to go deer hunting solo. He hunted as a teenager, before his vision changed, and he truly misses the time alone in the woods. His hearing is quite good, being in the woods with a guide the noise from the other person distracts him.
 - Can this be done safely?
 - What extraordinary efforts would need to be taken?
 - Is there still a risk?

- ❖ Tracey wants to ride her bike to her art class on Wednesday afternoon. She has been riding for several months but recently was late returning home, rush hour traffic was heavy and she was bumped by a passing car and fell. Her family wants to stop her from riding her bike. She enjoys riding, and the exercise is good. Riding gives her a feeling of independence.

Should she be allowed to continue riding her bike to class?

Does she understand the risk?

Is she willing to accept the risk?

What would make it safer?

Agreeing to limit on times.

A back up plan for bad traffic or weather

Alternate routes with less traffic

- ❖ Ellie wants to manage her finances. She is bipolar. When depressed she withdraws and fails to pay her bills. When manic, she goes shopping and takes tables full of strangers to lunch, depleting her account in just a few days. She has sufficient income from Social Security Disability and a small private pension to live comfortably, if the money is carefully managed. Because of side effects, additional medication is not recommended by her psychiatrist.

- Should Ellie be allowed to manage her money?

- What tools can be used to protect and empower her?
 - Two signature accounts
 - Auto deposit and auto payment
 - Limits on credit or debit cards
 - Affordable cash allowance