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### Healthcare for a Population without Health

The mentally ill are an especially vulnerable population in the United States. Many mentally ill individuals are not able to advocate for themselves and must depend heavily on care and protection from others. According to the council of state governments, 2,250,000 American adults suffer from severe mental disabilities and it is a sad reality that care for this population is not always adequate. In the last two decades, care for the mentally ill has undergone three important reforms: from moral treatment in the asylums in the early 1800s to “mental hygiene” in the psychopathic hospitals in the early 1900s, to a more community based mental health treatment in the late 1900s (Morrissey & Goldman, 1986). Each reform has brought with it better treatment of the mentally ill. Today, under the community health based treatment prototype, individuals who provide care for the mentally disabled have two primary duties: to do no harm and to foster the capabilities of their patients. Unfortunately, care ranges from excellent to abusive, and very little is done in the way of regulation. Intensive and proper care for the severely mentally ill should not be limited to a lucky few, but should be a standard of care. However, how should we decide what the standard will be? Where will the money come from? Finally, what does society gain by taking good care of this special needs population? These are all topics that I broach in this paper. The population of mentally disabled individuals that I discuss include only severely disabled individuals whose mental health cannot be completely restored by any means and will always impair their functioning.

### **Do No Harm**

The first duty of employees involved in treatment of the mentally ill is to do no harm. Unfortunately, not all employees make this their first priority. A New York Times investigation found that, in the state of New York alone, there were approximately 13,000 allegations of abuse in 2009 (Hakim, 2011). Such cases of abuse include sexual, physical and verbal abuse and severe neglect. According to the same article, only about 5% of these cases are reported to law enforcement and it is extremely rare that the offending employee is fired. Most commonly, employees that are turned in for abuse are simply moved to a different group home, where many of them abuse patients again. One of the most alarming stories cited in this article involved the supervisor of a New York state home, Mr. Sousie, and a 54 year old woman with severe disabilities. The article says that an employee of this home entered the patient's room to find her supervisor "standing between the woman's legs. His pants were around his ankles, his hand was on her knee and her diaper was pulled down" (Hakim, 2011, pg. 1). The employee called the police, who found semen on the victim. Mr. Sousie simply was transferred to a different state-run home.

Jonathan Carey lived for 13 years with autism and severe intellectual disabilities. In the fall of 2004, Jonathan's parents began to suspect that he was being abused and neglected at his school, The Anderson School in Dutchess County, NY. On October 10th, Jonathan's father made a surprise visit to the school to find "his son naked, bruised and lying in a bed soaked with his own urine. The boy had been isolated and denied regular meals for weeks as a behavior modification therapy for his compulsion to remove his clothes." Jonathan was 11 years old at the time. He was immediately removed from The Anderson School and relocated to the O.D.

Heck Developmental Center, which is a state run residential facility. Despite serious developmental setbacks from the trauma that Jonathan experienced at The Anderson School, including a diagnosis of PTSD, he began to make progress at O.D. Heck. Here, he enjoyed spending time at the stables and was sometimes allowed to ride as part of his therapy (Bolton, 2007). Sadly, the Careys did not get a happy ending at O.D. Heck. On February 16, 2007, Jonathan and another patient took a trip to the local mall with two O.D. Heck employees. While stopped at an ATM, one of the employees tried to restrain Jonathan, who was squirming and making noise in the backseat. Jonathan promptly stopped breathing. The employees continued their trip to the mall and an hour and a half later returned to the center where they said that the emergency had just occurred. Jonathan was pronounced dead an hour later (Bolton & O'Brien, 2007).

In 2004, after the abuse at The Anderson School, the Careys began fighting the system that was supposed to be protecting and caring for their son. According to state mental health laws and HIPAA, The Anderson School did not have to release information about Jonathan's care to his parents. The case was eventually dropped because the Careys could not gain access to the files that would have been evidence in their case against the school. After Jonathan's death, the Careys proposed a new law that would grant parents and caretakers of mentally disabled children and adults access to records from mental health institutions. As of July 18, 2007, Jonathan's Law is in effect in the state of New York (Dhammi, 2007).

These are examples of both the failures of mental health care and the government that polices it. Mr. Sousie sexually abused a disabled woman and received little to no punishment. Jonathan, a severely handicapped and non-verbal child, experienced multiple instances of severe abuse that eventually resulted in his death. While these are extreme cases of abuse and are not

the norm in mental healthcare, this type of abuse is all too common, especially in state run homes. Additionally, the state does very little to punish those who are guilty of abusing patients. Specifically in New York, The Civil Service Employees Association works hard to prevent employees of state homes from being fired, even in cases of abuse. Offending employees are simply relocated where many of them continue to abuse and neglect mentally disabled patients (Hakim, 2011). Before Jonathan's law was passed, parents could not even acquire information on abuse to pursue the issue themselves. Jonathan's law was a step in the right direction for mentally disabled children and adults in New York. On a moral level, it seems obvious that this kind of abuse is unjust. Mentally disabled individuals deserve basic care and respect. However, beyond basic care and respect, what does society owe the mentally disabled?

#### **Fostering Capabilities**

Although many mentally disabled individuals in the United States receive poor treatment, that does not have to be the case. In the 1970s, Leonard Stein and Mary Ann Test developed a program for treating the mentally ill that has been successful and popular. This evidence-based program, assertive community treatment (ACT), is based on a team approach, with a group of professionals working together to best treat severely mentally disabled community members. The professionals involved in this program work to help patients with medications, housing, financial matters, and other important topics. This is one of the most extensively researched treatment programs and one study found that, "compared to usual community care, ACT is highly successful in engaging clients in treatment, substantially reduces psychiatric hospital use, increases housing stability, and moderately improves symptoms and subjective quality of life" (Bond, 2002, pg. 2). Some critics argue that ACT is intrusive and paternalistic, however, the vast majority of studies have found that patients are happy with the treatment program and have

favorable outcomes. Today, states that would like to initiate an ACT program can send healthcare professionals to be trained in assertive community treatment and can then start their own state-run program.

ACT has had such success in treating severely mentally disabled individuals because it effectively integrates many features that are important for overall success. As discussed above, teams of professionals (usually including psychiatrists, nurses, social workers, and employment specialists) provide integrated treatment that covers the main areas of daily functioning. The professional team members often make home visits to provide treatment in the patients' normal habitat. In this way, treatment is geared to also include family members and other caretakers. The program focuses on problems that clients face in everyday life (such as chores, housing, financial matters, medications, etc.) and services are available 24 hours a day to respond to emergencies.

Additionally, treatment is individualized and life long. Even as patients improve, they remain in the program so that important relationships with healthcare professionals are not completely terminated. These are only some of the important characteristics of an ACT program that ensure its success.

According to the National Alliance on Mental Illness, ACT targets individuals who are severely ill and have not been successfully helped by other treatment methods. One of the traditional admissions criteria for ACT is frequent use of psychiatric hospitals, which is a large burden for taxpayers. ACT teams work towards discharge of long-term inpatients, which has been effective in helping downsize state hospitals (Bond, 2002). Many studies have found that ACT reduces the number of days spent in a hospital approximately 58% when compared to case management services alone and approximately 78% when compared to outpatient clinic care alone (NAMI.org). ACT teams also target "acutely ill" patients in an attempt to "deflect" them

from hospital use (Bond, 2002). The third target population is individuals who are not hospitalized but cause long-term issues in the community. By maintaining long-term relationships with such individuals, ACT is able help stabilize the patient and the overall community (Bond, 2002). Thus, it seems that ACT targets severely ill individuals in hopes of improving their quality of life and reducing the load on state run psychiatric hospitals. These same state run psychiatric hospitals, along with Medicaid, play a role in funding the ACT programs around the country.

Although this program is expensive to carry out, its success rates boast its effectiveness. This program provides severely mentally disabled individuals with traditional healthcare but also works to provide access to social determinants necessary for success. For example, ACT teams include professionals responsible for job training and assisting with enclave employment. This program successfully integrates both important parts of mental healthcare. It does no harm and also works consistently toward improving the capability and subsequent freedom of its patients.

It seems unjust that some mentally disabled individuals are treated as Jonathan was, while others stumble upon an ACT program. The disparity between the two types of treatment is astonishing and has little to do with the financial resources of the patients. It seems that much is up to luck. Unfortunately, it is not realistic to provide care of this intensity to every severely mentally disabled person. It is simply too expensive to employ enough teams of professionals (doctors, psychologists, therapists, etc.) to treat every severely mentally disabled American. The individuals on ACT teams are highly trained and specialized in this field of treatment and there are low patient to professional ratios. Thus, the cost associated with employing an entire ACT team is high and the number of patients treated per team is low. Additionally, someone from each ACT team is available 24 hours a day, 7 days a week for emergency care. These extended

hours create additional costs. Although it is not reasonable to expect ACT for everyone, consistent care that focuses on promoting physical health and daily function, should be the rule, not the exception.

### **Philosophical Guidelines**

“As a matter of justice, what do we owe each other to promote and protect health in a population and to assist people when they are ill or disabled?” (Daniels, pg. 11). Norman Daniels opens his book, *Just Health: Meeting Health Needs Fairly*, with this broad and philosophical question. Over the next 355 pages he explains why meeting health needs is required for promoting equality of opportunity and capability in society. Daniels defines “health” as having access to medical care as well as the cumulative experience of a set of social determinants during a lifetime. He argues that not providing healthcare or adjusting for social determinants of health (for example: education, recreation, crafts, reading, music), to the extent that the government is able, is depriving citizens of their right to function normally in society and is, for this reason, unjust. An issue that Daniels does not directly raise is how his moral guidelines apply to the severely mentally disabled, like Jonathan, who will never be able to function normally in society. He deals with an issue similar to this one when he discusses the elderly. The elderly, like the mentally disabled, do not have the capacity to function at the same baseline level as younger persons. However, this does not mean that there is not a level of functioning and well being that these two populations can reasonably claim. In this case, even distribution of healthcare and social determinants is not adequate to ameliorate the severe health needs of the mentally disabled. They require more than “even distribution,” they require more care and, unlike the elderly, require it throughout their entire lifetimes.

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Although severely mentally disabled individuals in the United States will never reach a “normal” level of functioning and will never be able to contribute much to the economy, society still has a moral obligation to care for them. These individuals have a severely diminished capacity to function in society relative to healthy citizens. However, there is still an opportunity for them to function at a normal level relative to their specific capabilities. For example, The Magnolia Center in Lexington, VA, is a day center for severely mentally disabled adults. The members of The Magnolia center will never be able to go to school or hold a high-level job. However, the employees work to improve their functioning to a level where they can enjoy other activities. Each day, the members and employees sit down for lunch together. The employees teach the members basic eating skills like holding a fork, cutting food, using a napkin. They also enforce table manners like saying please, thank you, and excuse me. As a result of this work, members who would otherwise not be able to eat at a restaurant are able to go out to dinner with their families and friends. Additionally, The Magnolia Center staff takes the members on frequent outings into the community, where important social skills are taught and refined. Due to the diligence of the employees at The Magnolia Center, some of the members function highly enough to hold enclave employment positions at places like Wal-Mart and Kroger. Employment is an important part of the psychosocial functioning of mentally disabled individuals. Although the majority of the tasks that they complete are simple and repetitive, having a job gives them a sense of meaning and purpose.

The employees at The Magnolia Center perform two additional important tasks for the members. The first is protecting the members from the harm that was exemplified in Jonathan’s story. Protecting the mentally disabled from harm is more costly than protecting others from harm. The safe environment at The Magnolia Center is vital to the well-being of its members.



Additionally, the employees encourage the members to participate in daily activities that are mentally and physically stimulating. Such activities include basic exercise, enjoying nice weather, and the production of the annual Christmas play that is open to the community.

Although the members are not functioning at the same baseline level as healthy Americans, their time at The Magnolia Center helps to improve their capability to function at a baseline level specific to their disabilities. Participation in a Christmas play, eating at a restaurant, or holding an enclave job greatly improve the quality of life of severely mentally disabled individuals.

The primary philosophical underpinning of this argument is that, although severely mentally disabled individuals will never be able to function at the same baseline level as healthy individuals, they still have a right to function according to their own basic capabilities. Amartya Sen defines poverty as a basic lack of capability. He chose the term “capability” to represent “the alternative combinations of things a person is able to do or be—the various ‘functionings’ he or she can achieve” (Sen, *Capability and Well Being*, pg. 32). A healthy individual has n-tuple sets of capabilities from which he or she can choose. In his theory, a *poor* person never had enough sets of capabilities from which to choose a path. He acknowledges that a person may be living in poverty because he or she squandered the available capabilities; however, this person is not actually poor because he or she had the opportunity to choose a different life. According to this logic, severely mentally disabled individuals may be the most poor of all. These individuals do not have a range of capabilities from which to choose and not because they squander their initial capabilities. Metaphorically speaking, they are dealt one card and “go fish” is not an option. However, they still have one card and we, as a society, are responsible for helping them achieve all that is possible with that card.

Sen begins to address what should be done for the severely mentally disabled when discussing inter-individual variation. Here he argues that providing equal capability and justice often times require unequal treatment. He gives the following example:

Consider the example touched on earlier of the person with a high metabolic rate, or a large body size, or a parasitic disease that wastes nutrients. He is less able to meet minimal nutritional norms with the same level of income, compared with another person *without* those disadvantages. If he is to be seen as poorer than the second person, despite the fact that both have the same income, the reason for this lies in his greater capability failure (the focus of our concern). The same set of facts can also be seen as indicating the greater inadequacy of his income *given* his personal characteristics and circumstances. To have inadequate income is not a matter of having an income level below a fixed poverty line, but to have an income below what is adequate for generating the specified levels of capabilities for the person in question (Sen, 1992, pg. 111)

Although he is not directly addressing the mentally disabled, Sen argues in this paragraph that if we are going to give attention to the capabilities of the population, we are going to have to take into account the special requirements that arise from the specific challenges that each person faces. This is especially true for the severely mentally disabled. Within this population, each individual has disabilities specific to himself or herself. In an attempt to foster the capabilities of such a population, caretakers must provide care that accounts for individual variation. This is where a program like ACT is again successful. ACT provides individualized treatment to each individual enrolled in the program. They do not have a blanket treatment program that is applied to everyone, regardless of their individual circumstances. Rather, they approach each patient as an individual, with ~~her~~<sup>their</sup> own disabilities and challenges to overcome.

Sen argues that society can reduce poverty by increasing the number of basic capabilities from which an individual can choose. For the healthy population, this can be done through education and job training. For the mentally disabled, this can be achieved through treatments like physical, occupation, and psychological therapy, medications, and socialization. Such

treatments are available through programs like ACT and day centers like The Magnolia Center. It is possible that the highest level of capabilities possible for this special population is performing in a Christmas play, enjoying a dinner with family, or visiting a library or museum. However, the employees at places like The Magnolia Center can use opportunities like these to teach its members about appropriate behavior. For example, while having lunch, one member began burping. The employee gently explained that burping at the table was not appropriate and that he needed to say “excuse me.” This is an example of how the limited capabilities of this population can be fostered through simple socialization experiences. The real poverty of the situation occurs when even these capabilities are not being fostered. Although it is not financially feasible for our country to provide pervasive care like that available through ACT for every mentally disabled individual, it is the responsibility of our society, especially those working in mental healthcare, to use every means available to help these individuals achieve the highest level of capability available to them.

### **Resources**

In a perfect world, resource constraints would not exist and every individual would be offered every life-improving treatment available. In this world, mentally disabled individuals would be able to function at their highest level due to extensive therapy and around-the-clock care by trained professionals. Essentially, everyone would receive care in an ACT program. However, this is not the case. As we saw in Jonathan’s story, mentally disabled individuals are often treated so poorly that their progress is diminished or even reversed. So, what can and should we offer the mentally disabled when we live in a world with serious resource constraints?

*Direct Cost to the Country*

According to Thomas Insel (2008)<sup>1</sup>, the annual cost of serious mental illness includes both direct and indirect costs. Unlike other health issues, the indirect costs associated with severe mental illness often outweigh the direct costs. Direct costs include healthcare (such as medication and doctor and hospital visits), disability benefits, cash assistance, food stamps, and public housing. In 2006, the United States spent approximately 16% of the nation's gross domestic product on healthcare; only 6.2% of the money spent on healthcare was for mental health (Insel, 2008). Approximately \$100.1 billion are spent each year on direct healthcare costs, such as medication and hospitalization, and an additional 24.3 billion are accrued from disability benefits, such as Social Security Income (SSI). SSI is one of the major areas of direct spending on mental health services. Through SSI, the government provides income supplements to the mentally disabled population to meet basic needs. According to ssa.gov, individuals are considered disabled if they have a disability or mental impairment, which "results in the inability to do any substantial gainful activity, or can be expected to result in death, or has lasted or can be expected to last for a continuous period not less than 12 months." SSI is an income supplement, funded by general taxes, for individuals who are aged or disabled and have limited income and resources.

An additional pathway of direct spending on healthcare for the mentally disabled is through Medicare. The social security office automatically enrolls individuals in Medicare that have been receiving SSI benefits for two years. According to ssa.gov, Medicare has two separate coverage plans that both apply to the mentally disabled. The first is hospital insurance, which helps patients pay for inpatient hospital stays and limited follow-up care. This type of coverage is

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<sup>1</sup> The National Institute of Mental Health (NIMH) cites Insel's research on their webpage. See [http://www.nimh.nih.gov/statistics/4COST\\_TOTAN.shtml](http://www.nimh.nih.gov/statistics/4COST_TOTAN.shtml).

free. The second type of coverage is general medical insurance, which assists with doctors' bills, outpatient care, and other medical services like physical and occupational therapy. This type of coverage requires the patient pay a monthly premium. According to The Department of Health and Human Services, the new Affordable Care Act for Americans with Disabilities improves healthcare for Americans with chronic diseases, including mental disabilities. This act "invests in innovations such as medical homes and care coordination demonstrations in Medicare and Medicaid to prevent disabilities from occurring and progressing and to help the one in 10 Americans who experiences a major limitation in activity due to chronic conditions."

#### *Indirect Costs to The Country*

The indirect costs associated with severe mental illnesses include factors such as lost earnings, reduced labor force, and cost of other issues related to mental illness such as incarceration and comorbid disorders. A study by Ronald Kessler and his research team (2008) estimated that in 2002, the total cost of serious mental illness was approximately \$317.6 billion dollars. Interestingly, \$193.2 billion (60.8% of the total costs) are due to lost earnings. According to Insel (2008), the \$193.2 billion estimate is a conservative estimate derived from a door-to-door study that surveyed loss of income for approximately 5,000 individuals with mental disabilities. Due to the methodology, the study was not able to survey individuals in hospitals, institutions, or jails, or homeless individuals. Thus, the estimate neglects a large sub-population of the mentally disabled. Loss of income associated with mental illness is a huge source of indirect costs in the United States. According to the Council of State Governments only 1 in 3 individuals with severe mental disabilities is employed, but 70% of these people report that they would like to have a job.

The Substance Abuse and Mental Health Services Administration (SAMHSA) estimated that in 2003, 58% of the costs of mental health are paid for by the public sector. According to SAMHSA, in 2003, state and local funding covered 36% of the costs paid for by the public sector. Unfortunately, according to a Stateline article by Christine Vestal, the amount of money that states are willing to spend on mental health care has decreased with the plummeting economy. “The drop-off is translating into a reduction in the number of psychiatric hospital beds, as well as fewer services for mental health emergencies and longer waiting lists for housing for the chronically mentally ill” (Vestal, 2010). The National Association of State Mental Health Program Directors estimated a 5% decrease in state spending on mental healthcare between 2009 and 2010. The cuts in spending have resulted in closed psychiatric hospitals and 24-hour crisis centers and more stringent eligibility rules for subsidized medications. These cuts are extremely drastic in some states. For example, the governor of Illinois proposed a \$91 million cut in spending but this number was reduced to \$35 million due to protests at the governor’s mansion. Despite the reduction in cuts, an estimated 70,000 Illinois residents may lose basic community services (Vestal, 2010).

~~It is interesting to consider how dD~~Decreases in direct spending on mental healthcare significantly impacts indirect costs on the country. In 2002, Michael Hogan, the chair of President Bush’s New Freedom Commission on Mental Health and the director of the Ohio Department of Mental Health (Hogan, 2002) said, “It goes without saying that the excess costs of untreated or poorly treated mental illness in the disability system, in prisons, and on the streets are part of the mental health care crisis. We are spending too much on mental illness in all the wrong places. And the consequences for consumers are worse than the costs for taxpayers” (Insel, 2008). It seems logical that neglecting the mentally disabled by limiting direct spending

will increase the number of mentally disabled individuals who utilize emergency room care and psychiatric institutions, as well as the number of homeless and incarcerated individuals.

Increasing these negative outcomes for the mentally disabled increase the already high indirect costs. [Moreover, they may not reduce the long-term direct costs for mental healthcare. Grace, it would help here to say something about the effectiveness of direct costs for specific programs to reduce the long-term direct costs and the indirect costs.](#)

### **Aggregate Health**

How does caring for the incredibly needy mentally disabled population affect care for the rest of the population? Aggregate, or population, health is an important topic to consider at this point. Population health is the overall health outcomes of a specific population, in this case, a country. Achieving good population health is incredibly important because the distribution of care and other determinants along these lines will reach and positively impact the largest number of people. However, a population can have good aggregate health figures and still be severely neglecting a specific subgroup of that population. The severely mentally disabled are one such subgroup. For example, even within the mental health spectrum, there can be vast inequalities in care. There are significantly more Americans with treatable mental disorders than there are individuals with severe, persistent mental illnesses. As a nation, we could ignore the needs of the severely disabled population in favor of treating the depression faced by more Americans.

Individuals suffering from depression are generally more highly functioning and are also capable of a more complete recovery than their more severely disabled counterparts. Returning the depressed to the workplace undoubtedly has a positive impact on the overall economy, making this spending seem justified. Treatment for the severely disabled may only allow for enclave employment positions, which would have a lesser impact on the economy. However, does this

justify ignoring the needs of the severely disabled? Although there may be less visible improvement in aggregate health numbers as a result of treatment for the severely mentally ill, this does not mean that their treatment should be neglected.

The mentally disabled population requires an unequal share of resources to reach lower than normal levels of functioning. So, if we cannot provide all populations with all of the care that they need, for whom will we provide? One extreme option would be providing the most health opportunities to those who have the greatest needs—those with serious illness or disease. But providing for these individuals may restrict our ability to provide to others in less dire need. For example, pouring funds into treatment of the severely disabled, in order to bring them to a baseline level of functioning, would detract from the education of a healthier cohort of individuals who will contribute more to the economy of the country. In terms of resources, we can often provide for many more individuals in less need with the same resources that it would take to provide for one seriously ill individual. Ultimately, distributing resources to favor those with the greatest need may reduce population health, and thus the opportunity for normal functioning for other, less demanding, populations. The other extreme would favor population health by providing only the health opportunities that provide the greatest net benefit to society at large. Individuals in this corner would likely argue for investing in projects that will have the greatest marginal productivity in return. For example, taking funds from the treatment of the severely mentally disabled and pouring it into education of the healthy youth. The distinction is between a utilitarian concern for the health of the population and the associated positive impact that aggregate health has on society at large; and attempting to provide equal opportunity for everyone. [Good job articulating a complex and highly important tension in thinking about the just distribution of health resources.](#)



Although it is not possible to blindly strive for the greatest aggregate health without consideration for those who are inevitably neglected, it is also not possible to pour the majority of resources into helping those who will never reach a normal baseline level of functioning. Daniels says that most people find themselves in the middle of these two extreme positions. In this grey area, people find themselves unsure about what percentage of resources should be allocated to aiding those with the most dire need, whether that need be medical treatment, therapy or a social determinant, like education. Equal opportunity for health for every population is not a realistic possibility because the distribution of health is severely limited by the amount of resources available for meeting health needs. No state is able to provide every single life enhancing health opportunity to every citizen; there simply is not enough money for that. Daniels argues that health inequalities are just when there is an even distribution of “the socially controllable factors affecting population health” (Daniels, pg. 27). However, this is not possible when there are limited resources available for health. Equal opportunity for the entire population is the ultimate goal in solving the healthcare problem; however, it is not enough to solve the issue of resource allocation. Under resource constraints, Daniels allows for inequalities in order to allow for population health. Striving for better population health requires foresight instead of simply immediate single-minded attention to equality of opportunity. This raises another important question: under resource constraints, who will decide how the available resources will be distributed in a diverse population?

#### **Accountability for Reasonableness**

As a method of solving the resource allocation problem, Daniels’ proposes *accountability for reasonableness* (AFR). He acknowledges that limit-setting, especially in terms of health, is destined to create controversy because even “fair-minded people” will disagree on some topics.

However, his proposed AFR method attempts to create a fair system for decision-making. AFR is based on the following important conditions: publicity, relevance, revisions and appeals, and regulation. Those who make limit-setting decisions are required to make available to the public the rationale behind their decisions. These rationales must provide a relevant explanation for how setting this limit is in the best interest of society, keeping in mind the resource limits. There must be some method by which a citizen can challenge a decision made by this process and there must also be a way that the decision can be revised if it is decided to do so. Finally, there must be some sort of regulatory body that ensures that these conditions are met. Daniels believes that this method of resource allocation promotes democracy by ensuring that the decision-making body honors those for which it is making decisions.

It is undeniable that reasonable people will have differing opinions on how to best distribute resources to effectively address both population health and the health of those in greater need. When discussing accountability for reasonableness in terms of the aging population, Daniels says that we will require those making decisions “to pretend that they do not know how old they are” so that they will not favor their own age group in the decisions made (Daniels, pg. 174). Along these lines, those making decisions that impact the mentally disabled should “pretend” that they do not know that they are mentally healthy and will probably always be. Reasonable decisions regarding this population should be made by a body of people who are capable of “pretending” that they too could one day be receiving the care that they distribute to the mentally disabled. If this and the other guidelines for the acceptability for reasonableness method are met, there is a range of options for treatment of the mentally disabled that I am prepared to accept.

It is extremely relevant to our society that we determine the importance of not only focusing on aggregate health but also on care for the most needy. It is also important that we see the impact of the indirect costs on the country. Additionally, there is currently no structured situation in which to determine the relevance of these topics. It is unfortunate that we do not have any good accounting of these issues and it is because we are not paying attention to this issue in a large way. This is where an AFR process could be largely beneficial.

### **Solutions**

One of the most important things that can be done to improve the care provided to the severely mentally disabled is to increase public knowledge. Unfortunately, thinking about the lifestyle of this population is not pleasant and thus, is generally ignored by society. I am my own case and point. Although I have a distinct interest in mental health, the experiences and knowledge that I have gained through my research for this thesis have made me realize how relatively uneducated I was about mental health. The fact that the New York Times dedicated front page space for an article about maltreatment of the mentally disabled is a step in the right direction. However, the sheer volume of abuse cases in the state of New York alone (approximately 13,000 allegations in 2009) indicate how little attention those caring for the mentally disabled actually pay to fostering the capabilities of their patients. The first major change that we need to make in favor of the severely mentally ill is raising awareness about the issue. Only through enforcing “do no harm” and by fostering the capability of this special population can we attempt to give them an equal opportunity to function in society. Granted their opportunity to function is greatly diminished when compared to healthy individuals, it is extremely *relevant* to this population that we, as a society, recognize their right to function at their own baseline level.

Using the AFR method requires that decisions be based on what is relevant to the best interest of society. Simply using the AFR method would require greater awareness of the ethical issues surrounding the mentally ill. Unfortunately, the current ethos and political climate in our society does not make knowledge about the severely mentally disabled relevant by refusing to discuss it. In order to use AFR as a method of solving the resource allocation problem, public awareness of this issue must be improved.

The next solution to the problems plaguing the mental healthcare system is to strictly enforce laws about abuse. Abusers should not be able to hide behind the protection of The Civil Service Employees Association or laws like HIPPA. It seems that there is a strong support system built around protecting those who are committing abuse, but not much that can be done in the way of legally protecting those who are being abused. This is the first thing that needs to change. The severely mentally disabled are an extremely vulnerable population, which survives on protection provided by others. We, as a society, need to do a lot more to ensure that this special population is actually being protected by those who are providing care and when the healthcare system fails, we need to provide protection.

It is also extremely important that we more strictly police the recruitment and training of employees working in homes for the severely mentally ill. This is especially important in state run homes, where abuse is so prevalent. Employees should go through a comprehensive training program upon being hired and additional training sessions should be held at least once a year. Training sessions should cover important new research and discuss statistics, as well as reviewing proper restraints and first-aid care. Employees should be taught how to encourage and uplift their patients in order to foster their capabilities and improve their quality of life. Efforts to improve the quality of care provided by these facilities should be never ending.

The United States is spending an adequate amount of resources on the treatment of the severely mentally ill. However, the vast majority of spending is in the way of indirect costs—cleaning up messes made by inadequate primary care. Although it will take increased spending and many years, I think that the best way to fix this system is to pour more money into primary care (direct costs). If, through increased spending, the United States can make programs like ACT and The Magnolia Center more prevalent, I think it would significantly reduce the indirect costs associated with severe mental illness. I estimate that we would end up spending the same amount of resources. However, targeting preventative care will greatly improve the capabilities and lifestyles of the patients. If this were the case, a greater percentage of this population would be able to hold enclave employment positions. Enclave employment is beneficial for severely mentally ill individuals because it gives them a sense of importance, but is also good for the economy. Additionally, increased spending on preventative care would reduce emergency room costs, and costs associated with incarceration and comorbid disorders. By maintaining the amount of spending at a relatively stable level but changing the focus of the spending, we can improve the treatment for the severely mentally ill and still focus on aggregate health.

Improved primary care would include changes in the distribution of healthcare and positive social determinants for the severely mentally disabled. Although strict fidelity to the ACT program is not financially feasible on a country-wide basis, many of the characteristics of ACT programs can and should be applied more universally. Through increased spending on primary care, every severely mentally disabled individual should be entitled to life-long psychological therapy. Therapists' caseloads should be reduced so that therapists can work in accordance with caseworkers, ensuring that no one falls through the cracks. When these individuals are neglected by the system, they become a burden on society by increasing spending

related to homelessness, incarceration, and comorbid disorders. A revised system should ensure that no one falls through the cracks. Additionally, treatment should focus on problems faced in everyday living. Working on such issues will help improve the daily functioning of these individuals. In order to really grasp everyday problems without relying completely on self-report, therapists should make frequent home-visits. By incorporating techniques such as these into care for all severely mentally disabled individuals, we can minimize the indirect costs on society by ensuring that no one is neglected. These techniques also provide a more just distribution of healthcare and work to foster the capabilities of the patients involved.

Along with a more even distribution of healthcare, we should strive for a more just distribution of social determinants. I will use The Magnolia Center as an example in discussing social determinants. The Magnolia Center does not provide any direct healthcare but works to expose its members to education, recreation, exercise, and socialization. While it would be easier and cheaper to sit in a room and watch television all day, the employees at The Magnolia Center take a more ethical route. They take the members on fieldtrips to nearby museums and libraries. Not only are these outings educational for the members, but also give them an opportunity to function in society and glean important knowledge of social skills. When they are not on field trips, the employees at The Magnolia Center plan crafts for the members that incorporate art, music and reading. Both fieldtrips and crafts provide good mental exercise for severely mentally disabled individuals; educational and recreational activities ensure that they are using their brains and imaginations. The members of The Magnolia Center are also encouraged to walk around or go outside, where they can stretch their legs and stay in relatively good shape. Finally, the socialization skills learned by the individuals at The Magnolia Center are of paramount importance. It is these skills that prepare them for enclave employment positions and allow them

to accompany their families to a restaurant. Most importantly, these socialization skills enable them to make friends and greatly improve their quality of life. All of the things that the members of The Magnolia Center experience through a just distribution of social determinants greatly improve their ability to function according to their own capabilities. This may be the best example of fostering capabilities.

Such a distribution of social determinants should not be limited to special places like The Magnolia Center; it should be a universal method of care. All schools, homes, daycare centers and the like, should be required to meet minimum requirements each year. These requirements should ensure that the employees at these facilities are providing their patients with educational, recreational, and socialization experiences. This is the only way that we can provide a just distribution of social determinants to special needs populations, like the severely mentally disabled.

Finally, there is no good accounting of a cost-benefit analysis related to mental healthcare. In order to gauge improvements in care, this needs to change immediately. The government needs to invest more into following the successes and failures of the mental healthcare system in order to determine how effective national spending is. In my research for this thesis, I became frustrated about the lack of accounting-type information available about the treatment of the severely mentally disabled. All mental healthcare should not be lumped into one category. Spending on depression is significantly different from spending on lifelong treatment for the severely mentally ill. We need to tease out our definition of mental healthcare so that we can have more accurate accounting of our spending on the severely disabled. It is important that we are able to discuss the cost-benefit analysis of our spending on this population, something that is not possible at this point. Highly important paragraph. It raised your grade!

## **Conclusions**

According to Norman Daniels, we are required to provide healthcare in order to ensure that every individual is able to function at some “normal” baseline level. Without basic healthcare, many individuals would not be able to reach this baseline. I suggest that we extend this logic to a population that will never reach any “normal” level of functioning, the severely mentally disabled. These individuals have a right to function at a baseline level relative to their own capacities, however diminished. The only way that we can provide them with just care is to ensure that those providing care are first, doing no harm and second, fostering their capabilities. It requires an unequal distribution of healthcare and positive social determinants. The characteristics of programs like ACT and The Magnolia Center should become standards of care to ensure that these individuals are receiving the treatment that they deserve.

Stories like Jonathan’s are much too common and are icons of the failures of our mental healthcare system. We need to prevent future failures by improving public awareness of the issues. This will allow us to use Daniels’ AFR method for distributing resources. We need to improve our protection of the mentally disabled by more stringently punishing those who commit abuse. We need to pour more money into primary care in order to minimize the indirect costs associated with the severely mentally disabled. Improved primary care would ensure a more just distribution of healthcare and social determinants. Finally, we need to improve our methods of accounting, so that we can really determine how effective our spending is. I think that if our society were able to make these important changes, it would greatly improve the lives of the severely mentally disabled.



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