

Background Guide

WHO

***GatorMUN XVII***

Dear Delegates,

Welcome to GatorMUN XVII and the United Nations World Health Organization! My name is Marcos Damian-Noyola and I am a second year at the University of Florida. Currently, I am working on my Bachelor's in Public Health and a Minor in Health Disparities. I currently serve on the executive board of the UF Model United Nations team as the Director of Member Recruitment and Retention. Other clubs that I'm active include being the Director of Public Relations NAMI: A Helping Hand, a mental health advocacy club, and a general member of Gators for Refugee Medical Relief. Outside of school I love going to the gym, hanging out with friends, and eating..like a lot.

The first topic that is listed in the background guide is Mental Health: Building Bridges in Society. This topic follows GatorMUN's theme of an "untold story" as it is an area of society that is continually neglected and needs more exposure to truly combat various mental illness that affects countless people. When debating this topic there should be an emphasis on marginalized communities in society, however, that is not to say that there should be no discussion nonmarginalized communities. The debate surrounding this topic should address why these marginalized communities are not receiving the necessary mental health services and how these services can be expanded to these communities. Moreover, seeing that noncommunicable diseases, specifically mental illness, are more prevalent in developed nations there should be a discussion as to how member states can create measures to decrease stigma and making the treatment process more efficient.

The second topic that follows is Gene Therapy: Mending the Relationship Between Government and Health Care. One of the interesting tidbits of this topic is that it is an area of health that has the potential of revolutionizing treatment and therefore yields an "untold story" for the human race. During this topic, there will be an emphasis on ethics and how newer gene therapy technologies can be utilized. During the debate, there should be a strong emphasis on how these technologies will remain available to all in the international community. In regards to the ethics portion of the debate, there should be discussion regarding how these newer technologies will be regulated and implemented. Seeing that discussion of this topic is relatively new to the international community it is advised that you look at what the WHO has done.

Delegates are required to submit position papers that highlight their Member States' positions on each topic. Past international and domestic action taken and potential solutions regarding each topic should also be included. If you have any questions or concerns do not hesitate on reaching out to gatormun@gmail.com. Position papers must also be submitted at this email. I cannot wait to hear what each of you bring to the table.

Sincerely,

Marcos Damian-Noyola

General Assembly Director

Quorum

A majority of voting members answering to the roll at each session shall constitute a quorum for that session. This means that half plus one of all voting members are present. Quorum will be assumed consistent unless questioned through a Point of Order. Delegates may request to be noted as "Present" or "Present and Voting."

Motion to Open Debate

This opens the floor for debate, allowing other points or motions.

Motion to Set the Agenda

This motion determines the order in which the topics of a committee will be debated. Permission to speak will be accorded to one speaker for and one speaker against, and a two-thirds majority is required for the motion to pass.

Motion to Open the Speaker's List

Opening the Speaker's List requires a simple majority to pass. A delegate may only be present on the Speaker's List once, but may re-enter after he/she has spoken. If the Speaker's List expires, debate then closes.

Motion to Set Speaking Time

Speaking Time must be indicated by this motion from the floor before any members of the body may speak on the Speaker's List. This motion must also accompany any motion for a Moderated Caucus. In a Motion to Set Speaking Time for the formal Speaker's List, a delegate may also specify a number of questions or comments to automatically affix to the Speaking Time. These designated questions or comments may also have Speaking Time or Response Time (in the case of a question) limits, but these are not required. The Director may rule any Motion to Set Speaking Time dilatory. This motion requires a simple majority. Any delegate may make this motion between formal speakers in an effort to change the Speaking Time.

Motion to Close the Speaker's List

The Speaker's List may be closed upon a motion from the floor. Permission to speak will be accorded to one speaker for and one speaker against, and a two-thirds majority is required for the motion to pass.

Motion to Suspend the Rules for the Purpose of a Moderated Caucus

This motion must include three specifications:

- a. Length of the Caucus
- b. Speaking time, and
- c. Reason for the Caucus.

During a moderated caucus, delegates will be called on to speak by the Committee Director. Delegates will raise their placards to be recognized. Delegates must maintain the same degree of decorum throughout a Moderated Caucus as in formal debate. This motion requires a simple majority to pass.

Motion to Suspend the Rules for the Purpose of an Unmoderated Caucus

This motion must include the length of the Caucus. During an unmoderated caucus, delegates may get up from their seats and talk amongst themselves. This motion requires a simple majority to pass. The length of an unmoderated caucus should never exceed twenty minutes.

Motion to Suspend the Meeting

This motion is in order if there is a scheduled break in debate to be observed. (ie. Lunch!) This motion requires a simple majority vote. The Committee Director may refuse to entertain this motion at their discretion.

Motion to Adjourn the Meeting

This motion is in order at the end of the last committee session. It signifies the closing of the committee until next year's conference.

Motion to Table the Topic

If a delegate believes that the flow of debate has become stagnant, he/she may make this motion. To Table the Topic is to halt debate on the present Topic, save the speakers' list and all draft resolutions, and move on to the next Topic on the Agenda. The delegate making this motion may also choose to specify a previously tabled Topic. This motion requires a two-thirds vote to pass. The Topic may be returned to at any time by tabling the present Topic and adding the phrase "for the purpose of returning to Tabled Topic _____," to this motion. If no Topics have been previously tabled, debate must follow the established Agenda. This motion is to be used sparingly.

Points of Order

Points of Order will only be recognized for the following items:

- a) To recognize errors in voting, tabulation, or procedure,
- b) To question relevance of debate to the current Topic or
- c) To question a quorum.

A Point of Order may interrupt a speaker if necessary and it is to be used sparingly.

Points of Inquiry

When there is no discussion on the floor, a delegate may direct a question to the Committee Director. Any question directed to another delegate may only be asked immediately after the delegate has finished speaking on a substantive matter. A delegate that declines to respond to a question after a formal speech forfeits any further questioning time. The question must conform to the following format:

Delegate from Country A raises placard to be recognized by the Committee Director.

Committee Director: "To what point do you rise?"

Country A: "Point of Inquiry."

Committee Director: "State your Point."

Country A: "Will the delegate from Country B (who must have just concluded a substantive speech) yield to a question?"

Committee Director: "Will the Delegate Yield?"

Country B: "I will" or "I will not" (if not, return to the next business item)

Country A asks their question (it must not be a rhetorical question.)

Country B may choose to respond or to decline. If the Delegate from Country B does not yield to or chooses not to answer a question from Country A, then he/she yields all remaining questioning time to the Committee Director.

Points of Personal Privilege

Points of personal privilege are used to request information or clarification and conduct all other business of the body except Motions or Points specifically mentioned in the Rules of Procedure.

Please note: The Director may refuse to recognize Points of Order, Points of Inquiry or Points of Personal Privilege if the Committee Director believes the decorum and restraint inherent in the exercise has been violated, or if the point is deemed dilatory in nature.

Rights of Reply

At the Committee Director's discretion, any member nation or observer may be granted a Right of Reply to answer serious insults directed at the dignity of the delegate present. The Director has the ABSOLUTE AUTHORITY to accept or reject Rights of Reply, and the decision IS NOT SUBJECT TO APPEAL. Delegates who feel they are being treated unfairly may take their complaint to any member of the Secretariat.

Working Papers and Draft Resolutions

Once a Working Paper has been submitted, approved, distributed, and formally introduced to the body, it can and will be referred to as a "Draft Resolution." In order for a Working Paper to be submitted to the Committee Director, it must be in correct format and bear the names of a combination of a number of Sponsors and Signatories necessary to introduce, as determined by the Committee Director.

Sponsors are the writers of the Working Paper, and agree with it in its entirety. They should be able to vote 'yes' for the paper during voting procedure. Signatories are those delegates interested in bringing the Working Paper to the floor for debate, but do not necessarily agree with its contents.

A delegate can motion to discuss the working paper during a moderated caucus or unmoderated caucus. A delegate can also motion for an author's panel, which is essentially a moderated caucus moderated by the authors. It is the chair's discretion on the maximum amount of authors allowed on the author's panel.

Friendly Amendments

Friendly Amendments are any changes to a formally introduced Directive that *all* Sponsors agree to in writing. The Committee Director must approve the Friendly Amendment and confirm each Sponsor's agreement both verbally and in writing.

Unfriendly Amendments

Unfriendly Amendments are any substantive changes to a formally introduced Directive that are not agreed to by all of the Sponsors of the Directive. In order to introduce an Unfriendly Amendment, the Unfriendly Amendment must have the number equivalent to 1/3 of Quorum confirmed signatories. The Committee Director has the authority to discern between substantive and nonsubstantive Unfriendly amendment proposals.

Plagiarism

GatorMUN maintains a zero-tolerance policy in regards to plagiarism. Delegates found to have used the ideas of others without properly citing those individuals, organizations, or documents will have their credentials revoked for the duration of the GatorMUN conference. This is a very serious offense.

Motion to Close Debate and Voting Procedures

A motion to close debate may only pass with a two-thirds majority. Once this motion passes, and the committee enters Voting Procedure, no occupants of the committee room may exit the Committee Room, and no individual may enter the Committee Room from the outside. A member of the Dias will secure all doors.

Once moving into voting procedures chair can only accept these motions:

- A point of order to correct an error in procedure
- An appeal of the decision of the chair
- A motion for division
- A motion for roll call vote
- A motion for adoption by acclamation
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No talking, passing notes, or communicating of any kind will be tolerated during voting procedures.

Each Draft Resolution will be read to the body and voted upon in the order which they were introduced. Any Proposed Unfriendly Amendments to each Draft Resolution will be read to the body and voted upon before the main body of the Draft Resolution as a whole is put to a vote. The Committee will adopt Directives and Unfriendly Amendments to Directives if these documents pass with a simple majority. Specialized committees should refer to their background guides or Committee Directors for information concerning specific voting procedures. Unless otherwise specified by the Secretariat, each Committee may pass as many resolutions as it agrees are necessary to efficiently address the Topic

Delegates who requested to be noted as "Present and Voting" are unable to abstain during voting procedure. Abstentions will not be counted in the tallying of a majority. For example, 5 yes votes, 4 no votes, and 7 abstentions means that the Directive passes.

Roll Call Voting

A counted placard vote will be considered sufficient unless any delegate to the committee motions for a Roll Call Vote. If a Roll Call Vote is requested, the committee must comply. All delegates must vote: "For," "Against," "Abstain," or "Pass."

During a Roll Call vote, any delegate who answers, "Pass," reserves his/her vote until the Committee Director has exhausted the Roll. However, once the Committee Director returns to "Passing" Delegates, they must vote: "For" or "Against."

Voting with Rights

During a Roll Call vote delegates may vote "For with Rights" or "Against with Rights." Delegates will be granted 30 seconds to explain their reasons for voting for or against a draft resolution. This time will come after the tabulation of votes.

Delegates should use this option sparingly. It is meant for delegates who feel that their vote may seem off policy, despite it being correct. The acceptance of rights is up to the director's discretion. If a speaker goes off topic during their allotted time the director will rule their speech dilatory and move to the next motion in order.

Accepting by Acclamation

This motion may be stated when the Committee Director asks for points or motions. If a Roll Call Vote is requested, the motion to Accept by Acclamation is voided. If a delegate believes a Directive will pass without opposition, he or she may move to accept the Directive by acclamation. The motion passes unless a single delegate shows opposition. An abstention is not considered opposition. Should the motion fail, the committee will move directly into a Roll Call Vote.

Background

The World Health Organization was established on April 7 of 1948 with the following goal statement: "WHO works worldwide to promote health, keep the world safe, and serve the vulnerable. Our goal is to ensure that a billion more people have universal health coverage, to protect a billion more people from health emergencies, and provide a further billion people with better health and well-being." The purpose of the WHO is to lead initiatives regarding the public and to target noncommunicable and communicable diseases throughout the regions found throughout the world. As a committee, they cannot enforce any resolutions unless member states agree on it. Through the organization, initiatives can be led, promoted, and monitored through its various resources. It is currently composed of 194 members from the six respective regions of the world (Africa, the Americas, South-East Asia, Europe, Eastern Mediterranean, Western Pacific). Given the large platform the WHO has, it is able to harness relationships between civil society organizations, the private sector, foundations, and governments.

Without the World Health Organization, some monumental health initiatives would not have been accomplished. By the end of the 1970s, the WHO was able to declare smallpox eradicated. This would not have been successful without collaboration with UNICEF on the Expanded Programme on Immunization. Combating tuberculosis has been another effort that the WHO has partaken in. Through the expansion of treatments, diagnosis, and preventative measures, the WHO has been able to save 53 million lives from tuberculosis. Taking similar measures in the early 2000s has allowed for there to be a drop of 60% death related to malaria cases. Clearly, the efforts of the WHO have been widely successful throughout the international community.

Topic 1: Examining Mental Health Standards in Communities

Introduction

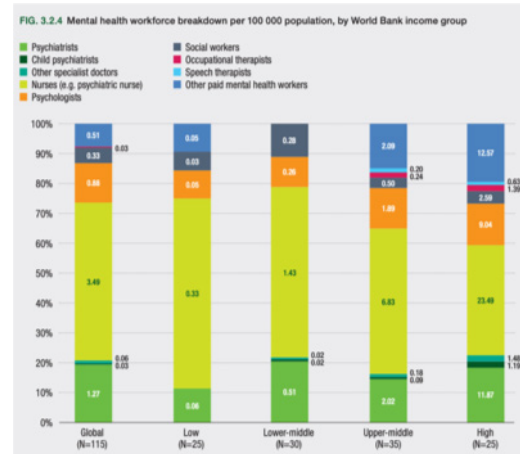
When discussing health in general, the World Health Organization notes in its constitution that it is not simply the absence of disease but a combination of physical and mental attributes that allow for well-being. Mental health, as described by the WHO, is “a state of well-being in which every individual realizes her or his own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his own community.”

There are factors that lead to detriments in mental health, specifically social, psychological, and biological ones. Social factors may relate to any violence or persistent socio-economic pressures. Individuals especially living in conflict zones, such as in South Sudan, Syria, and Lebanon, are especially prone to be facing mental disorders. WHO estimates that almost 1 in 10 individuals living within conflict regions are facing moderate to severe mental disorders, such as depression, anxiety, or psychosis. Other life events that can result in mental detriments are stressful work conditions, gender discrimination, social exclusion, and human rights violations. Certain psychological characteristics are associated with some disorders, and possessing any related ones makes individuals more susceptible to facing mental health challenges. Genetic factors also play a large role in the development of illnesses.

Those who have a family member with mental illness are typically found to have been passed down genes that make them more susceptible. Although an individual's susceptibility to mental illness may be inherited, it does not necessarily mean they will develop it. Factors range from abuse and stress to other traumatic events, all of which can bring about the development of the illness if the person has inherited its respective susceptibility.

In order to understand the severity of the issue of mental health throughout the international community, it is important to note the varying statistics that have been made available by the WHO. It is estimated that by 2030, depression will be the most significant cause of disease burden globally. Currently, there are more than 450 million people that are suffering from mental health-related disorders. Out of these, millions of people, 3 out of every

4 individuals who have developed severe mental disorders are not receiving any treatment. Regarding adolescent and children population, close to twenty percent of the individuals have mental health-related problems. This issue is even greater in low and middle-income nations seeing that they have the greatest percentage of individuals with these issues despite having

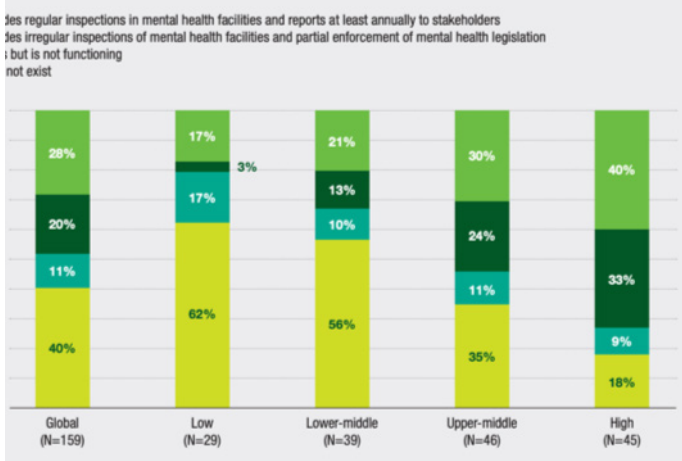


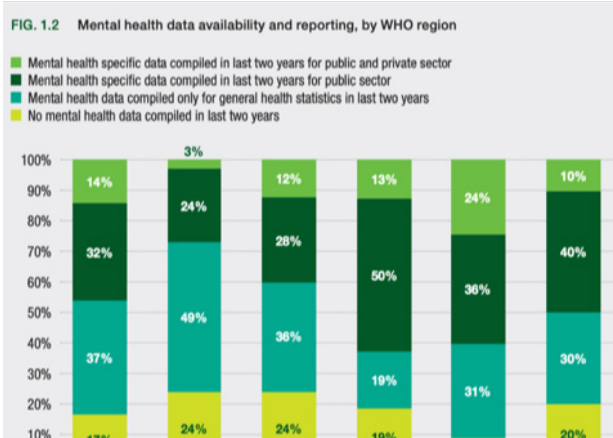
the poorest availability of mental health resources. To put this into perspective, these developing nations only have one psychologist for every one to four million people. Figure 3.2.4 accurately depicts the severity of the situation as the ratios show the number of mental health personnel per 100,000 people. To reiterate a previous point, this issue becomes especially critical during times of war, and other major disasters as the rates of mental disorders tend to double. As one can see, the severity of this issue is uncanny and requires greater attention from the international community.

International Response and History

In 2013, to address the growing severity of the issue, the World Health Assembly decided to launch the "Comprehensive Mental Health Action Plan for 2013-2020." The approval of this action plan was a monumental moment for the international community as it prompted the need for communities to face an issue that has been neglected for years and called upon the international community to address and eradicate the stigmatism and discrimination regarding mental health. The goal that this action plan has made is "To promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity, and disability for persons with mental disorders." WHO has listed four objectives that accompany this overarching goal. The first objective is to allow for more efficient and strengthened governance that allows for the implementation of mental health services. The second objective is to find ways to integrate mental health services in communities in a comprehensive way. The third objective is to execute measures that allow for the prevention and promotion of mental health concerns. The fourth objective is to have nations develop information systems, research, and evidence corresponding to mental health.

One of the most successful outcomes of the "Comprehensive Mental Health Action Plan for 2013-2020" is the integration of the WHO Mental Health Gap Action Programme (mhGAP). This program essentially facilitates the implementation of the Action Plan by having yearly collaborative forums in Geneva and collating resources from throughout the international community. One of the attainments of the mhGAP is the Mental Health Atlas Project. This project was designed to collect information on the 194 member states of the WHO and track their progress in implementing the four aforementioned objectives highlighted within the Action Plan. This project is updated every three years and releases a report on its findings. From the latest 2017 report, some of the key findings are as follows. In regards to the governance for mental health, only 48% of WHO Member States have been able to develop or update any plans or policies relating to mental health in accordance with international human rights standards. Figure 2.2.4 highlights some eye-opening information regarding the existence of compliance entities that assess human rights standards in nations. From this figure, it becomes apparent that from low and lower-middle-income countries that answer the Mental Health Atlas survey, over sixty-five percent of nations do not even have a compliance entity that exists or is functioning.

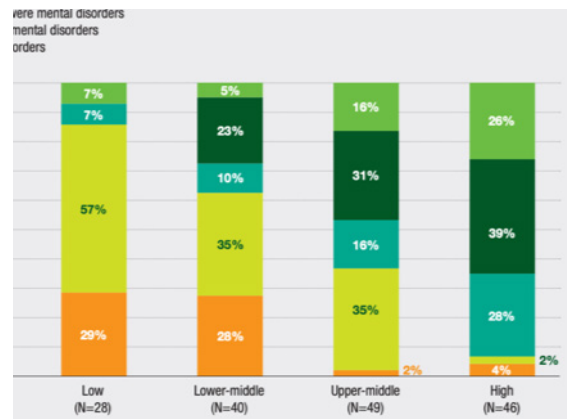




Additionally, the ability of these Member States to implement programs that allow for prevention and promotion tactics in mental health is only at 63%. From this report it is apparent that many of these nations are having difficulty collecting population data corresponding to mental health, seeing that only 37% of all Member States collect very specific mental health data, and another 29% of Member States only collect general mental health statistics. Figure 1.2 shows mental health data availability and reporting on a geographical basis, and it further illustrates the status of this objective.

The 2017 Mental Health Atlas report notes the great disparity of mental health services provided by nations. Figure 4.4.1 compares the support from governments in providing monetary benefits for those who wish to seek mental health services.

From this figure, it is evident that people living with mental disorders in low and lower-middle-class income level nations face the greatest percentage in receiving little to none governmental support in acquiring treatment services.



Key Issues

One of the key issues found within the mental health services industry is the immense human rights violations that occur. In many nations, individuals are faced with limited to no access to mental health care since they live in impoverished communities. In other nations, those who are not offered community-based health services only have the option of going to psychiatric institutions. Community-based health services are typically offered to people living with more severe disorders, such as schizophrenia, borderline personality disorder, and chronic depression. These disorders are typically seen from people in extenuating circumstances, such as poverty and incidents of sexual or physical victimization. However, some of these people are provided services such as subsidized housing, peer support, and employment services, which goes to help them along in the recovery process via community-based health services. It is at psychiatric institutions where many basic human rights are violated by undergoing harsh living conditions and degrading practices. The treatment that is found within these institutions is parallel to how they are treated outside of a medical context. Many are ostracized from any community involvement and are denied basic human rights, like clothing, shelter, and food. Many also face discrimination when trying to obtain housing, employment, and educational opportunities. The repercussions of this discrimination are that individuals who face mental health challenges are subject to entering a poverty-stricken life, therefore, limiting their ability to obtain treatment or even recover.

Additionally, when looking at the furthering of mental health services, one has to look specifically at the causes of discriminatory behaviors against specific mental health diseases. One of the leading causes of discriminatory behaviors against those individuals who are facing mental health detriments is simply the stigmatism associated with it. A component that contributes

to stigmas is the influences that culture play on mental health. Culture and ideals dictate how people manage and treat mental illness. For instance, Asian groups are more likely to keep their personal problems to themselves rather than expressing their distress. This type of ideal may limit this group from seeking treatment and getting the help they ultimately need. Similarly, African Americans, when compared to whites, are more likely to handle personal problems themselves and seek spiritual support. This may prompt them in wanting to seek support from outside medical sources. Essentially, these cultural ideals are what inhibit certain cultural groups from seeking mental health services. Both of these ways of dealing with issues limit discussion on the topic of mental health, therefore, limiting public knowledge of its importance. Additionally, there are different kinds of stigmas that exist. For example, there are also stigmas against mental illnesses stating that they cannot be treated and that individuals are difficult, unintelligent, and incapable of making conscious decisions. A more specific example of stigma in mental health is that against schizophrenia. Individuals who have this disease are typically associated as being violent, unpredictable, and are perceived as dangerous. This results in them being feared by society. However, studies have shown that those “with severe mental health conditions commit a very small proportion of violent crimes and that the widely held prejudices about schizophrenia are inaccurate and unfair.” Stigma and cultural values in mental health are what increases the chances of people being discriminated against, ostracized by society, and not seeking treatment.

Unfortunately, another issue that is associated with mental health in the international community is the prevalence of suicide. The latest statistic is that 800,000 people die as a result of suicide every year. Additionally, studies have shown that after one individual commits suicide, it increases the likelihood of more people committing suicide. It is important to note that seventy-nine percent of suicides occur in low- and middle-income countries. The age bracket that faces the greatest rates of suicide is the 15 to 29-year-old’s making suicide the second leading cause of that age bracket’s deaths. What plays a factor in this uncanny statistic is that only 38 countries have reported in establishing a national strategy that combats and prevents suicides. Some of these programs focus on the early identification and treatment of individuals who are facing substance and mental health disorders. The complexity of suicide would need to require collaborative efforts from multiple sectors, such as justice, politics, media, education, and law, of society in order to create preventative measures.

Furthermore, one of the key issues made apparent in the Mental Health Atlas 2017 report is that there is a great disparity in monetary resources that are being spent on the expansion of mental health services within nations. Increasing access to these services in developing nations is crucial in combating mental illness. Currently, in low and lower-middle-income nations, less than 1 US dollar per capita of government expenditure is going towards mental health. On the other hand, high-income countries spend more than 80 US dollars. A point made by the WHO is that investment into mental health results in good returns for the economy. The WHO states that for every US dollar that is invested in treatment services for frequent mental illnesses, such as anxiety and depression, a monetary return of four US dollars in increased health and being able to work. Currently, the common disorders and nations’ inability to offer access to care and detection has led to a yearly international loss of one trillion US dollars.

Regional Context

Financial resources vary greatly between different regions in the world, as stated before. These resources are imperative in allowing for the development of health services and go towards costs such as training, administration, and promotional activities. Figure 3.1.1 in the 2017 Mental

Health Atlas depicts expenditure per capita and shows that Southeast Asian and African countries have almost twenty times less expenditure per capita. Other disparities, as mentioned before, include the prevalence or lack thereof of mental health workforce personnel only for every 100,000 in the population. From Figure 3.2.1, what can be concluded is that the European regions have the greatest ratio of 50 people in the workforce for every 100,000 as compared to only 11 or less for all other WHO regions.

In the United States, health disparities between different groups are widely prevalent. There are multiple factors that play into this. To begin, those a part of minority groups are less likely to receive or seek mental health services. In fact, in 2015, it was determined that of the individuals who had an illness, 48% of the white population would obtain health services, but this is compared to only 31% of Hispanics and blacks and, 22% of Asians would obtain health services. Another interesting statistic found in the US population is that women are more likely to seek help when dealing with mental health issues as compared to men. The reason why ethnic minorities are less likely to seek these services is dependent on multiple barriers. Some of these barriers include language barriers, greater stigmas within minority populations, and lack of insurance or underinsurance. Another barrier is the distrust in the health care system. This distrust may be rooted in the human rights violations that occurred in the 1900s. For instance, federally-funded sterilization programs occurred in the United States during the 20th century as a form of social control and segregation. These sterilization programs were essentially eugenic measures taken by the government to deal with “undesirable” populations, such as people of color, the disabled, the mentally ill, people with low socioeconomic status, and immigrants.

International and regional data regarding LGBTQ+ individuals are sparse; however, sources from the United States provide insightful information on the social group. Through the study supported by the Council on Minority Mental Health and Health Disparities, it was determined the LGBTQ individuals are two times more likely to face mental health disorders such as depression, anxiety, and substance misuse, than heterosexual individuals. Suicide attempt rates are four times greater for this community and two times greater for individuals questioning their sexuality as compared to heterosexual youth. The rates in considering a suicide attempt are even more severe in the community itself, seeing that it is thirty percent for those who identify as and less than eight percent for individuals of different sexualities. This information is enlightening of the vulnerability of the LGBTQ+ community and is reflective of what other individuals in the international community may be facing.

The mental health care systems around the world are inconsistent and have led to continued human rights violations. One nation in particular, Indonesia, has faced criticism from the Human Rights Watch in March 2016. Due to the lack of mental healthcare, Indonesians facing mental illness are restrained or chained within cells and cages. The Human Rights Watch report describes the unsanitary and inhumane conditions these people live in. These practices are referred to as *pasung* and continue despite being outlawed in 1977. It is not rare that those who are facing poverty have no other option to institutionalize their family members facing mental health issues as there are no other readily forms of treatment. In comparison, other nations like Argentina are praised for having the highest amount of psychologists per capita in the entire world, about 200 to every 100,000 people. The high number of psychologists and people being seen by one can be attributed to the cultural boom that occurred after the fall of the dictatorship in 1955 allowing for quick modernization, which included psychoanalysis. Therapy in Argentina is seen as prestigious and a way for self-improvement, which has allowed the population to be more receptive to accepting mental health care.

Questions to consider

1. What measures can be taken to limit the stigma surrounding mental health in minority populations?
2. How can nations limit the number of undiagnosed cases of mental illness?
3. What can the international community do to bridge the lack of health services that are available to minority populations?
4. How can regional statistics be improved specifically in developing nations to capture the issue of mental health more effectively?
5. What incentives can be created to have governments increase the availability of mental health services where lacking?

Topic 2- Addressing the Implications of Gene Therapy

Introduction

The growth of bioengineering in the past few decades has resulted in the expansion of biomedical sciences in order to help humans around the world through various means. However, there are many ethical implications associated with this expansion that have not been completely considered. The integration of bioengineering technology is prevalent today in agriculture, gene therapy, and medicine manufacturing. Since its adoption, only clinical trials have been approved on using gene-editing techniques on humans (however, some people have taken the technology into their own hands). This research has played a vital role in providing more insight as to how the technology can benefit humans. However, this technology can bring unforeseen risks to society, which can be seen with the costs and providing unnecessary aesthetic modification, which will bring opposition to the implementation of this technology.

Since the 1970s, the growth of molecular biology technologies and techniques has benefited humanity. Enzymatic engineering is an example of an outcome of the growth of molecular biology. Enzymatic engineering has allowed for the mass production of antibiotics. The production of penicillin enzymes, for instance, can be sped up by inserting the penicillin enzyme in the DNA of *E. coli*. Similar to recombinant DNA, penicillin is the outcome of fermenting the penicillin enzyme. The large use of antibiotics has helped combat bacteria, but the unregulated and overuse of antibiotics has resulted in antibiotic-resistant bacteria. The overuse of antibiotics is an example of how the unregulated use of certain practices can result in a larger complication. Complications such as this need to be taken into account when looking at the international use of new biotechnology practices such as gene therapy.



The integration of genome-editing techniques is being used throughout the international community. More specifically, the CRISPR-Cas9, as stated by Your Genome, is a technique that allows for a segment of a genome to be edited permanently. This technology has the ability to alter, add, and remove unwanted sections of DNA, which in turn edits the human genome. CRISPR uses an enzyme known as Cas9 that functions like molecular scissors, which allows for the physical cutting

of DNA sections. The sections that are cut out are then replaced. In order to ensure that the right section of DNA is cut out, then a piece of guide RNA physically guides the Cas9 to the section of DNA that needs to be altered. After the section is removed, the cell recognizes that a portion of the DNA has been damaged and uses its repair mechanisms to fix it. As scientific advancements are made, there are more options available to society. This technology has brought the avenue of editing an embryo, which is much more different than editing a human somatic cell (body cells). If one edits the genome of an embryo (edits embryonic stem cells), then that individual is editing the germline. In other words, the person making the edits isn't just editing the one embryo, he or she is editing all of the generations that come after it. Thus, the person editing the embryo is editing humanity.

The use of gene-editing tools such as CRISPR-Cas9 is to introduce the possibility of removing the existence of disease and illness. When looking at this topic and how it can be used to address health problems, it is important to look at it in terms of both communicable and non-communicable diseases. Communicable diseases are what are known as infectious diseases or diseases that are spread through contact. These types of diseases can usually be treated through medications and prevented through the administration of vaccinations. Non-communicable diseases are known as chronic diseases or diseases that last for an extended period of time and are typically the result of the familial genetic history. Although the symptoms of non-communicable diseases can be treated, inheritable diseases cannot be cured. The appearance of these inheritable diseases is a result of environmental and genetic factors or epigenetic factors. Diabetes is an inheritable disease that can illustrate this concept. One may be genetically coded to express diabetes, but the chances of phenotypically expressing the disease are increased if one has a poor diet, which is an environmental factor. Using CRISPR would theoretically eliminate any chances of the genetic disease expressing itself as the mutation would be completely removed. By eliminating these inheritable diseases, a better quality of life can be achieved. These diseases account for seventy percent of deaths globally and heavily affect developing nations. However, it is important to note that non-communicable diseases affect developing nations as well, specifically cancers, diabetes, and cardiovascular diseases. Inheritable diseases have an effect on all nations as they limit the longevity of people, therefore, limiting the efficiency and development of the nation as a whole.

History

As biotechnology continues to develop rapidly, governments are left susceptible to scientists as they only know what regulations to make after the new technology has been made. The World Health Organization notes the potential this type of technology can have on the international community and has taken strides to continue the conversation regarding any future implementation and regulation of it. One of the most recent actions taken by the WHO is the implementation of an Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. This advisory committee is responsible for looking at any implications that can be associated with genome editing, such as that relating to scientific, legal, social, and ethical challenges. The committee will be essential in providing assistance in the implementation of any type of governance mechanisms that will allow for the regulation of genome editing. Their first meeting was held in March of 2019, and the outcome was three recommendations set by the committee. The first recommendation was to introduce a more structured approach to collecting information regarding any type of future or ongoing research. This is essential as it would allow for transparency within the international community. The second recommendation expresses the sentiments of the committee in believing that "it would be irrespon-

sible at this time for anyone to proceed with clinical applications of human germline genome editing.” The third recommendation provided is to determine the societal views surrounding genome editing. Seeking this type of engagement will allow for there to be a better understanding of the types of genome editing that would be seen appropriate in the region.

There have been other noteworthy summits that have taken place on the international stage, which have highlighted important concerns. The 2015 International Summit on Human Gene Editing looked at the genetic editing from the perspectives of somatic and haploid cells. In regards to somatic cell research, the summit came to the conclusion that it is appropriate for there to be clinical applications of genetically modified cells as they would not result in the altering of future generations. The application of this type of cell editing would be able to follow already implemented frameworks for gene therapy that would allow for its regulation. The summit notes the difficulty in implementing clinical applications of germline editing as it would result in these edits being transferred to future generations. Some concerns brought about are that there may be a risk of inaccurate editing, difficulty in determining possible interactions edits may have with other genetic variants, and that these edits are permanent. All these concerns can have a negative impact on future generations that have inherited an edited genome. Through this summit, it was concluded that the international community should be creating regulations that are standard across all regions and establish what is deemed an acceptable clinical application of this technology. These two objectives will limit activity that does not keep human welfare and health a priority.

The Committee on Human Gene Editing from the National Academy of Sciences came out with a collective study report in 2017 called Human Genome Editing: Science, Ethics, and Governance. This report reflects similar concerns that the WHO and International Summit on Human Gene Editing state. Likewise, the report concludes that the current regulation frameworks available are enough for using somatic cells but not germline cells. It makes a point that there are still too many safety, technical, and ethical issues that can arise during clinical applications of germline therapies. What distinguishes this report is that it gives recommendations regarding oversight systems that should be placed into effect. In the report, seven principles (which are promoting well-being, transparency, due care, responsible science, respect for persons, fairness, transnational cooperation) are highlighted that should be taken into consideration when implementing oversight systems. It is important that these recommendations from various organizations are kept in mind in order to diminish the issue of germline editing.

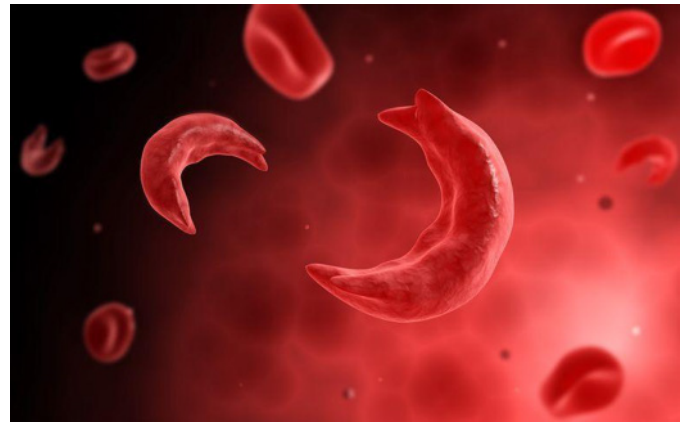
Key Issues

A subject that typically arises from the potential use of the gene-editing tool CRISPR is the possibility of designer babies. Designer babies are babies with genetic sequences that have been selected in a manner that eradicates defects that may be present or ensures that specific gene expression is present. The use of this technology could possibly result in the engineering of a “perfect” human as it could eliminate the presence of unwanted features, such as genetic diseases and physical characteristics. A new term that has resulted from the venturing into genetic engineering of humans is “modern eugenics,” which is defined as “the science of manipulating an individual’s genetic makeup, or genotype, with the intention of altering his or her observable traits, or phenotype.” This new term has resulted in the differentiation between negative and positive eugenics. Negative eugenics is the practice of utilizing genetic engineering to prevent disease, whereas positive eugenics would utilize the same techniques for nontherapeutic purposes, like physical or mental enhancements. Overall, both types of eugenics have the potential

of increasing the health disparities and discrimination found within the world.

An implication with the use of human engineering practices is that it can create a superior human being as it would be "perfect" in every aspect. If scientists one day reach this ability to create a genetically modified viable embryo, then an ethical concern is brought up such that genetic enhancement can result in inequality within societies. Through this type of enhancement, there can be smarter and stronger babies, but as previously stated, such enhancements can open the possibility of discrimination due to socioeconomic gaps. It is important to realize that the accessibility to this technology will be limited as it is newer, and with all new technology, there is unequal access. This means that there would be a distinct difference between those who can afford the technology and those who cannot. This economic divide is what will lead to an ever apparent social gap within society. Those who have the ability to access the technology will be able to extend their lifespans if the technology becomes successful in targeting inheritable diseases, such as cancers and inborn mutations. On the other hand, people who will not be able to afford the technology will continue to face a life full of medical adversity. This divide strengthens the possibility of discrimination and in a way, can redefine what it means to be a human. In the case of a CRISPR-Cas9, people worldwide would have the ability to eliminate the defects within each individual, which has the potential to make those individuals genetically superior to others. A superiority-inferiority complex could arise and lead to further division between communities, specifically developed and developing nations. In turn, this division can limit medical advancements between different societies while also limiting the development of those communities, especially in terms of economic and social development.

Another note to make is that the line between normal and enhanced is hazy. For example, improving musculature, the arrangement of muscles in the body, in people with muscular dystrophy would be helpful, but improving the musculature of those who are genetically disposed to be weaker could be against ethical principles. Any future application of genetic editing techniques would have to take into account the differences between normal and enhanced. If there should be a differentiation between enhancement and disease prevention through the use of gene-editing tools, then the international community should be responsible for defining what qualifies the two different uses. One of the ethical implications that result from using this technology is the thought of what classifies characteristics as being genetically or physically constraining. Of course, genetic diseases would still be seen as physically and mentally inhibiting, but other characteristics such as dwarfism may not be seen that way. Implementing this technology would change the perception of what society sees as acceptable and could lead to discriminatory practices. People could lose sight and appreciation of the key differences between every individual. Eliminating unwanted features would eliminate the genetic diversity within the international community as well. Genetic diversity is imperative to the success of the efficiency of the human race. Without mutations, humans would not be able to adapt to their environments throughout history. An issue with using gene-editing technology on humans is that there would have to be a classification between positive and negative mutations within one genetic framework. Editing all mutations within a human would only make them more susceptible to dying an environment as they are simply not genetically fit for it. For example, when looking at the ev-



er-present debate of antimicrobial resistance, if people were to become basically genetically identical to one another, then there could be new diseases that could wipe out huge masses of people. This is because there would not be enough genetic diversity within the community to adapt and respond. As another example of the potential harm of genetic therapy, one should consider the case of sickle cell anemia. Many would look at sickle cell anemia as an illness since it has certain complications associated with it as it changes the shape of an individual's red blood cells. Thus, many would look at it as an illness that needs to be cured. However, it protects those individuals with sickle cell anemia from contracting malaria so that the supposed illness has actually benefited many people, especially in Africa. Therefore, it can be seen that even illnesses themselves can have pros and cons associated with them, even for something as simple as malaria that occurs due to a missense mutation in DNA. However, also in this perspective, one could see the benefits of using the technology as it could be used to alter the genome in a way that makes it suitable for any particular environment. An implication of this technology is that the use of it can go unregulated and lead to experiments that may not be seen as ethical.

A more recent event in China has prompted the international concerns of lack of regulations in regard to gene-editing humans. In 2018 Chinese scientist He Jiankui before the Second International Summit on Human Genome Editing revealed that he had successfully genetically engineered two twin embryos to be HIV resistant. Additionally, before his announcement of the birth of the twins, he had

already developed 31 embryos with CRISPR present in them. This rogue experiment consists of multiple couples, and thus multiple pregnancies and the incidence of the birth of the 2018 twins is only the first of his experiments. Shortly after, the international community was in an uproar as there are many concerns associated with this type of engineering. Scientific bodies throughout the international



community do not fully support the use of this technology yet, as there is a general consensus that there are still underlying factors that can result in negative generational impacts. These twins that have already been born were genetically modified within the embryonic stage, and thus will pass on their CRISPR modified genes to any children that they have, and so on. That means that this one rogue experiment has the potential to impact many generations to come, despite the fact that scientists are still unaware of the long-term impact this will have on those individuals. This instance brings to light the lack of regulations associated with genome editing. Currently, there is no single standard of regulation that is followed by all nations and restrictions that do exist vary heavily between states. The difference in regulation between China and other nations, like the United States and the United Kingdom, can simply be visualized through the timeline of CRISPR technology utilization. It was only in 2017 when the USA and UK scientific bodies were given the go-ahead to start using the technology, but China had already started years before. It is important for there to be an international standard as to what deems an acceptable use of this technology.

A concern that comes up from the possibility of implementing this type of technology is accessibility. Developing nations do not have the necessary monetary resources and infrastructure to perform any type of genetic service. This type of technology has the potential to improve the livelihoods of individuals within these developing nations facing genetic diseases. In the past few years, the development of point of care devices will hopefully allow for the implementation of these technologies in developing nations. Point of care devices can be described as being “gene therapy in a box,” which essentially eliminates the multimillion-dollar infrastructure needed to deliver gene therapies. This “therapy in a box” simplifies the process of producing modified somatic cells. One of the great benefits of this device is that it requires less staff to run them, which eliminates the issue of lack of scientific manpower in developing nations. Some of the first clinical trials occurred in 2008, where these devices were used to manipulate blood stem cells to encompass a resistance gene that has the purpose of preventing chemotherapy damage to blood cells. These cells were infused in patients who had glioblastoma, one of the deadliest brain cancers, which would allow for higher doses of chemotherapy to be taken. Those patients who were in the earlier stages of cancer and were receiving treatment were living years longer than the average patient with glioblastoma. This example shows how the application of this technology can yield positive health outcomes for those living in developing nations.



The cost of gene therapy plays a large role in accessibility to treatment around the world. To put it into perspective, MIT Technology Review plotted gene therapy prices by eligible patients a year, and the trend that was found was that if the number of eligible patients increased, then the cost of treatment would decrease. From the graph, one can see that Yescarta, a drug that combats large B-cell lymphoma, is the cheapest drug as it has the highest number of eligible patients. The application of CRISPR alongside Yescarta is currently in the works which would allow for the body to more readily accept the treatment and therefore increase the number of patients who would be eligible. This increase in

eligibility would drive down the price of the treatment. What makes CRISPR unique with respect to its ability to increase the eligibility of patients and drive down the costs of treatments is in the technology itself. Older forms of gene therapy require one of a kind proteins that can take an extended amount of time to design, and that cost well over \$1000. On the other hand, CRISPR utilizes RNA to work on damaged genes. The RNA template that is made costs only around \$65 with a starter kit, uses free software, and is available in a matter of a few days. What even makes this RNA more special is that it can be utilized a multitude of times through reprogramming to identify different genes.

Questions to consider

1. How can the international community ensure that these technologies remain available for developing nations?
2. What type of regulations should be created to create uniformity among the international community in regards to gene therapy regulation?
3. Should there be an opportunity to increase the amount of clinical research on germline cells?
4. How can governments and private research companies work together to support the regulation of gene-editing technologies?
5. Should the international community adopt measures to prevent the genetic discrimination of individuals?

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