Introduction

General¹

The goal of healthcare is to cover, either partially or entirely, a person's medical expenses. Access to healthcare can vary by demographic and location, and thus disparities can result in differing access to healthcare services.

Federal responsibilities in regard to this issue entail creating legislation and national healthcare strategies, managing and paying for Medicare, Medicaid, and CHIP, regulating pharmaceutical products and medical technology, and running and subsidizing health insurance marketplaces for private insurance.

Definitions²

- Premium: plan cost
- **Premium tax credits:** a refundable credit that helps eligible individuals and families cover the premiums for their health
- **Deductible**: out-of-pocket amount paid before insurer begins to pay
- **Co-payment**: fixed amount paid for a covered service
- **Benefit**: payment insurance company makes to a provider in case of illness or injury
- **Coverage**: the conditions under which the insurance company will pay
- Network: a largely American concept where a group of medical providers are contracted by insurance companies for the highest payment level



• **Out-of-pocket**: money paid for services than is not covered by insurance

Current Structures in Place³

- No uniform health system and no universal healthcare coverage
- Mix of public and private, for- and non-profit insurers
- **Medicare:** for those 65+ and those with long-term disabilities or ESRD
- **Medicaid:** for low-income families, the blind, and individuals with disabilities
- **CHIP:** for low-income families that earn too much for Medicaid but cannot afford private insurance
- ACA expanding coverage to a marketplace for low- and middle-income individuals

¹ <u>Commonwealth Fund</u>

²<u>Healthcare</u>

Commonwealth Fund

MENTAL HEALTHCARE

BACKGROUND

Mental illnesses can be described as conditions that negatively affect one's "emotional, psychological, and social well-being." These illnesses can manifest in a variety of ways, ranging from depression and anxiety disorders to substance abuse and PTSD.

Their reach is widespread: over a fifth of

adults in America suffer from diagnosable mental illnesses⁴, and adult suicidal ideation rate has continued to climb year-on-year since 2011⁵.

On top of this, many Americans suffer a variety of detriments as a result of mental illness, including sleep deprivation, eating problems, a lack of energy, mood instability, and substance abuse⁶. While these problems can be debilitating, the issue at hand is treatment. When these Americans seek help with their mental illnesses, they run into many societal barriers, resulting in **less than half of those with mental illnesses receiving any mental health care at all**, let alone adequate or appropriate care⁷.



⁴ Nami MHSTATS

⁵ MHNATIONAL

⁶ Mental Health

⁷ Nami MHSTATS

HISTORY

Traditionally, American mental healthcare has ranged from nonexistent to "deinstitutionalized," centered around community or private treatment rather than federally funded support.

Only in the last four decades or so has real progress been made; today, there is an effective treatment plan for nearly every diagnosable mental illness, and delivery of services has become the prevailing issue in the field⁸.

Community Mental Health Act of 1963:

The first use of federal funding for mental healthcare. This provides federal funding for community mental health centers and research facilities in the United States. This legislation, passed as part of John F. Kennedy's New Frontier, led to significant deinstitutionalization. Mental Health Systems Act of 1980: Some presidential administrations have made attempts to prioritize mental health but these groups have been relatively unsuccessful when it comes to yielding universally productive results⁹. However, some useful legislation was written on the basis of the Carter administration's reports: notably, the Mental Health Systems Act of 1980, which provided grants to community mental health centers.

Affordable Care Act: Also colloquially known as Obamacare, the Affordable Care Act defined essential health benefits that required individually purchased health insurance plans to cover mental health and substance abuse services.



⁸The US Mental Health Delivery System Infrastructure: A Primer ²Public Policy and Mental Illnesses: Jimmy Carter's Presidential Commission on Mental Health

TREATMENT

While disjointed and often ineffective, America has a relatively expansive network of mental healthcare providers that serve many communities in different venues. From the more traditional psychologists and psychiatrists in hospitals or outpatient clinics to social workers and nurse practitioners in informal venues, many options exist for the varying severities and symptoms that Americans struggle with¹⁰.

Two of the most common modern treatment avenues for different mental illnesses include **psychotherapy** and **pharmacotherapy**. **Psychotherapy**: mental health counseling within a structured setting with a psychotherapist **Pharmacotherapy:** the prescribing of psychiatric medication used to improve patient quality of life.

Finally, there are other treatment methods that are supplements to the overall effectiveness of the mental healthcare network, like assertive community treatment, which includes support structures like medication delivery and family response training. Treatments like this increase the comfort and ease of delivery of mental healthcare services¹¹.



Types of Mental Health Providers

¹⁰ Nami | About Mental Health Treatment

¹¹ Unite For Sight

PROBLEMS

The American mental healthcare support network is riddled with problematic practices and inefficiencies. Even before a patient visits a healthcare provider, problems exist.

Many Americans that suffer from mental illnesses **go undiagnosed out of fear and stigma against seeking societal assistance**. Certain demographic groups, such as African American and Latino populations, are even more likely to be distrusting of the healthcare system and its practices, which can contribute even more to this issue¹².

Another problem lies in the distribution of mental healthcare providers and the corresponding medication across the country. Specifically, **in rural and impoverished areas, there is often a lack of medical specialists**, including mental healthcare providers, who can effectively serve and meet the needs of the local population. On top of this, many of these areas lack accurate analysis tools to assess the quality and demand for additional mental healthcare¹³. Even in areas that do have access to providers, in some communities, healthcare networks fail to integrate mental healthcare with physical healthcare in a convenient and easy manner.

Finally, due to the privatized nature of healthcare plans in America, **many insurance plans either underfund or dismiss mental illness entirely within their programs**. This is often paired with **higher copayments or lower treatment limits** for those with mental illness, which can cause financial issues for many Americans needing mental healthcare.

On top of this, since mental healthcare isn't integrated into our care network system as well as other forms of healthcare, many insurance and healthcare companies **lack sufficient data** (and, subsequently, analysis) concerning mental healthcare. In order to better care for those with mental illness, many experts advise that **more funding and attention** should be allocated to mental healthcare analysis.



¹² <u>Measuring Disparities across the Distribution of</u> <u>Mental Health Care Expenditures</u>

¹³ Unite for Sight

SOLUTIONS

Firstly, many healthcare professionals bemoan the difficulty and length of the development "pipeline" that new and more effective healthcare practices must go through in order to reach actual patients. Investing in more effective feasibility studies with retroactive feedback mechanisms would streamline the process of implementing new practices, shortening this "pipeline" which is so essential to healthcare development¹⁴.

When it comes to the federal government, which is growing its role in healthcare implementation year on year, there is a lot of room for improvement. Specifically, regarding analysis of regions where mental healthcare is underdeveloped, allocating federal funding towards the use of technology to track practices and to research low-income populations, adaptable care practices would be an effective solution which responds to the needs of underserved communities.

In the same vein, Congress could make more effort into collaborating with private healthcare organizations in order to better analyze the need for highly trained mental healthcare professionals and share information regarding treatments¹⁵.

As mentioned previously, America has a vast, but often disjointed mental healthcare system,

with some communities relying almost entirely on community-based or alternative treatment, while others have plentiful and easy access to modern and institutionalized mental healthcare providers. Integrating existing community resources and sharing responsibilities between overworked specialists and non-specialist general providers would expand coverage and lower the stress on certain parts of the healthcare system¹⁶.

LEGISLATION

Not all of these problems can be tackled at once, but some legislators and third parties are attempting to remedy them with pending legislative action.

Lower Health Care Costs Act: This act can prevent surprise medical bills and reduce prescription drug pricing

Mental Health Services for Students Act: This Act tries to fund schools that collaborate with community mental health professionals in order to better recognize early signs of mental health issues in school environments¹⁷.

 ¹⁴ <u>Biomedical Central</u>
¹⁵ <u>Congressional Research Service</u>

¹⁶ Rural and Low Source Settings

¹⁷ Mhnational

QUESTIONS

- Many of the problems with the mental healthcare system listed here are most likely unsurprising. However, understanding the barriers to mental health treatment is another issue entirely.
 - For example, organizations like the World Health Organization have highlighted a stigma revolving around mental health as their greatest issue. Do you agree? What do you personally think is the most significant barrier to mental health care and why?
- Most of the scientific community has come to a consensus on the effectiveness of psychotherapy and pharmacotherapy, but some exploration is still being done into alternative mental health treatment.
 - Do you think that alternative mental health treatment is viable, either partially or fully integrated with currently utilized treatment methods? Do you have any experiences with either system?
- Mental health and its subtopics have been getting a lot of media and political attention recently, especially in the wake of tragedies like mass shootings that leave questions involving the national mental health situation.
 - However, despite all this discussion, not much headway is being made and statistics continue to show either stagnation or decline in the nation's mental health. Why do you think that the ratio between discussion and progress is so disproportionate?
- Discussions about mental health are often vague and abstract, far removed from personal life. Make it personal: what would it take to encourage you to actively seek out mental healthcare, whether it be in a school, work, or personal environment?
 - In your experience, is there anything school systems can do in addition to what they do now to ensure that their students are in good mental health?

IMMIGRANT HEALTHCARE

BACKGROUND

Naturalized Citizen: after three to five years of living in the United States, immigrants can apply for citizenship and receive all citizenship responsibilities and benefits¹⁸.

Permanent Resident: legal residents who are NOT citizens of the country. This is a prerequisite to apply for citizenship, and can be required through employment, family relationships, or other channels¹⁸

Undocumented Immigrant: a foreign-born person who doesn't have a legal right to be or remain in the United States¹⁹

As of 2012, there were approximately **11.7 million unauthorized immigrants** living in the United States²⁰. 3.7 percent of the total U.S. population and about 5.2 percent of the labor force are undocmented immigrants²⁰. The federal legal barriers to accessing health care have been linked to high rates of uninsured status and poverty for immigrant populations ²¹. Of people who qualify for Medicaid based on their low income, two-thirds of noncitizen immigrants live below the federal poverty line and more than half are uninsured²¹.

<u>HISTORY</u>

According to "Barriers to health care for undocumented immigrants: a literature review", national policies excluding undocumented immigrants from receiving health care were the most commonly cited barriers to health care" ²².



Figure 1: In the noneldery population, 25% of lawfully present immigrants and 46% of undocumented immigrants were uninsured ²³.

Affordable Care Act: while naturalized citizens receive the same access and coverage as U.S.-born citizens, lawfully present immigrants are subject to the individual mandate and related tax penalty, including the five-year-or-more waiting period for most lawfully residing, low-income immigrant adults. Additionally, undocumented immigrants recieve no federal coverage; they are

¹⁸ <u>Explainer: Who Is An Immigrant? | migrationpolicy.org</u>

¹⁹ Who Is an Undocumented Immigrant? | Nolo

²⁰ Facts About Immigration and the US Economy: Answers to Frequently Asked Questions | Economic Policy Institute

²¹ Federal and State Policies Affecting Immigrant Access to Health Care

²² Barriers to health care for undocumented immigrants: a literature review

²³ Health Coverage of Immigrants | KFF - Comprehensive Background Guid

not allowed to purchase private health insurance at full cost in state insurance exchange(s)²⁴.

Personal Responsibility and Work Opportunity Act of 1996: unauthorized immigrants and most authorized immigrants with less than 5 years of US residency cannot receive federally funded benefits²¹.

Health Equity and Access under the Law for Immigrant Families Act of 2021

Findings: "Denying health insurance coverage or imposing waiting periods for health insurance coverage on the basis of immigration status unfairly hinders immigrants' ability to reach and maintain their optimal levels of health and undermines the economic well-being of their families" ²⁵.

POLICY BARRIERS²³

Undocumented immigrants are ineligible for marketplace coverage options (or private insurance options), premium tax credits, or other savings due to their immigration status. Many immigrants, including most lawful permanent residents or "green card" holders, must wait five years after obtaining qualified status before they may enroll in Medicaid or CHIP (Children's Health Insurance Program). Fear, confusion about eligibility policies, difficulty navigating the enrollment process, and language and literacy challenges prevent even eligible immigrants from getting insurance. Without coverage, immigrants rely on "safety net clinics", or and hospitals for care and often go without needed care.



*Figure 3: Of the total U.S. population, 25% are children of immigrants or noncitizens*²³.

EMPLOYMENT



Figure 2: In the nonelderly population, a greater percentage of immigrants are low income in comparison to lawful citizens²³.

²⁴ Immigrants and the Affordable Care Act (ACA)

^{25 &}lt;u>Text - S.1660 - 117th Congress (2021-2022): HEAL for</u>

20 percent of immigrants in the United States live below the poverty line, compared with 16 percent of native-born citizens ²⁰. 49 percent of people in NYS are provided health insurance by their employers²⁶.

Immigrants often have difficulty finding jobs (see graphic above). This puts them at a disadvantage. 20 percent of immigrants in the United States live below the poverty line, compared with 16 percent of native-born citizens²³.

²⁶ How Many Americans Get Health Insurance from their Employer?

QUESTIONS

- Access to healthcare can be the difference between life and death. When care is needed, and is not available to these groups of people, that can risk a life.
 - Do you believe healthcare is so crucial to livelihood? Do you believe it should be a right to all people? Why or why not?
- The Affordable Care Act, ACA, is currently applied to U.S. born citizens and lawful immigrants.
 - Should ACA be expanded to cover undocumented immigrants? Why or why not?
- How can we improve the policies to make the process of being eligible easier for immigrants?
- Many immigrants who come to the United States for the first time face a language barrier, not just in daily life, but also in healthcare.
 - This can go on to become a barrier to access. What are some ways to accommodate the language barrier for new immigrants to the United States?
- Stony Brook's Renaissance School of Medicine has a Home Clinic that is free for any members of the Long Island community to access for free care.
 - This is an example of the safety net clinics discussed earlier that many immigrants rely on. Is this something that should be expanded?
- Overall, what are some policy changes that you would like to see implemented to improve any barriers for immigrants to access healthcare?

HEALTHCARE FOR PEOPLE WITH DISABILITIES

BACKGROUND:

Disability: According to the CDC, a disability is any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them. In summary, the possession of the following qualities may constitute as having a disability.

- Impairments
- Activity Limitations
- Participation Restriction

Disabilities include but are not limited to impairments in: vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships²⁷.

Americans with Disabilities Act: Passed in 1990, this legislation instituted civil rights protections for individuals with disabilities²⁸.

Forced Sterilization: The involuntary removal of individuals' reproductive abilities²⁹.

Eugenics Movement: A late 19th century movement advocating for the removal of "genetically unfavorable" peoples from the human race via strategies like forced sterilization. These practices were aimed against groups who were considered genetically unfavorable i.e. Black and Indigenous people, women in poverty²⁹.

SSDI: Social Security's Disability Insurance (SSDI) Benefits are federally funded by the U.S. Social Security Administration (SSA). Social Security pays disability benefits to persons who have worked long enough and have a medical condition that prohibits them from working for at least one year, or is life-threatening³⁰.

In order to qualify for SSDI, working "long enough" is characterized by having at least 40 work credits. Half of these credits must have been earned in the past decade before the onslaught of the disability. There are discounted credit requirements for younger workers. An individual earns one credit for every \$1150 of income earned, as of 2022.

HISTORY OF RIGHTS FOR PEOPLE WITH DISABILITIES:

The disadvantaged position of persons with disabilities is confirmed by a long history of legislative and judicial decisions that challenged discrimination and exclusion.

Buck vs. Bell (1927): The eugenics movement, which rose to prominence in the late 19th century, called for the elimination of individuals who were deemed "genetically

²⁷ Impairments, Activity Limitations, and Participation Restrictions | CDC

²⁸ <u>Agenda for Fighting Disparities</u> | Health Affairs

²⁹ Early American Eugenics Movement

³⁰ Social Security | SSA

unfavorable.³¹" The court argued that "imbecility, epilepsy, and feeblemindedness are hereditary." These traits were deemed unfavorable; hence, individuals with the potential of reproducing these characteristics in future generations were barred from doing so. In other words, the Buck vs. Bell case allowed for the legal sterilization of inmates. Beginning in the 1960s and 1970s, advocates pressed for the deinstitutionalization of forced sterilization so that children with disabilities could be raised by their families, and adults could participate in their communities with needed services and support. *However, this case still remains legal at the federal level*.

Title V of the Social Security Act (1935):

This act provided resources to all states for services to children with handicapping conditions. "Today, one third of the Title V Maternal and Child Health Block Grant to states must be spent on children with special healthcare needs."

Rehabilitation Act Section 504 (1973):

This Act was the beginning of substantive federal legislation protecting persons with disabilities from discrimination and promoting opportunities for independence and self-determination.

Education of All Handicapped Children Act (1974): This act provided for free and

appropriate public education in the United States, guaranteed to children with disabilities.

Americans with Disabilities Act (1990): Passed in 1990 and amended in 2008, this policy enabled civil rights protections for individuals with disabilities. This was the *world's first comprehensive legislation* on the declaration of equality for people with disabilities. The ADA allowed individuals with disabilities protection from discrimination in employment, programs, and services provided by public entities (including transportation), public accommodations, and telecommunications³².

Developmental Disabilities Act (2000):

The federal government established the Administration on Intellectual and Developmental Disabilities (AIDD) to oversee the implementation of the Developmental Disabilities (DD) Act and Bill of Rights Act of 2000. DD Act programs in every state and territory empower individuals with developmental disabilities and their families to help shape policies that impact them. DD Act programs conduct important research and test innovative new service delivery models. This network of programs serves as a model internationally for collaboration at state and national levels to improve all facets of the lives of people with developmental disabilities.

³¹ Buck vs. Bell | The Embryo Project Encyclopedia

³² <u>Persons With Disabilities as an Unrecognized Health</u> <u>Disparity Population</u>

THE PROBLEM:

People with disabilities are more likely to be in poor health and to seek medical help at a higher rate than people without impairments. They also have a higher rate of secondary conditions and use preventive services at a lower rate than the general population³². Furthermore, issues with care disproportionately affect those with impairments. Existing prejudices among health care providers regarding disability, a lack of adequate training, and a lack of accessible medical facilities, examination equipment, sign language interpreters, and tailored modifications are some of the challenges to overcome.

SUSCEPTIBILITY TO NEGATIVE HEALTH OUTCOMES:



Source: <u>Eliminating Health And Health Care</u> <u>Disparities Among The Growing Population Of</u> <u>People With Disabilities.</u> Health Affairs.

This graphic illustrates that disabled populations are significantly more susceptible to negative health outcomes in the obesity, smoking, and inactivity sectors relative to their able-bodied counterparts.

Barriers For Minority Populations:

There exists "disability-related health disparities" that perpetuate the negative health outcomes that persist as a result of having a disability. Such negative health outcomes, such as the ones relayed in the previous figure, work in tandem with the nuances of intersection. "These are not consequences that inevitably follow the simple fact of *impairment*." People with disabilities (PWD) of color for example, resultantly face many challenges when trying to quality health care like discrimination. It is imperative to recognize such nuances and the difference in experiences in healthcare acquisition for people of varying demographic characteristics like impairment, race, ethnicity, or sexuality. ³³"



Source: <u>Disability Rights Education & Defense</u> <u>Fund</u>

This figure depicts the prevalence of disabilities among certain racial demographics. It is evident that minority groups constitute a significant component of these populations,

³³ Disability Rights Education & Defense Fund

yet are still disproportionately subjected to negative healthcare outcomes.

Income Cap:

"Social Security disability insurance (SSDI) is available to people who can no longer work due to a disability (physical or mental). But only those who've paid taxes into the Social Security system for at least several years are eligible for SSDI. Those who are approved for benefits receive monthly SSDI payments that are determined by their earnings records over the last 35 years (the average amount is \$1,358 in 2022). A person with a disability applying for or receiving SSDI can't earn more than you usually can make no more than \$1,350 (\$2,260 if you are blind) a month by working; this isn't because of an income limit, but rather because the SSA wouldn't consider that person disabled.34"

SOLUTIONS:

Allowing for programmatic access to healthcare in local institutions by incorporating policies and procedures as appropriate could be a plausible solution at the local level. Programmatic access means that the policies and procedures that are part of the delivery of healthcare do not hinder the ability of people with disabilities to receive the same quality of care as other persons. Where usual healthcare practice may impose barriers, modifications in policy or procedure may be necessary to assure access³⁵. Another mechanism is through reframing unconscious biases and stigmas against disabled populations. This targets the attitudinal barriers disabled populations often have to grapple with.

LEGISLATION³⁶:

Disability Employment Incentive Act:

"This bill expands tax credits and deductions that are available for employers who hire and retain employees with disabilities. The bill expands the work opportunity tax credit to include the hiring of employees who receive Social Security Disability Insurance (SSDI) benefits."

H.Res.552 - "Recognizing the importance of independent living for individuals with disabilities made possible by the Americans with Disabilities Act of 1990 and calling for further action to strengthen home and community living for individuals with disabilities."

H.Res.757 - "Expressing the sense of the House of Representatives that Congress should enact the Voters with Disabilities Bill of Rights to establish that voters with disabilities have equal access to the ballot as nondisabled persons."

H.R.5551 - Improving the Health of Children Act

"Specifically, the bill reauthorizes the National Center on Birth Defects and Developmental Disabilities. The center carries out activities to

³⁴ Social Security | SSA

³⁵ Disability Rights Education & Defense Fund

³⁶ Congress

advance the health and well-being of vulnerable populations, including infants with birth defects, children with developmental disabilities, and individuals of all ages with disabilities or blood disorders."

QUESTIONS:

- How would the possibility of overturning Buck vs. Bell contribute to this movement for improving the quality of healthcare for people with disabilities?
- How does education impact the quality of healthcare? Should there be reform in medical/dental education in disability competency?
 - If no, why not?
 - If yes, how would reform in this sector improve healthcare access to disabled populations?
- What can be done on the federal level to alleviate inaccessibility of proper healthcare to disabled populations?
- Which mechanism of alleviating healthcare inequities for people with disabilities do you believe would maximize the impact? Programmatic access at local levels or larger federal legislation? Could one inevitably lead to another?
- How do you think the individual (you and I) can advocate for rights for disabled people in healthcare?