The Missing Piece of the Puzzle

Utility and the Just Allocation of Health Care Resources

Senior Honors Thesis

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Part I: Chapter 1 – Grasping the Resource Allocation Crisis

The current American health care system is plagued by three main factors: out of control spending, allocation inequalities and profound scarcity. For example, the United States spend above 14% of its GDP on health care as opposed to other nations which spend between 5-6% (Daniels and Sabin, 19). Despite this large pool of monetary resources, our health care system faces significant scarcities. "At the end of 2007, there were over 105,000 individuals on the waiting list for an organ" (Yokam). Beyond organ scarcity, our health care system is fraught with allocation inequalities. As a society, we spend an enormous amount of our allocated health care budget on the most ill: 72 % of all medical costs are used to treat the sickest 10% of our population (Light, 65). In addition to sinking our resources into the most ill among us, America also fails to allocate health care resources equitably among ethnic groups. "In 2001, 35% of Hispanics had no health insurance coverage, compared with 20 percent of blacks and 15 percent of whites" (Levy and Sidel, 7).

As a society, we are utilizing resources, both human and monetary, at astounding rates. Yet, medical resources are limited and our allocation outcomes are less than just. All in all, we are facing a medical resource crisis in which rationing is reality. This is a global problem which manifests itself differently in many countries, however, I will focus on the United States. I limit the scope, not to ignore the international character of the dilemma, but rather to focus on a specific test case whose exploration will hopefully yield wider applications in the international health care community.

The scarcity is particularly poignant in today's society for three reasons. Aging populations, increases in expectations about what medicine can do and an ever expanding demand for technology, all contribute to the urgency of the current health care crisis (Daniels and Sabin, 1). People are living longer which means they utilize more health care resources than the previous generation due to their expanded lifespan. In addition to using more resources over a longer lifetime, consumption of resources by aging patients peaks in the last months of their lives. "The last six months of your life might well look like this: You'll see doctors, mostly specialists, 46 times; spend more than six days in an intensive care unit and

stand a 27% chance of dying in a hospital ICU. The tab for your doctor and hospital care will run just over $23,000" (Appleby). Additionally, as medicine continues to provide "miraculous" solutions to previously incurable diseases and conditions, people demand these new, expensive treatments in greater numbers, more often. Finally, rapid technological development is always expanding what is possible, creating exponentially larger resource demands for both new research and the application of technology. All and all, our society is demanding more from the same, already strained health care resource pool.

Chapter 2 – The Root of the Problem : Why Health is Special

Some suggest we simply allocate more resources to health care, and by doing so, minimize, if not eliminate any difficult allocation decisions. However, we must also acknowledge that health is not the only need for which society, specifically the government, must provide. Since society's welfare depends on more than health alone, healthcare must be allocated a slice of the resource pie, not allowed to gobble down the whole pie, or more than its fair share. Although unrestrained spending in health care may lead to greater health, it would detract in significant ways from the other dimensions of well-being such as security, industry and economy, that citizens expect to be fulfilled. The decision regarding how much to spend on health care versus other societal needs, is a macro-allocation decision and one that I will not pursue further here. I will exclusively consider the issues of micro-allocation, namely how given resources are distributed within the health care resource pool.

Even though health care expenditures must share resources with other dimensions of well-being, there is a general consensus that health is a fundamental value in society. To be clear, health is the goal and health care is the mechanism by which the goal of health is pursued. Many believe we need health in a primary way. Health is something that everyone wants and needs, at least to a minimum standard, no matter what else they may desire. People desire a minimally decent level of health so that they can pursue and hopefully achieve their goals and life plans. By keeping people close to normal functioning, health care preserves the capabilities individuals need to participate in the political, social and economic life of

their society" (Daniels, 1985, 4). This notion of normal functioning is based on the biomedical model which states: health is the absence of disease and diseases are deviations from the normal functional organization of a typical member of a species" (Daniels, 1990, 280). Health is a prerequisite to normal functioning in a way that other commodities, like cars, are not. For example, many people want cars and may even think that they *need* cars. But a car is not a prerequisite to normal functioning; an individual can lead a normal, functional life without a car. But this is not the case with health. If health occupies this special priority in our society, then our institutions have an obligation to provide health care in the same way they provide for other essential dimensions of society, such as right to free speech.

Although health is so fundamental, it is also different from other fundamental rights or goods that we wish to protect. Consider the fundamental needs of nutrition and shelter. It is theoretically possible to ensure adequate shelter and nutrition for all people in our society. In principle, the resources and the capabilities exist to meet these definable, finite needs. We can place a roof over everyone's head and a meal in their stomachs, but it is impossible to ensure normal functioning for all members of society. It is simply not possible to make everyone in our society "healthy" in the sense that they will attain normal functioning. Some people, such as quadriplegic individuals, require vast human and monetary resources and perpetual treatments, but never actually reach normal functioning due to severe, permanent handicap. Since health entails this unique abyss of need, health care resources will always be scarce and rationing will always be necessary.

Another characteristic which makes health unique and problematic is the difficulty in defining the good of health care. In feeding the hungry or housing the homeless, the goals and the mechanisms are quite clear; provide food/housing or the means to food/housing. But health care goals are not quite so straightforward. Some of the widely recognized goals of health care policy include:

1) the best possible care for all
2) equal care guaranteed for all
3) freedom of choice on the part of the health care provider/consumer
4) containment of health care costs (Engelhardt, 65).

But one of the major impediments to realizing or even pursuing any of the above goals is defining what the good in health care truly is. People value health and health care on astonishingly diverse levels. Some individuals choose to gamble and hardly invest in their health at all, whether it be financially or through a lack of nutrition or physical exercise. Others set aside large portions of their income or time in the form of health insurance or exercise and balanced diets. Defining the good in health care is also complicated since people in society tend to identify with actual patients suffering from real diseases more than potential problems of unidentified people. For example, the cost of ten to fifteen heart transplants is enough to finance a prenatal program that could protect and save the lives of three times as many unborn children (Daniels, 1985, 222). When such a prenatal program was cut, "a 50% increase in infant mortality was observed"(Daniels, 1985, 222). The public often favors the transplant program because the individuals benefiting are identifiable people with perceivable needs as opposed to the unrealized lives of babies. When trying to balance between rehabilitative needs and preventative programs, public opinion greatly favors the rehabilitative programs because they help tangible patients with suffering with which others can sympathize. On the other hand, preventative programs help abstract patients whose suffering has not yet occurred. Considering this outlook, it is difficult to ascertain a consensus regarding the good of health care.

The issue of justice in health care is a complicated question that calls on resources from the philosophical, political, economic and social spheres. Due to these vast and often contradicting points of view, it is no wonder that health care distribution has been and still is such a difficult issue. Although a viable health care program will likely maintain key roles for each of these areas, as this is a philosophy thesis, I will confine my exploration to the philosophical realm. From this point of view, I plan to consider the major theories of utilitarianism, Rawlsianism, modified Rawlsianism, essentialism and finally moderate essentialism. Each theory has applications in dealing with health care resource allocation. I will explain their strengths and weaknesses through case discussions and then propose my own theory which strives to avoid the pitfalls of my predecessors while incorporating their strengths.

Part II: Chapter 3 – From the Hospital to the Philosopher's Den

Now that the origin and reality of the scarcity is understood, we can move away from the scientific facts and figures toward philosophy's potential solutions to this crisis. The original question remains: how is it possible to allocate scarce medical resources in the most socially just manner? When one considers this question, or any question of social justice, what is at stake is the reconciliation of liberty and equality. These magnanimous principles provide great ideals and often greater conflicts. Any discussion of social justice hinges of the relative weights given to these principles. We strive to respect the autonomy of citizens, whether they be physicians or patients. We simultaneously strive to provide health care as equally as possible. But liberty and equality are oftentimes at odds with each other, and this is especially true in health care resource allocation. For example, one of the questions that arises again and again is how much liberty can we take away in the service of equality? Another key concept considered in this debate is utility. Utility represents how much benefit is derived from a given resource. The reality of the scarcity facing health care today mandates that utility is considered in allocation decision-making. As each theory is explicated, the diversity of priority assigned to these principles will become clear.

PART III: Chapter 4- Utilitarianism

Consequentialism is one of the classical ethical theories and in its most popular form this theory is known as utilitarianism. There are two varieties of utilitarianism: act and rule utilitarianism. Although there have been many derivatives and subtle distinctions within the theories, the main definitions are as follows:

> Act utilitarianism: The view that an act is morally right if, and only if, of the acts available to the agent, it would produce the greatest total net utility.
>
> Rule utilitarianism: The view that an act is morally right if, and only if, it is required by a rule the establishment of which in social practice would promote the greatest total net utility (Darwall, 241).

Upon first glance, these theories appear to provide a straightforward and just approach to ethics and specifically resources allocation. With a limited amount of resources, distribute them so that the most people reap the greatest benefit. In the area of health care, bearing in mind the dire scarcity, utilitarianism appears to rise to the challenge. Distribute health care resources, such as organs, funds or dialysis machines, so that the greatest number of people receive the greatest benefit possible.

However, strict act utilitarianism, that is utilitarianism which considers this principle the single, absolute principle guiding our actions, will be forced to suggest some horrendous actions. For example, a classic bioethical objection to act utilitarianism is the following case:

> L., a 48 year old man, who is otherwise completely healthy, has been injured in a car accident and is currently undergoing surgery. He is in critical condition but the surgeons are hopeful.
>
> In the same hospital, there is a patient on floor three suffering from kidney failure, who desperately needs a kidney. On floor five, a cardiac patient will soon die without a new heart. On floor two, a trauma victim needs new corneas in order to restore her vision.
>
> Is it not the case that the utilitarian principle of the greatest good for the greatest number requires that L. be "allowed to die" or perhaps even killed outright so that the other patients can be aided, on balance producing the greatest good for the greatest number?

The honest act utilitarian must suggest that this deplorable action, of either failing to save or killing L. is in fact the ethically correct action. Although this case is extreme and some would argue only applicable to act utilitarianism, the real case of the Oregon health plan provides a similarly chilling window into rule utilitarianism.

In the early 1990s in Oregon, government leaders initiated a public process to fairly establish limits on Medicaid spending. The leaders were forward with both their intention to ration and to do so fairly. "Crucial to the process was the effort to incorporate public values through town meetings, phone surveys and public hearings" (Daniels and Sabin, 10). The legislators then considered how the public valued different services and established priorities along these lines, as limited by the given health care budget. After deliberating and gathering public input, the authorities in Oregon "prepared a list of 709 paired medical conditions and treatments ranked according to clinical effectiveness" (Strosberg, 3).

While there were many services included, given the limited budget, less prioritized service were unlikely to ever get funded. These services included: "conditions that might improve spontaneously (such as viral sore throat), conditions for which a home treatment is effective (for example, sprains) and conditions for which treatment is either not generally effective or futile (such as surgery for low back pain and aggressive medical treatment for end stage cancer and AIDS, and for extremely premature babies)" (Strosberg, p. 4). However, the general prognosis for the approach was optimistic. The 1991 legislature passed a budget for Medicaid that funded programs through line 587 [of 709], which includes virtually all (98 percent) of the services in the "essential to basic care" section, and a few (7 percent) of the services in the "very important to individuals but of minimal gain and/or high cost" section. However, the results were disastrous. "Capping teeth had a higher priority than surgery for appendicitis" (Daniels and Sabin, 3). In other words, Medicaid in Oregon was prepared to pay for every single Medicaid patient to have his or her teeth capped, but was not willing to pay for a single appendectomy These results were the outcome of utilitarian thinking. "An appendectomy then cost about $4000; many times the cost a capping teeth. Simply aggregating the medical benefit of many capped teeth yielded a net benefit greater than that produced by one appendectomy" (Daniels and Sabin, 32). Despite the fact that appendicitis is life-threatening if untreated, Medicaid refused to pay for this service, instead using the funds to cap teeth.

Even though Oregon attempted to incorporate public opinion and strive for reasonableness, the results of the rationing plan were anything but reasonable. Allowing a patient suffering from appendicitis to remain in a painful, life-threatening yet treatable situation so that hundreds of other Oregonians can have their teeth capped is unacceptable to most. In general terms, the problem with the Oregon plan was that a truly "decent minimum" was not actually provided for all. Rather, by virtue of the expense of their treatment, some people received minimums that were more or less decent. Allen Buchanan captured this worry: "The chief difficulty with utilitarian arguments is that they are not capable of providing a secure foundation for a right to a decent minimum for everyone" (Buchanan, 60). For example, in the Oregon rationing case, individuals with cavities were provided a decent minimum of health care, but individuals with appendicitis were denied this decent minimum of care, on the basis that it cost too much and

provided too little net benefit. In effect, not every individual in a utilitarian society is taken to have independent value, but rather is considered only in so far as he or she contributes to the aggregated cost/benefit reasoning.

Considering the avid criticism prompted by these cases, utilitarians have responded. Many utilitarians argue that they do in fact take each person seriously. Specifically in the area of health care distribution, Joseph Fletcher notes, "In the ethics of health care distribution we must be utilitarians, at least in the sense of seeking the greatest good (health for the greatest number possible)" (Fletcher, 51). Fletcher argues that utilitarianism in health care resource allocation is not somehow disrespectful of the individual, but rather, "being impersonal in allocation decisions is in no way antipersonal, it is multipersonal. To sacrifice one for many is not an abstraction, but the valuing of 'many ones'; it is the sum of real, particular and personal individuals" (Fletcher, 51). Fletcher advocates utilitarianism for the very reason that the theory does in fact respect each individual to his or her fullest. The best way, according to Fletcher, to demonstrate this absolute respect is by applying a utilitarian calculus. "To be ethical requires knowledge and careful calculation, because loving concern is the same as justice – it has to be distributed" (Fletcher, 51). Since we face difficult rationing decisions as a function of necessarily limited resources, we must be calculating and utilitarian to ensure that we honor each individual.

Fletcher is not alone is endorsing the utilitarian viewpoint, another thinker, R.M. Hare also advocates utilitarianism as a viable and successful standpoint from which to approach the health care crisis. Generally, Hare notes that our considered judgment about an ethically difficult issue leads us to prescriptions about what one should do. "If we realize that our prescriptions would also have to be followed in cases upon which we were on the receiving end of the actions, we shall be allowed to give equal weight to the interests of all parties in the situation" (Hare, 10-11). This principally equal view leads us to a form of utilitarianism. "The essence of utilitarianism is that we should do the best we can to serve the interests of all parties affected by our actions, treating the equal interests of them as equally weighted" (Hare, 11). However, both Hare and Fletcher fail to free themselves from substantial objections. If we were truly act utilitarians, like Fletcher suggests we "must be" in health care decision-

making, we would still sacrifice L., our car accident victim, in favor of the other patients in the hospital. We would be "multipersonal" in our ethics and value each individual, noting the greater benefit obtained from the sacrificing L., we would do so. But this still seems ethically wrong and repugnant to most people.

If it is true that most are completely repulsed at the notion of sacrificing L., why is this so? Is it that our utilitarian calculating nature is underdeveloped? Perhaps, but nonetheless we continue to reject this behavior. Instead, we hold killing and murder, regardless of the reason, in utter contempt. This virtually universal rejection suggests that utilitarianism is in fact missing something about ethics and justice when it condemns L. to his unfortunate fate. This missing link in utilitarianism is the concept that each individual has a value that cannot be outweighed by a utilitarian calculation. When utilitarianism suggests that we ought to be calculating utilitarians in deciding how to act and specifically how to allocate medical resources, they have missed something by simply aggregating benefits and suffering in order to make decisions.

We believe there are constraints against killing L. and the Oregon prescriptions. There are constraints against harm. We do not simply sum benefits and suffering when choosing a course of action. We cannot sacrifice L. because his life belongs to him, it is not a chit in the vast utilitarian calculus but rather a indivisible part of L. himself. In failing to take into account this fact of humanity, the utilitarian misrepresents what it means to be an individual. This misrepresentation leads to the unacceptable and potentially downright repulsive results discussed above and ultimately renders utilitarianism insufficient as a theory for evaluating the justice of health care resource allocation.

Chapter 5 – Rawlsian Theory

In his influential work, A Theory of Justice, John Rawls endeavors to uncover principles of justice that will promote a society founded on "justice as fairness". According to Rawls, if a society is organized and constructed in a just way, the outcomes of the society will also be just. Although Rawls

does not directly incorporate health care into his theory, his approach has spawned many applications in this area. But, before considering how Rawls's theory can be applied to the health care resource allocation question, it is necessary to understand Rawls's theory on his own terms.

In striving to build a just society, Rawls appeals to two lexically ordered principles[1]. These principles are as follows:

> First Principle
> Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.
>
> Second Principle
> Social and economic inequalities are to be arranged so that they are both:
> (a) To the greatest benefit of the least advantaged, consistent with the just savings principle
> (b) Attached to offices and positions open to all under conditions of fair equality of opportunity (Rawls, 266).

According to Rawls, these two principles are those that would be reached by individuals placed in a hypothetical situation Rawls refers to as the "original position". The original position is Rawls's unique interpretation of the state of nature. However, Rawls does not arrange his original position in order to conceive of an actual historical state or a primitive condition of civilization. Rather, Rawls considers individuals in his original position to represent typical citizens in society who are normal, rational and mutually disinterested. Additionally, Rawls limits the knowledge of the individuals in the original position. Rawls places them behind a "veil of ignorance". He creates this device in order to "nullify the effects of specific contingencies which put men at odds and tempt them to exploit social and natural circumstances to their own advantage" (Rawls, 118). This veil separates the individuals in the original position from specific facts about their life. Specifically, there are five classes of information that are off limits to the inhabitants of the original position:

1) No one know his place in society, his class position or social status.
2) Nor does he know his fortune in the distribution of natural assets and abilities, his intelligence, his strength and such.

[1] Although he defines and redefines these principles throughout his career, I will consider the principles as stated in the later half of A Theory of Justice (1999).

3) Nor, again, does anyone know his conception of the good, the particulars of his rational plan of life, or even the special features of his psychology such as his aversion to risk or liability to pessimism or optimism.
4) Nor does anyone know their society's economic or political situation, or the level of civilization and culture it has been able to achieve.
5) Nor does anyone know to which generation they belong (Rawls, 118).

However, despite all the limitations regarding their personal situation, the inhabitants of the original position do know some things. "It is taken for granted that they know the general facts about human society. They understand the political affairs and principles of economic theory; they know the basis of social organization and the laws of human psychology" (Rawls, 119). In fact, it is assumed that there are no limits to the general knowledge that these individuals possess. But knowledge of particulars, especially those regarding their own characteristics, is completely hidden from them, to avoid any bias that would arise if they knew their own situation. For example, a wealthy man in the original position who knew that he was wealthy, being also rational, mutually disinterested and normal, would likely select principles that would maximally benefit the wealthy, as opposed to the most equitable and just principles.

While Rawls limits the individuals in the original position by placing them behind a veil of ignorance, he also endows them specific capabilities. Rawls asserts that all people in the original position have rationality, normal functioning and are mutually disinterested. By granting the individuals in the original position rationality, Rawls invokes a widely-accepted notion of what it means to be rational. "In the usual way, a rational person is thought to have a coherent set of preferences between the options open to him. He ranks those options according to how well they further his purposes; he follows the plan which will satisfy more of his desires rather than less, and which has the greater chance of being successfully executed" (Rawls, 124). In other words, a rational individual has preferences that he wishes to maximize by making choices likely to result in his desired ends. However, Rawls makes a slight, yet significant modification to this traditional notion. Rationality can often be combined with envy of one individual by another, but Rawls insists that his "rational individual does not suffer from envy." (Rawls, 124). Rawls considers envy to be a "destructive feeling" which would not be strong if his principles are

adopted in society (Rawls, 125). Since Rawls doesn't think envy would play a large role in his well-ordered society, he dismiss it from the original position.

In addition to being rational, Rawls designs the individuals in the original position to be mutually disinterested. Simply, they do not feel "strong and lasting benevolent impulses" (Rawls, 13). "Since each desires to protect his interests, his capacity to advance his conception of the good, no one has a reason to acquiesce in an enduring loss for himself in order to being about a greater net balance of satisfaction" (Rawls, 13). There is no malificence between individuals in the original position, but there are no acts of charity or either.

Lastly, the individuals in the original position fall within the normal range of health and participation in society throughout their entire life. "The first problem of justice concerns the relations among those who in the everyday course of things are full and active participants in society and directly or indirectly associated together over the whole span of their life." (Rawls, 84). In order to accurately represent this primary problem in the original position, Rawls assumes "that everyone has physical needs and psychological capacities within the normal range" (Rawls, 84). While this assumption has very definite implications for how Rawls's theory responds to health care, before those are considered, it is useful to understand why Rawls limits his individuals to "normal". Rawls claims that this limitation is made "so that questions of health care and mental capacity do not arise. Besides prematurely introducing matters that may take us beyond the theory of justice, the consideration of these hard cases may distract our moral perception by leading us to think of persons distant from us whose fate arises pity and anxiety" (Rawls, 83-84). Rawls limits the inhabitants of the original position in an attempt to keep the focus on the main question of justice and to reinforce the mutually disinterested nature of the participants.

Once Rawls has crafted the individuals of his original position and situated them behind a veil of ignorance, he posits that there are some things all people in this position would desire. He calls these entities 'primary goods'. "With more of these goods men can generally be assured of greater success in carrying out their intentions and in advancing their ends, whatever those ends may be" (Rawls, p. 78). Although Rawls does not claim to give an exhaustive list of primary goods, he does name a few goods

that would be included. These are: rights, liberties, opportunities, income, wealth and the social basis of a sense of self-worth (Rawls, p. 78).

After Rawls has specified his original position and defined the things people in the original position desire, his theory again returns to the two principles of justice. Rawls suggests that in the original position, "the veil of ignorance makes possible a unanimous choice of a particular conception of justice" (Rawls, 121). This conception is, of course, distilled into the two principles of justice. According to Rawls, participants in the original position, behind the veil of ignorance, and desiring the maximum amount of primary goods, would naturally choose his two principles of justice as the foundation of their ideal society. "Thus it seems that the parties would prefer to secure their liberties straightaway rather than have them depend upon what may be uncertain and speculative actuarial calculations" (Rawls, 139). According to Rawls, in attempt to simultaneously maximize primary goods and protect liberties, the people of the original position would arrive at the two lexically-ordered principles of justice.

Once Rawls constructs and explains the reasoning behind his principles of justice, he considers how these principles would be applied in the ordering of a society. The primary subject of justice is the basic structure of society. For if the basic structure is unjust, the subsequent organizations and institutions of a society will likewise perpetuate the injustices, expanding them outward like ripples in a pond. Rawls defines basic structure as "a public system of rules defining a scheme of activities that leads men to act together so as to produce a greater sum of benefits and assigns to each certain recognized claims to a share of the proceeds"(Rawls, 74). In order to illuminate how this distribution might occur, Rawls calls upon pure procedural justice. Pure procedural justice refers to "a correct or fair procedure such that the outcome is likewise correct or fair, whatever it is" (Rawls, 75). What factors and institutions are charged with carrying out this pure procedural justice? Rawls suggests that, "only against the background of a just basic structure, including a just political constitution and a just arrangement of economic and social institutions, can one say that the requisite just procedure exists" (Rawls, 76). In order to ensure justice, Rawls insists upon a just constitution and institutions.

But this seems vague; how do the individuals in their original position aim at securing the basis for this justice? From the basic structure determined in the original position, Rawls gradually lifts the veil of ignorance from the people so that, step by step, they may build their society in the most just manner. In the Rawlsian theory, there are four stages: the original position, which has been outlined above, the constitutional convention, the legislative stage and finally the judicial stage. Each stage offers the people more information about the unique and specific society and culture to which they belong.

Now that Rawls's theory is understood, its application to health care can be considered. Considering his comprehensive theory of justice, it is not surprising that Rawls's approach has been extended to health care and the question of how to arrange our health care system in a maximally just manner. However noble this extension may be, there is a major problem in applying Rawls to questions of health care justice. Returning to the characteristics of the individuals in the original position, it must be noted that these individuals are not only mutually disinterested and rational, but also normal functioning individuals. While these characteristics served Rawls very well in his explication of the original position and its application to the basic structure of society, these limits, namely the "normally functioning" constraint, marginalizes Rawls's ability to respond to the problem of justice in health care.

By confining his individuals to normal functioning, the severity and sheer number of health care issues facing our society today simply do not arise for Rawls. It is not surprising that he does not account for health as a primary good, because everyone is already healthy in his ideal society. Rawls could perhaps account for the variability in health care needs of his citizens given that they would undoubtedly vary within the normal range. He could provide for regular visits to a doctor, but not much beyond that. This exposes a serious limitation of Rawls's theory which prevents him from forming an adequate response to the medical resource allocation question.

In order to consider health and the justice in health care institutions, the inhabitants of Rawls's theory would have to be redefined. Therefore, the Rawlsian theory cannot, on its own terms, provide for the wide range of health care needs that are a reality in our society where normal functioning is not the standard but the goal for a significant amount of the population. And as such a goal, health care resource

allocation remains a primary, crucial issue for the subjects of justice and opportunity, but a goal that Rawls alone cannot bring us closer to achieving.

As we will see in the next section, other thinkers have in fact modified Rawls's theory in attempts to understand its implications for health care. But as it stands, Rawls's theory is an inadequate position from which to assess and overcome the current health care crisis.

Chapter 6 – Modified Rawlsian Theory

In attempt to rescue Rawls from critics who lament the inadequacy of his theory of social justice, Norman Daniels, a student of Rawls, takes on the challenge of modifying Rawlsian theory to account for the reality of health inequalities. As was discovered in the previous section, Rawls doesn't consider health care or health in his theory because the Rawlsian citizens are "normal". Daniels notes, "there is no distributive theory for health care because no one is sick" (Daniels, 1981, 164). But the reality is that not every member of society is "normal" throughout the entire course of their lives. Some individuals, like a quadriplegic, will never reach the "normal" functioning threshold, while most will slip in and out of health during their lifetime. Accepting this as a fact of our existence, Daniels considers the implications for Rawls's theory. "If it is important to use resources to counter the advantages in opportunity some get in the natural lottery, then it is equally important to use resources to counter the natural disadvantages induced by disease [both as a result of natural lottery as well as the social one]"(Daniels, 1981, 166). If health is unequal, then Rawlsian theory is presented with a new factor it must account for in its pursuit of justice.

Before considering how Daniels's argument tackles health in Rawls's theory, it is worth noting that Daniels is not merely accepting the Rawlsian theory as the correct theory of justice, but instead is positing the following contingent argument. *If* Rawls is in fact correct about social justice, *then* Rawlsian theory can be supplemented with an account of health care distribution. Specifically, Daniels focuses on the fair equality of opportunity principle in Rawls's theory. "If an acceptable theory of justice includes a

principle providing for fair equality of opportunity, then health care institutions should be among those governed by it" (Daniels, 1981, 160-161). Daniels also suggests his theory may be applicable outside of pure Rawlsian theory. "But my account does not presuppose the acceptability of Rawls's theory. If rule or ideal code-utilitarianism, or some other theory, establishes a fair equality of opportunity principle, my account will probably be compatible with it" (Daniels, 1981, 161). Nevertheless, Daniels chooses to focus on Rawls's theory, as it exemplifies a strong adherence to the fair equality of opportunity principle.

As discussed in the previous chapter, Rawls is concerned with the opportunity individuals have to pursue careers or life plans. Therefore, equality of opportunity, according to Daniels, is valuable due to its strategic importance. "A person's well-being will be measured, for the most part, by the primary goods that accompany placement in such jobs and offices" (Daniels, 1981, 166). In other words, the opportunity that a person has to pursue jobs is instrumentally crucial to well-being. Since this is the case, the equality of this opportunity ought to be protected in order to allow a level playing field for all. As we saw in Rawlsian theory, the playing field is leveled by ensuring primary goods for all.

However, once health inequalities are introduced, the field shifts, disadvantaging those who are not functioning within the normal range. In order to once again level the playing field, a society must also account for the disparities in health which directly affect an individual's opportunity to compete for jobs and fulfill life plans. "Impairment of normal functioning through disease and disability restricts an individual's opportunity relative to that portion of the normal range his skills/talents would have made available to him if he were healthy" (Daniels, 1990, 281). This normal opportunity range is what Rawls, and subsequently Daniels, strive to protect. Rawls believes that his theory faithfully accomplishes this through primary goods. But for Daniels, primary goods do not tell the whole story; it is not enough to merely ensure an individual's bundle of primary goods, because health disparities change how an individuals can use their primary goods. "Life plans for which we are otherwise suited are rendered unreasonable by impairments of normal functioning" (Daniels, 1990, 280). With the introduction of this new disparity, Daniels considers what the Rawlsian society can do to protect equality of opportunity. A move made by some is to simply add health to the Rawlsian list of primary goods. Yet, Daniels points

out that the quick and dirty solution of merely adding health as a primary good is deceptively easy and theoretically problematic. Issues of how to weight primary goods arise[2] and if we elect to treat health care services as specially important then we would be unfaithful to the Rawlsian notion of 'general primary goods', and simultaneously generate a long list of goods designed to meet each need (Daniels, 1981, 164). Simply adding health to the list of primary goods does violence to Rawls's initial conception of primary goods. Daniels offers a different, more faithful way, to incorporate health into Rawls's theory of justice.

Daniels suggests that health care be considered within the Rawlsian background institutions. Rawls charges these so-called background institutions with providing for fair equality of opportunity. These institutions are the very important basic, but general framework for further explication of societal structure as the veil of ignorance is gradually lifted. "In so far as meeting health care needs has an important effect on the distribution of health, and more to the point, on the distribution of opportunity, the health care institutions are plausibly included on the list of basic institutions a fair equality of opportunity principle should regulate" (Daniels, 1981, 165). According to Rawls, at the level of background institutions the main concern is constitutive rules, not "strategies and maxims for how best to carry out those rules" (Rawls, 49). Daniels would suggest that at the background institutional level, the main concern is weaving health care into the fair equality of opportunity fabric to used to create the society, not to answer questions of, say, whether a competitive market or universal health care system is best. Both Rawls and Daniels would suggest that these types of considerations come later in the process, perhaps at the legislative stage when more about the specific society is known. However, health care, because of its intimate relationship to opportunity, is necessarily included among the background institutions responsible for constructing a foundation that protects fair equality of opportunity.

Daniels suggests that the non-idealized Rawlsians would, adhering to Rawlsian principles of justice, arrive at four layers of background institutions pertaining to health care. The first of these layers

[2] Although this may be a legitimate argument against incorporating health as a primary good, it is important to note that Rawls himself does not provide any weighting system for the primary goods, since he sees them as sufficiently general and equal.

acts to minimize the likelihood of departure from normalcy. Daniels suggests that these institutions would primarily include:

> public health, environmental cleanliness, preventative personal medical services, occupational health and safety, food and drug protection, nutritional education and educational and incentive measures to promote individual responsibility for healthy lifestyles (Daniels, 1981, 168).

At this primary layer, health care background institutions mainly rely on preventative medicine and education. The second layer Daniels proposes attempts to correct for departures from normal functioning. These services include institutions that account for personal medical and rehabilitative services (Daniels, 1981, 168). This layer would likely encompass cancer treatments and stroke rehabilitation as well as more minor issues such as casts for broken bones. Next, Daniels suggests that a third layer of institutions accepts responsibility for trying to keep individuals as close to normal functioning as possible. This layer of institutions strives to attain the idealization of the original Rawlsian theory, whenever feasible. These institutions include: "institutions more involved with extended medical and social support services for the moderately chronically ill and disabled and the frail elderly" (Daniels, 1981, 168). For example, this layer would be responsible for providing for the care of handicapped persons and patients with diseases such as Multiple Sclerosis. Lastly, Daniels suggests the Rawlsian representatives would arrive at a fourth level of institutions "for those who in no way can be brought closer to the idealization" (Daniels, 1981, 168). This last level accounts for people who are terminally ill or those individuals who are severely mentally and/or physically handicapped, such as those individuals in a persistent vegetative state. However, Daniels is quick to point out that complications arise within this fourth level. "Indeed, by the time we get to the fourth layer, moral virtues other than justice become prominent" (Daniels, 1981, 168). However, regardless of complicating factors, Daniels stands by his theory. Health care considerations central to the fair equality of opportunity at the basic institution level take the shape of these four layers.

Happily, Daniels also goes beyond the theoretical in attempt to avail his readers of some truly practical implications and applications of his theory. Daniels claims that his conception of normal opportunity range is able to give an action-guiding framework for resource allocation: "we get a crude

criterion – impact on normal opportunity range – for distinguishing the importance of different health care needs" (Daniels, 1981, 177). When making resource allocation decisions, Daniels urges society to prioritize those needs with the greatest impact on normal opportunity range. Furthermore, Daniels argues that this approach from the standpoint of opportunity requires we attend to both acute therapeutic services as well as preventative and public health measures.

> The point is that people are differentially at risk of contracting such diseases because of work and living conditions. Efficacy aside, preventative measures have a distinct distributive implication from acute measures. The opportunity approach requires we attend to both (Daniels, 1981, 177).

In other words, justice does not only require that we allocate resources to promote fair equality of opportunity among services responding to debilitating events such as heart attacks, but rather we must also protect opportunity through educational/preventative programs such as smoking cessation and nutritional programs.

In summary, Daniels suggests that the most faithful extension of Rawlsian theory includes health care among the background institutions where it will take the shape of four layers, each meeting a distinct demand of health care. Practically, Daniels advocates the degree of importance to fair equality of opportunity as the benchmark with which we can prioritize health care services, but adds the crucial constraint that justice requires both preventative as well as acute therapeutic services be considered.

As Daniels delineates the implications for health care among Rawlsian background institutions, he also exposes one of the major limitations of his theory. That is, how are we deal with the fourth layer of health institutions, designed for those who are irretrievably outside of the normal functioning range? Daniels notes, "We are not required to pour all our resources into the worst cases, for that would undermine our ability to protect the opportunity of many others. But I am not sure what the approach requires here, if it delivers an answer at all" (Daniels, 1981, 171). However, Daniels points out that he is not alone in his confusion at this level; it is unlikely that distributive theories are founded on such difficult cases, but more likely they are centered around cases in which "we have a better understanding of what kind of health care is owed" (Daniels, 1981, 171). Regardless of this fourth layer problem, Daniels in

aware that his theory also runs into problems on a more general but vitally important front. "The approach provides little help with another sort of hard case, the resource allocation decisions in which we must choose between services which remove serious impairments of opportunity for a few people and those which remove significant but less serious impairments from many" (Daniels, 1981, 171). According to Daniels, the modified Rawlsian theory is not able to account for these concerns at the practical level. Daniels does not dismiss these "tough cases" but rather suspends judgment until the basic theory is applied.

Another, more unique, problem for Daniels's theory considers the expansive and expensive nature of health care needs. Combined with technology, these widespread, costly needs create a "bottomless pit" that would prevent society from responding to other types of needs. Charles Fried argues that legitimizing individual claims to fulfillment of health care needs allows "hijacking" of resources by health care and individuals. Ultimately, Fried argues, this hijacking would force society to omit other social goals (Fried, p. 126ff). The worry is that we would end up worshipping the opportunity to pursue goals, but give up the actual pursuit. However this concern is not explicitly applicable here since the scope of this paper deals only with the funds allocated to health, specifically avoiding questions of how much health care should be able to take form the total pie in favor of considering how we should split the given slice. Yet, this objection yields some interesting insights that are worth considering. Specifically, Fried points to the aging population's heavy consumption of health care resources. As was discussed in Part I, the elderly consume massive amounts of resources in the last months of their lives. However, Daniels argues that Fried misunderstands the normal opportunity range and its relative age-dependent status. According to the Daniels's theory, normal aging does not involve "departure from normal species functioning"(Daniels, 1981, 172). However, it can be noted that although age-related claims on health care are not, under Daniels's account, the prerogative of basic health care needs, that does not necessarily diminish their importance in a given society (namely ours). As technology continues to extend what is possible, the normal opportunity range is a changing and ever-expanding list of expected abilities, for both the elderly and the general population. Especially the elderly are not content to accept their mental

and physical degradation as 'normal'. In fact, most of the elderly resent their health status and seek relief and improvement from hundreds of specialists and surgeries every year. Essentially, this process is continuously redefining what basic health care includes, incorporating greater and greater amounts of resources. This flexible account of normal opportunity range means that the bottomless pit argument is still a worry. For how can we possibly expect or even strive for the normal opportunity range if it is a consistently moving and expanding target? A distributive theory accounting for such considerations is becoming increasingly desirable.

Although the bottomless pit and fourth layer issues pose problems to Daniels theory, the unpalatable implications of his theory are made clear by considering the general resources distribution options provided by Churchill in his allocation case (See Appendix A). From among the vast list of possible programs, the modified Rawlsian would choose programs which benefitted those outside of the normal functioning range and those which corrected for both natural and social disadvantaged, including programs for disadvantaged minorities, insurance for the uninsured, handicapped health care. Unfortunately, Daniels's theory fails to tell us how to weight these programs. Are the layers arrived at by the background institutional analysis lexically ordered? If so, the fourth layer would never even be a factor since our health care resources would be depleted far before even fulfilling the first three layers. Regardless of this potential extension, it is likely that if we built our health care system in a Rawlsian manner that we would leave out care for those irretrievably beyond the normal range because we would be emphasizing restoring and protecting the normal opportunity range. Assuming the absolute priority of protecting normal functioning, it would be an illogical and irresponsible use of resources to give health care to those who will never attain this normal range. We would not provide care for encephalic infants or care for individuals in a persistent vegetative state[3]. If given the 17 billion in the Churchill allocation scenario, we would use the funds for the worthy causes of the handicapped, and those programs designed to aid minorities, but abandon those permanently beyond the possibility of normal functioning. But, a

[3] Encephalic infants are infected with a rare virus which attacks their brain and spinal cord. The virus is life-threatening and some mildly effective treatments are available but are very expensive.

terminally ill person's life still has value, both to society and himself, so why should he be excluded from his share of health care benefits? Although Daniels, has provided a useful modification to the Rawlsian theory, it fails to account for our general intuitions that even individuals who will never become "normal functioning" deserve health care.

Chapter 7 – Essentialism

Amartya Sen proposes yet another approach to social justice called essentialism which opposes both the Rawlsian primary good approach and the utilitarianism focus on outcomes[4]. According to Sen, both theories lose sight of an important component of social justice. Sen disagrees with the Rawlsian focus on the means to well-being (namely the primary goods) over the extent of freedom. Specifically, Sen points out that two individuals possessing the same bundle of primary goods do not automatically enjoy the same level of well-being. "Two persons holding the same bundle of primary goods can have very different freedom to pursue their respective conceptions of the goods (whether or not these coincide). To judge equality- or for that matter efficiency-in the space of primary goods amounts to giving priority to the means of freedom over any assessment of the extent of freedom" (Sen, 1992, 8). Furthermore, Sen does not think that Daniels's modified Rawlsian approach does enough to account for the demands of social justice. Sen himself takes another step by advancing the fair equality of opportunity principle further. Sen "corrects for more aspects of bad luck than simply meeting medical needs and focuses on assuring people of the capabilities or 'positive freedom' they need to function as free and equal citizens" (Daniels and Sabin, 17).

But before delving into Sen's theory, it is also important to note that Sen adamantly rejects the utilitarianism approach as well. According to Sen, the utilitarian is primarily culpable for focusing exclusively on the achievement of well-being and completely ignoring the freedom to make decisions. The utilitarians overlook this crucial distinction between the freedom to achieve and actual achievement.

[4]Essentialism has also been championed by Martha Nussbaum, but with a more stringent notion of well-being based on the particular Aristotelian conception of the good.

"Welfarism in general, and utilitarianism in particular see value, ultimately, only in individual utility, which is defined in terms of some mental characteristic, such as pleasure, happiness or desire. This is a restrictive approach to taking note of an individual advantage … it ignores freedom and concentrates only on achievement…" (Sen, 1992,6).

Finding fault with both the instrumental approach of the Rawlsian and the outcome-based core of utilitarianism, Sen introduces his own view representing the constitutive elements of well-being in the context of social justice. Although Sen works from within an egalitarian structure, he suggests that this is not out of necessity and his theory may in fact have wider applications in other theories of well-being and social justice. In order to explain his theory, Sen begins with an account of how humans live. According to Sen, living can be seen as a set of interrelated 'functionings'. Functionings include a wide range of 'doings and beings'. Some of these doing and beings are simple such as being "adequately nourished, escaping preventable morbidity and avoiding premature mortality" (Nussbaum and Sen, 36). However some functionings are "more complex things such as being happy and having self-respect" (Nussbaum and Sen, 36). This somewhat cumbersome language aims to encapsulate the various forms a person's life may take or the roles they may play. Although some functionings are more complex and others are more basic, Sen regards all functionings as intimately related to being. "Functionings are constitutive of a person's being and an evaluation of well-being has to take the form of an assessment of these constituent elements" (Nussbaum and Sen, 39). According to Sen, functionings are an inseparable, essential part of well-being and, as such, must be accounted for in a theory of well-being.

Most people have various functionings from which they choose. They choose a specific career path from a host of alternatives. They choose hobbies and recreational activities. Sen defines a person's 'capability' as "the various combinations of functionings (beings and doings) that a person can achieve" (Nussbuam and Sen, 40). In other words, a person's capability is determined by a set of functionings from which they choose how to function or live. The wider a person's 'capability' is determined to be, the wider the range of possible functionings.

Next, Sen suggests that freedom is intimately connected to this theory of functionings and capability. "If achieved functionings constitute a person's well-being, then the capability to achieve functionings will constitute the person's freedom –the real opportunity-to have well-being" (Nussbaum and Sen, 40). In establishing the connection between functionings and capabilities, Sen has linked the two through freedom[5]. For example, consider the difference between fasting and starving. Although both situations have the same outcome (i.e. prolonged hunger), the crucial distinction is that the fasting person has the *freedom* to choose to eat, but is exercising her capability to choose a specific functioning. However, the starving person has no other alternative from which to choose (i.e. her set of available functionings is severely limited) (Sen, 1992, 52).

In explicating functionings and capabilities, as well as the role of freedom, Sen believes he has created a theory that captures the true core of well-being. "In a capability-based assessment of justice, individual claims are not to be assessed in terms of the resources or primary goods the persons respectively hold but by the freedoms they actually enjoy to choose the lives that they have reason to value" (Sen, 1992, 81).

But returning to our original inquiry, what does this essentialist view of well-being suggest about the distribution of scarce medical resources? How should these resources be divided within society? Although Sen doesn't give very precise specifications on how this is to be accomplished, he is very clear that the essentialist theory does in fact imply a fair distribution of health care resources.

> Any conception of social justice that accepts the need for a fair distribution as well as efficient formation of human capabilities cannot ignore the role of health in human life and the opportunities that persons, respectively, have to achieve good health – free from escapable illness, avoidable afflictions and premature mortality. Equity in the achievement and the distribution of health gets, thus, incorporated and embedded in a larger understanding of justice (Sen, 2002, 660).

[5] According to Sen, freedom may be intrinsically valuable as well. "Freedom is then at least instrumentally valuable, but potentially intrinsically valuable as well for a good social structure" (Sen, 1992, 41). Sen then gives an argument for the potential intrinsic value of freedom, but since this does not amount to any practical difference in his theory's application I have not included here. (See Sen, 1992, 50-52).

Sen also suggests that the appropriate way to conceive of health within his theory is to think of health as a 'functioning'. "Some functionings are very elementary, such as being adequately nourished, being in good health, etc." (Nussbaum and Sen, 31)[6]. Sen establishes that a conception of social justice must a) take into account health, specifically the opportunity to achieve good health and b) that health itself is a 'functioning'. In his theory, Sen empowers the notion of capability in the decision-making process leading to fair distribution of social resources. However, he does not dismiss the vital importance of outcome and process information in this decision-making procedure. "I must also stress that the informational basis of justice cannot consist only of capability information, since processes too are important, in addition to outcomes" (Sen, 2002, 661).

How is health care resource allocation to be embedded within Sen's larger notion of social justice? Sen suggests that health is a functioning, and as such, a constitutive part of well-being. Specifically, various levels of health are represented by a person's capability to achieve them. But Sen is eager to note that capability information alone is not enough. Rather the informational basis of justice ought to be concerned with capabilities, outcomes and processes together.

If Sen and other essentialists considered the Churchill allocation case (See Appendix A), what sorts of programs would they prioritize? Well, on a first glance, it seems that the practical applications of Sen's 'capabilities' and Daniels's basic institutions/primary goods hardly vary at all. What is the difference between protecting fair equality of opportunity and capability? As we saw above, Daniels thinks that Sen's theory requires more than his theory, which suggests only that an individual's bad luck in the natural and social lottery be removed. Sen's theory suggests that social justice requires taking an additional step, not only to remove disadvantages, but to protect and "assure people of the capabilities, or 'positive freedom', they need to function as free and equal citizens" (Daniels and Sabin, 17).

It seems that Daniels and Sen would both prioritize similar programs in the Churchill case, but that the essentialist would simply be more dissatisfied with the outcome. Not only would the essentialist

[6] Although Peter Fabienne suggests that it may be more useful to see health a set of functioning (e.g. being able to move, being free from pain, etc.) as opposed to a single functioning, this distinction has little, if any impact on the practical implications of Sen's theory to health care resource allocation.

lament how the available funds cannot alleviate all the "bad luck" of the natural and the social lottery, but also, the limited budget prevents much, if any, headway being made in the are of "positive freedoms" since all the resources would be consumed at the more primary level of correcting for bad luck.

We may however, be able to make some distinctions between the practical application of the modified Rawlsian theory and the essentialist theory if we shift our focus to Sen's criticism of the Rawlsian and modified Rawlsian positions. According to Sen, these positions focus on the wrong thing; namely resources. Two people with the same bundle of resources do not automatically achieve the same things, rather there is a wide diversity of human capabilities. Under Sen's theory, focusing on capabilities, health care resource allocation would most likely focus on promoting citizens' capabilities to achieve functionings of their choice, starting with those who are the worst off. In order to defend and promote the capability to achieve the functioning of health, Sen would likely prescribe that we support health insurance for the uninsured and health care coverage for the elderly. And we are already over "budget" for the $17 billion available. This prescription differs from the outcome of the Daniels approach because it focuses on the worst off of the disadvantaged.

While Sen's theory points out a crucial distinction between capability and goods as well as outcomes, his theory is problematic in its own way. Sen acknowledges the need for information about outcomes and processes as well as capabilities; but he doesn't describe how these three layers of information are to be synthesized into a complete approach to social resource distribution. If we must account for outcomes, processes and capabilities, how are we to weigh the importance of each?

Furthermore, two of Sen's most avid critics are the moderate essentialists, namely Ruth Faden and Madison Powers. Although we will revisit their complete theory shortly, it is worth noting at this point their main objection to Sen's essentialism, which is, the impetus for their own theory. Powers and Faden accuse Sen of misunderstanding well-being. According to Powers and Faden, there are some dimensions of well-being that are valued for their outcomes as well the capability they induce. For example, Powers and Faden consider the role of reasoning in our well-being. "Theoretical reason matters not only because of the desirability of the outcomes or states of being (being knowledgeable), but also

because a morally significant aspect of our well-being consists in our active role exercising our essential human capabilities, thereby bringing about those states" (Powers and Faden, 38). On the moderate essentialist view, the essentialist misinterprets well-being by overemphasizing capability, whereas reality suggests that we often value both outcomes and capabilities.

G.A. Cohen also criticizes the essentialist, arguing that in fact it is only outcomes in certain cases that matter at all. Consider small babies who clearly do not have the capability to feed themselves. Cohen notes, "Small babies do not sustain themselves through exercises of capability" (Cohen, 21). Rather, what matters to the small baby is being nourished, not the capability to nourish himself. There are cases, such as the infant case, in which capability is simply not the proper focus of justice. If Sen replies that this case is only applicable to small babies, then it is possible to point to other cases in which the same is true for adults. Powers and Faden suggest, "Even for adults, our active participation in bringing about our own well-being is not definitive of our well-being...Being healthy matters to our well-being whether or not that state is achieved by our actions or by the action, say of governmental bodies that secure for us potable water" (Powers, 39). According to the critics, Sen is sidelining consequentialism too much, focusing on capabilities, despite our judgment that some states of well-being are valuable for their outcomes, either partially or exclusively.

As we will see in the next section, the moderate essentialists, Powers and Faden, build off Sen's foundation, attempting to alleviate the consequentialist worries and create a more complete picture of how health care resources might be distributed in a socially just manner.

Chapter 8 – Moderate Essentialism

Just as Amartya Sen presents an argument borne out of criticism of the Rawlsian and utilitarian approach, his own approach generates criticism which takes the form of a new theory in its own right. Ruth Faden and Madison Powers refer to themselves as 'moderate essentialists'. As an outgrowth of the Rawlsian vs. utilitarian debate, their theory suggests a particular way to distribute health care resources,

but before delving into their views on the matter, the moderate essentialists have much to say about the foundation of their theory.

Like many social justice theories, Powers and Faden begin with an account of well-being. The thinkers list the following components as aspects of well-being: health, personal security, reasoning, respect, attachment and self-determination (Powers, 16-29). According to Powers and Faden, each dimension of well-being is "a separate indicator of a decent life which it is the job of justice to facilitate" (Powers, 29).[7] From this conception of well-being, Powers and Faden craft their own theory regarding social justice. They form their theory so that it may "serve as a basis appraisal for how well social structures are carrying out the obligations of social justice" (Powers, 29).[8] The moderate essentialist theory is rooted in the dimensions of well-being with the goal of being a basis upon which social structures may be evaluated.

From their dimensions of well-being and the goal of appraising basic structures, Powers and Faden create a non-ideal theory of justice. They aim to create a theory that can "offer practical guidance on questions of which inequalities matter most when just background conditions are not in place" (Powers, 30). This approach contrasts sharply with the Rawlsian 'ideal theory' which imposes conditions that are hypothetically optimized in order to work out a theory. For example, Rawls does not have to cope with gender, ethnic or religious discrimination in laying out their theories of social justice. But Powers and Faden argue that these factors, although discounted in the Rawlsian theory, are important in decision making regarding resource allocation. Rawls, in stripping the original position inhabitants of their personal knowledge also robs them of any awareness of their own needs, which, according to Powers and Faden is an incorrect way to think about distribution. Instead, Powers and Faden advocate

[7] However, Powers and Faden are not making the claim that a life deficient in a particular dimension is not worth living, rather they strive to make the moral claim about what justice means in the context of well-being thus defined (Powers, 29).

[8] Akin to the goal of Rawls, the moderate essentialist theory is not intended to serve as a complete theory of well-being, but rather a tool by which we cab assess social structures.

beginning with the problematic reality and finding solutions to fit the given circumstances[9]. "We care not abstractly about the distributive shares each person would think fair, absent any awareness of his or her own needs; we ask first what the needs are and work backwards toward some account of the distributive share of material resources" (Powers, 37). From this unique starting point, Powers and Faden go onto build their own non-ideal theory.

Despite the fact that the moderate essentialists propose a non-ideal theory, Powers and Faden are not totally opposed to Rawls's entire theory. In fact, they agree with Rawls on the subject of social justice. "Our theory does follow Rawls in so far as we agree that the primary subject of the principles of social justice is the basic structure of society, the arrangements of social institutions" (Powers, 31). Yet, Powers and Faden interpret the basic structure somewhat more broadly than the traditional Rawlsian conception. The moderate essentialists acknowledge that the background structures surely include political, social, economic and legal institutions, but think there is more to be considered as well. "We do not take an exclusively institutional view of the basic social structures. Social conventions and customs have similarly profound and pervasive effects on human development" (Powers, 31-32). According to Powers and Faden, social customs and conventions are crucial in the pursuit and attainment of social justice. "The respect of others and the development of sympathetic identification with and attachment to others are necessary for forging intimate relationships and sustaining bonds of justice" (Powers and Faden, 32)[10]. Once Powers and Faden have stipulated that their theory is a non-ideal theory, focusing on both the social and institutional aspects of background justice, the moderate essentialists elaborate on their views regarding the central questions of social justice.

Upon considering the present inequalities in our society today, Powers and Faden observe that the persistent inequalities are those that are interconnected through patterns of systematic disadvantage.

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[9] Powers and Faden do not consider themselves resigned to simply making the best out a poor situation, but rather think that this starting point will provide more direct access to ways of solving present inequalities. The moderate essentialists also believe that this view will then offer "guidance for achieving human well-being in all its dimensions" as society progresses (Powers, 31).

[10]Powers and Faden cite John Stuart Mill's work " On Liberty" as the inspiration for this inclusion in their theory (Powers, 32).

"Inequalities of one kind beget and reinforce other inequalities" (Powers, 31). Although different inequalities may, and likely do, affect different dimensions of well-being, Powers and Faden see connections between them. "While each dimension represents something of distinct moral salience, the factors affecting them are rarely causally distinct" (Powers, 31). For example, an individual who suffers from poor or lacking education may struggle with reasoning and may then, as a consequence, struggle to find and keep a rewarding career. The lack of stable career may lead to dire economic situations and perhaps even a marked decline in health as a result of depression or drug abuse.

In order to tackle these persistent, interconnected inequalities, Powers and Faden suggest that the central concern of justice goes beyond the capability approach suggested by Sen.

> The actual development and exercise of reason is essential to the functioning of society and the well-being of others, no less than respect. The same might be said of a certain level of good health. The moral importance of each of these dimensions, therefore, is inaccurately accounted for as centrally concerned with development of capabilities that individuals can exercise if they choose. The central concern of justice, then, is with the achievement of well-being, not the freedom or capability to achieve well-being (Powers, 40).

Powers and Faden do not think that the focus of justice should be the capability or the freedom or the opportunity to achieve well-being, for what good does this approach do anyone if individuals do not *choose* to develop these opportunities/capabilities/freedoms? According to Powers and Faden, none; and that is why they promote the actual achievement of the dimensions of well-being over the potential for their attainment. However, Powers and Faden recognize that the attainment of well-being cannot be pursued at any cost to the society and individuals. Their account "sets further limits on what others might justly do to bring about good outcomes" through dimensions of well-being such as respect for persons and self-determination (Powers, 40). So although Powers and Faden protect the primacy of achieving well-being over the opportunity or capability to do so, they are not endorsing the pursuit of this goal at the expense of any individual's self-determination or respect for others.

In turning to health, Powers and Faden begin with two goals. "We believe that there are twin moral impulses that animate public health: to improve human well-being and to do so in particular by focusing on the needs of those who are the most disadvantaged" (Powers, 82). However, as stated above,

these health-related goals are tempered by other dimensions of well-being. "Moreover, any theory that takes seriously respect and self-determination as essential elements of well-being…[prioritizes] what we can do for ourselves and for our children – that is, the active role we play in bringing about the desired states" (Powers, 84). So although health, particularly the health of the disadvantaged, is to be improved, Powers and Faden do not suggest that this is to be done at any cost. Rather, the goal of health can be pursued, but only within the boundaries of respect and self-determination.

In response to how health resources should be distributed, Powers and Faden, if presented with the Churchill allocation case would choose programs focused on the individuals most disadvantaged, attempting to correct the systematic patterns of disadvantage discussed above. These programs would likely include insurance for the uninsured and then those who are terminally ill, through no fault of their own. The moderate essentialist theory would also likely support neo-natal intensive care units as well as prenatal health programs, in attempt to stave off systematic patterns of disadvantage. However, the moderate essentialist has already exceeded the allowed budget without even fully covering these four programs.

The moderate essentialist theory is a relative new comer to the health care ethics scene, and as such, there is no robust refutation to discuss. Nonetheless, one of my main objections centrals around the moderate essentialism theory of well-being. Although Powers and Faden present a theory of well-being divided into dimensions, I am unsure of how these dimensions are to be ranked and connected in practice. For example, Powers and Faden are careful to cite that the dimensions of respect and self-determination limit how much can be done in pursuit of a just distribution of health care resources. But what counts as sufficient or deficient self-determination? Especially in America, we are viciously self-determining and most attempts to meddle in our affairs are quickly and swiftly condemned as impeding our self-determination. But what if a little less self-determination yields enormous strides in the justice of health care resource distribution? This objection generally targets the worry that different people value each dimension of well-being differently. Some place higher importance on self-determination than attachments, while others consider health to be of crucial importance while respect is not that important to

them. Since this objection has not been officially made in literature I am not sure how Powers and Faden would respond, but perhaps they would suggest the following. There is a certain (but nearly impossible to define) base-level of each dimension that is absolutely necessary to secure well-being. Beyond this basement, sure, values attached to dimensions may vary, but a society is not fulfilling its obligations of social justice if it is not attaining this basic level in each dimension. This theory would seem to suggest that it is justifiable to remove 'excess' amounts of well-being from one person in order to secure the basic level in another individual. While I am not sure it is the intended direction of the moderate essentialist view, it is certainly a path that their theory could head down and if they wish to avoid it, Powers and Faden must give an account of how their theory does so. For I think that many people would be unsettled, if not outraged, at the prospect of justice requiring that 'excess' well-being be removed from an individual and redistributed to needier individuals. So while the moderate essentialism contribution adds yet another perspective to the resource allocation discussion, it is ultimately incomplete.

Part IV: Chapter 9 – Moving Towards a Better Theory

After considering the available theories, I have come to the conclusion that no one of these theories on its own is sufficient or free from significant problems. Utilitarian theory justifies the great suffering of a few for mild good of many, while the Modified Rawlsian theory excludes patients who are irretrievably beyond normal functioning and dumps a large portion of resources to the sickest and oldest part of a society. Essentialism offers a new perspective in the form of the "capabilities" approach, but fails to offer a complete account of how these capabilities combine with outcomes and processes to form a complete theory of justice. Lastly, moderate essentialism promotes the primacy of achieving well-being above the capability or opportunity to do so, but appears to lack any sort of restriction from redistributing excess well-being to those not achieving sufficient well-being.

As a result of the inadequacies of the current theories, I have developed some principles which aim to elucidate some of the possible solutions to the problems of the current theories. Before beginning

to explain my theory, however, I would like to note that, much like Powers and Faden, my theory is non-ideal and accounts for the same dimensions of well-being as theirs (namely: health, self-determination, reasoning, attachment, respect and personal security). It begins with the reality of the persistent scarcity and injustice of health care resource allocation and considers what can be done to bring our society closer to justice. Also, my theory is not intended to be an extension of any one of the theories explicated above, but rather a synthesis of their powerful insights and a resolution of their difficulties.

When considering the most pressing problems of the other theories, I came to three main goals that I wanted my theory to realize. In my theory I aim to:

1) avoid justifying the great suffering of a few for the good of many
2) avoid justifying the redistribution of "excess" well-being
3) explain the connection between outcomes, processes and capabilities

In order to accomplish these goals, I then considered what elements were required to realize these aspirations in society. After listing these elements, I will give a brief, but hopefully thorough account of how these elements will lead to the realization of my goals in a society like ours. Lastly, I consider what some (but by no means all) objections to my theory may be.

Chapter 10 – The Three Elements

In order to realize the goals listed above, there are some distinct, foundational elements that must be present within the society in question. The first of these elements aims to protect an individual's well-being. The principle is as follows:

> an individual's well-being belongs solely to them and no other individual or governing body may justly remove well-being from an individual, regardless of what level of well-being the individual may have achieved.

This principle aims to avoid the pitfall that Powers and Faden fall into in their moderate essentialist theory. As stated in Chapter 8, the moderate essentialists don't explicitly account for the protection of individual well-being if the case arises that redistribution of some individual's excess well-being may result in attainment of sufficient well-being for another or group of others. For example, if an individual

is supremely healthy due to proper diet, exercise and yearly physicals, it is not permissible for society to "redistribute" the excessive health (in the form of, say, yearly physicals) away from this individual to other individuals, even if those individuals are not achieving well-being in the area of health.

Another element that must be included is the concept of utility. The egalitarians, such as John Rawls and Norman Daniels, vehemently criticize the utilitarians for ignoring the claims of social justice, but similarly, the theories of Rawls and Daniels (among others) lack a central place for utility. Why is utility important in a social justice discussion? It is especially important in the discussion of health care resources allocation because, as we know from Part I, the scarcity of health care resources is daunting. It is not enough to merely allocate these resources in an equitable way, complete justice requires that the resources are also distributed so that they aide as many people as possible to the greatest extent possible.

Before turning to the last element of my theory, it is necessary at this point to delve into the practical implications of my insistence upon utility. First, I want to clarify that I am not advocating the Oregon rationing system. As we noted earlier, the main problem with the Oregon system is that it did not actually ensure a "decent minimum" of care for every member of the society. What I am imagining is a system that does in fact ensure a decent minimum for everyone. Under my system, an individual requiring an appendectomy would be able to receive one. What falls within my conception of a decent minimum? At this point I need to make a crucial distinction between exotic treatments and crucial treatments. This is a distinction that is readily understood and applied under the British system of health care. In Britain, basic and acute services are accessible and free to individuals, but some treatments have been deemed 'exotic' (such as renal dialysis over a certain age) (Hare, 214). Exotic treatments are often experimental, expensive or provide marginal benefit to the patients. Treatments that would otherwise be considered crucial may be deemed exotic if they are futile as well. Exotic treatments are available in Britain, but only to those who choose to specially insure for them or pay out of pocket.

But how is a society to draw the line between exotic and crucial treatments? It appears as if Americans have no concept of the difference. If there is a treatment available, regardless of its known effectiveness or cost, Americans demand it. But the consideration of utility can undermine this

assumption. By covering these exotic treatments, our society's health care system is effectively shooting itself in the foot. In providing exotic treatments, our health care system is crippling its ability to provide treatment, both preventative and acute, to vast numbers of individuals. This can be seen if we refer back to the Churchill allocation case (See Appendix A). The heart transplant program costs twice as much as the prenatal program but affects only 12.5% of the individuals who would otherwise benefit from the prenatal program. Additionally, it is worth remembering that there is nothing unique about the death of a renal dialysis patient or organ transplant patient. "Is the human tragedy and personal anguish of death from lack of an organ transplant any greater than that of an infant dying in an intensive care unit from a preventable problem brought about by a lack of prenatal care?" (Crenshaw, 34). The answer is, of course, no.

Considering the enormous amount of individuals aided by the prenatal program and the equivalency of a loss of life in either category, it is possible, under my theory to view the heart transplant program as exotic. The actual line differentiating exotic treatments from crucial treatments will vary within a given society. A society's funds and medical prowess may allow organ transplants, while others will relegate them to exotic treatment status. This distinction will ultimately depend upon both the 'slice' of resources allocated to health care system and 'tax toleration' or how much the individuals in the society are willing to contribute to their health care. This system does suggest that in America, we may need to rethink what we assume are given treatments. It may seem impossible to do this once the proverbial technology cat is out of the bag, but if the society commits itself to greater justice in the health care, it may be necessary[11].

Another necessary element of my theory is the notion that processes, outcomes and capabilities all matter in the evaluation of social justice. I argue that my theory can account for all of these elements within the scope of just health care resource allocation. I can account for the importance of processes in social justice by advancing that fair processes would, in fact be realized. The process surrounding health

[11] Additionally, it should be noted that this distinction between exotic and crucial treatments does not entail that exotic treatments should not be available under my theory, but only that they are relegate to special insurance programs and/or payment out of pocket, as in Britain.

care resource allocation would be just since everyone in the society would be provided with basic care. This care would exclude exotic treatments impeding the delivery of basic care. However, exotic treatments would nonetheless be available to all on a special insurance program. Also, my theory accounts for the protection of capabilities in two ways. The theory protects the capability of individuals to do and be the things they desire, absent from basic health care concerns. Without health care costs, individuals are freed from the dilemma of choosing between poor health or crippling costs. Secondly, my theory protects the capability of individuals to, if they wish, purchase additional health care coverage in order to extend the protection of their functionings further. Through this dual focus on capability, the individuals in a society operating under my health care resource allocation framework would have their capabilities protected. Lastly, my theory accounts for outcomes through its incorporation of utility concerns as an essential element of health care resource allocation decision making. In a society individuals are not only concerned with the processes and their capabilities, but also the outcomes of the system as a whole. Incorporating utility as a foundational element of my theory assures these individuals that all three are accounted for.

Chapter 11 – Putting the Pieces Together

Now that I have laid out the goals and the elements by which I hope to achieve them, the question undoubtedly arises, how are these elements to fit together in order to realize the goals? As I suggested in Chapter 3, when considering social justice, a theory must weigh equality and liberty. My theory endeavors to include both liberty and equality but also to introduce the crucial principle of utility. My theory protects liberty through the first principle which maintains that an individuals well-being is theirs and theirs alone. My theory also accounts for the principle of equality by providing universal basic care to all members of society. Lastly, my theory accounts for utility by prioritizing utility in choosing how to allocate health care resources. But utility cannot be the most important principle in my theory or else I, like the utilitarian, would be forced to accept the sacrifice of L. in service of the great utility derived from

the re-allocation of his organs. Instead, I argue that utility, rightly placed, belongs as an essential part of the balance between liberty and equality. Under my theory, liberty and equality are equally essential as guiding principles; however utility is a fundamental principle which aides in defining the equality of a system. Utility is not lexically ordered beneath liberty and equality, but rather is more important, more central to my theory. Utility is a major component of what makes a system equitable and is not ordered below equality, but rather as an essential part of equality itself. For, utility is not something to be considered post-theorizing about social justice, but rather a principle that in order for a system to be fully just, must be included in the original formulation of theory.

Chapter 12: Possible Objections and Responses

My theory will likely draw some objections, many of which I cannot foresee. However there are some arguments that I have considered as likely objections to my theory. At this point I will explain a few of these potential objections and how my theory is able to respond to them. One argument against my theory is the objection that my theory will not, in actuality, perpetuate justice, but the actually widen the gap between the have and have-nots in our society. When I proposed that the decent minimum would not include exotic treatments but these could alternatively be obtained through special insurance or private money, the implication is that this theory would result in a two tiered system. Under this view, my theory would result in a decent minimum for all, but the wealthy would invest in an expensive, higher tier of care. While in and of itself this may not be objectionable (and is in fact the type of system the British employ), a subtler worry emerges. Under this system, technology would be driven by the private money flowing in through the upper tier. As technology progressed, the new treatments would likely be expensive and exotic, available only to those participating in the upper tier. The objection is that my theory, in practice, actually widens the gap between the individuals who can afford health care and those who cannot.

I think that my argument may respond to this worry in two ways. First, it is worth noting that the line between crucial and exotic treatments is not set in stone. Not only does this distinction vary among particular societies, but it will also change depending on the given technological state of a single society. As a society progresses, treatments that were once exotic may become crucial as their techniques are optimized and their cost lowered. On this view of exotic treatments, the upper tier of my theory's health care system is actually improving the care for everyone in society, expanding what may be included in the decent minimum. Secondly, my theory can respond to this objection by noting that although not everyon has access to the higher echelons of treatment, they will nonetheless be guaranteed a decent minimum of care. By guaranteeing everyone this level of care, my theory is unraveling the systematic patterns of disadvantage that Powers and Faden are so concerned with. By receiving free guaranteed basic health care, everyone will be in a much better position to achieve doing and beings then they would be without basic health care. Previously disadvantaged individuals would have (at least) one element of disadvantage removed, opening up greater opportunities for them. In this sense, my theory provides for the possibility of a smaller gap between the disadvantaged and the wealthy.

Another objection which has been raised against other theories, most notably the modified Rawlsian, is the question of what my theory requires for individuals who remain irretrievably beyond normal functioning. This questions arises when a theory is asked to advise on how to allocate resources for patients who are in persistent vegetative states or are terminally ill. As we saw in Daniels's modified Rawlsian theory, it seems unacceptable to abandon these individuals, but their care is very expensive and often qualifies as exotic. My theory does allow for these individuals or their caretakers to invest in exotic care. But what if the patient and their family cannot afford exotic care coverage? Is my theory condemning them to death or a miserable existence? I think that instead, my theory can plausibly respond to this objection. I do not suggest either that we abandon them or are bound to provide them with all the treatments desired. Instead, I think that my theory could plausibly assert that in dolling out resources based on equality influenced by utility, some resources should be set aside for these patients. Exactly how much resources should be set aside and how these resources are to be divided depends on the

particular society's pool of health care resources and how they value these individuals. In effect, my theory could allow for the creation of a separate slice of the health care resource pie to be totally devoted to individuals permanently beyond the normal threshold. This slice, although limited, would ensure that these individuals have some resources and are not completely abandoned by society.

Chapter 13 – Toward a Better Future

Although these objections attack from only two possible perspectives, I believe that my defense has provided insight into how my theory may respond to some of the tough allocation decisions facing our society today. I hope that I have added something of value to the discussion on how best to allocate health care resources. For although this crisis manifests itself in the health care system and political debates, in order to effectively achieve social justice, I firmly believe that ultimately it is the philosophers' voice which must be heard. The economic figures and the political legislation are certainly necessary, but the character of reform can be set by the philosophers and social justice theorists who are intimately acquainted with what it means to allocate resources justly. These individuals begin with ethics and principles not numbers and figures.

Furthermore, in choosing a type of ethical foundation from which to construct this reform, my view has mandated that utility be considered central to the decision-making process, not in an overbearing way, but in a vital way nonetheless. It is not enough for utility to be considered only in the application, after a reform has been constructed. Rather, utility belongs at heart of the decision-making process so that our society can face the health care resource allocation crisis knowing that we are making decisions that are rooted not only in respect for individuals, but also in utilizing the resources in the best possible way for the most benefit.

Although this thesis focused exclusively on the United States, my demand for utility within the social justice approach can be applied internationally as well. In other countries, scarcities are even more

pervasive than in our own. For these countries, utility is just as important if not more; for social justice demands that every bit of benefit possible may be squeezed out of the given resources, especially when the resources are insufficient.

Perhaps the United States can move from a country with a health care system in crisis, to a country whose system is a model for other countries. Perhaps, we may yet be able to create a just system from the present chaos and injustice of the current arrangement.

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Appendix A: The Churchill Allocation Case (taken from Churchill, 147-148)

The Federal Government has placed a cap on any new health care expenditures. The eight programs listed below have been proposed for funding. The total cost of all programs would be $30 billion, but only $17 billion is available[12].

A) Continuation of Renal Dialysis Program
    a. $2 billion annually for 75,000 persons
B) Institution of Comprehensive Prenatal Health Program
    a. $2 billion annually. Black infant morality rates are double those of white.
C) Expansion of Neonatal Intensive Care Technology
    a. $1.5 billion annually for 200,000 infants
D) A Totally Implantable Artificial Heart Program
    a. $3 billion annually for 25,000 people
E) Health Insurance for the Uninsured
    a. $8 billion annually for 25 million persons
F) Expansion of Cancer Research
    a. $2 billion annually
G) Improve Health Care Coverage for the Elderly
    a. $10 billion annually for 27 million persons
H) Continuation of Support for Persons in Persistent Vegetative States
    a. $1.5 billion annually for 10,000 persons

[12] In actuality, these figures are outdated and the current total health expenditure in our country is about $2 trillion dollars. Nonetheless, our uninsured population has risen, currently holding around 43 million persons. Although the specifics of this case are not up to the minute, it shows the general allocation dilemma well.