Policy Research in Mental Health Disabilities

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ABSTRACT: Policies surrounding individuals with disabilities that do not function from a deficit lens have been a relatively modern evolution. The once-dominant medical model that was applied as a one size fits all intervention regarded disability as a pathology warranting treatment. With the advent of new and more inclusive policies and legislature, disability studies have become a multifaceted discipline garnering the advocacy and resources it needs to engender change for the population. Outdated treatment models, infrastructure, and resources designed to serve the community are being reassessed through the more contemporary and inclusive lens of societal accommodation. The language surrounding individuals with disabilities has changed to a person first orientation, as there is power in language, and one is no longer relegated to their entire identity being their ability status. Although the stated supports progress and is cause to believe an inclusive society is on the horizon, the marginalization and exclusion of individuals with disabilities within most societal frameworks prevail; the hard work has only just begun. This literature will highlight the disparities and stigma surrounding individuals living with mental health disabilities while highlighting the policies, services, and resources surrounding the population that remain ineffective.

KEYWORDS: Critical disabilities studies, mental health disability and race, policy research and disability, Kendra's Law, Assisted Outpatient Treatment (AOT).

ANALYSIS OF MENTAL HEALTH DISABILITY

Disabilities studies espouse an important truth- the way most individuals understand disability is a lens that has been socially constructed. To accommodate the construct of "normalcy", i.e., ability, disability continues to be framed as a deficit to be remediated. The emerging discipline of critical disabilities studies provides further edification on the social construct and systemic constituent of disability- how societies and institutions "dis-able" an individual (Horejes, 2013). The United States has long prided itself on being a country that offers liberty and justice for all, equal opportunity, and equity regarding access to resources. One can only presume quality healthcare, which can arguably be considered a basic human right would be accessible to all citizens in a country touting the stated entitlements. Such also suggests that mental healthcare, a tremendous yet often overlooked constituent of healthcare, is a resource that all have equal access to. Disappointingly, yet unsurprisingly, it is not. One can confidently say that there is no better way to perpetuate stigma and ignorance than to avoid engaging in conversations about an uncomfortable subject. Conversations surrounding mental illness, and mental health needs in general, remain uncomfortable for most laypersons. The lack of importance mental health disabilities and general mental health needs are regarded with is a loud example of the societal currency the afflicted populations have (Ben-Moshe, 2011). Arguably, one might say that unless an individual has been affected firsthand or secondarily by mental illness, it is a subject most would rather avoid. The same can be said about the broader topic of disability.

It is difficult to quantify the number of Americans living with mental illness or general unmet mental health needs. Many individuals continue to go without treatment or diagnosis- consequently unaccounted for and resulting in a more conservative statistical tabulation than an accurate projection. Whereas fear of stigma and the subsequent shame in seeking help are still leading causes for one to not pursue mental health services, the leading reason treatment is not accessed is a straightforward one, services are simply unavailable or inaccessible, or are available and accessible, but extremely poor quality. Individuals with more acute mental health disabilities continue to overcrowd criminal justice systems and are one of the largest groups to face housing insecurities. Suffice it to say, surrounding the community of individuals with mental health disabilities, and individuals with less acute needs, but needs nevertheless, policies and legislature fail (Scarbrough, 2018). The suffering populations become oppressed and in more grave cases, dangers to themselves and others within the community.

POLICY LENS

Policy analysis is often inspired by the realization of current frameworks no longer being effective or in some cases the realization that they never were. Regarding policies relevant to individuals living with mental illness, the latter applies, most were never consistent with the needs of the population, nor was what was offered accessible. Though progress can be quantified, inaccessibility

to resources and treatment interventions consistent with needs is a pervasive issue. For many, cost remains a significant barrier to treatment. Mental health providers are often compensated with wages inconsistent with the standard cost of living, causing skilled clinicians to discontinue accepting insurance (if they ever did) nor be willing to work in community settings. Aside cost, other common barriers to service for individuals suffering from psychiatric disabilities are unawareness that community mental health services are available, inundating amounts of paperwork to simply make a preliminary assessment appointment, and depending on where one is located, e.g., the more remote parts of the country, geographical limitations. By comparison, there is a dearth of accessible mental health resources and providers vs. other healthcare services (Langholz, 2014). Reforming healthcare policy is a strategy often employed when fiscal resources are thin; it is an attempt to reallocate existing resources to matters weighted with greater importance while cutting resources allocated to matters considered less important. Mental health resources typically find themselves on the lower spectrum of importance. Following its reform, the Affordable Healthcare Act (ACA) lacked consideration for mental health services and addiction treatment which led to dire implications for individuals suffering from such conditions. What remained as part of baseline mental health coverage was insufficient and difficult to access for a myriad of reasons. As previously stated, mental healthcare providers in community clinics are often paid salaries inconsistent with the cost of living, and what insurance is willing to reimburse for mental health services is also often inconsistent with the cost-of-living wages. Such causes better-skilled clinicians to be unwilling to work in a community setting and unwilling to work with insurance, thus not offering services to a large portion of individuals that direly need them. The engine of inaccessibility is most often fueled by ineffective policies surrounding mental health, and the unfortunate truth of mental health not being held with the same significance that somatic health is (Rochefort, 2018). For beneficiaries, ACA reforms resulted in the termination of previously covered mental health and substance misuse treatment. Treatment resources that were narrow to begin with became almost entirely unavailable.

The failing policies and legislature surrounding mental health have often been designed and implemented in response to a catastrophic event. Established in 1909, Mental Health America (MHA), has been the country's longest-standing advocate for protecting individuals with mental health conditions. A community-based non-profit, MHA pioneered the importance of providing mental health resources for individuals living with mental illnesses. MHA was also a first in promoting the importance of mental health and mental health education. It is disheartening to take stock well over 100 years later and account for how much still needs to be established, as unmet mental health needs have risen to the status of a public health crisis. MHA addresses service issues quite well- their initiatives and action plans are readily accessible on their website. Still, much is lost between policy and the effectiveness of implementation. Although MHA has been a leading institution in developing better policies surrounding individuals with mental illnesses, statistics remain concerning, and in referencing the aforementioned, stats surrounding mental illness are often more conservative than what is accurate. For example, more than 50% of adults living with mental illness do not receive treatment (approximately 27 million), and in the past 10 years, there has been a yearly increase in the percentage of adults with acute mental health needs reporting unmet needs and inaccessibility to treatment. Furthermore, youth and adults alike continue to lack sufficient insurance, this too is an unabated issue increasing yearly, as is the rate of substance misuse among youth and adult populations. The greater disparities are appearing among younger populations. To highlight one example, an estimated 60% of young adults living with major depression are not receiving adequate treatment, even in parts of the country with greater access to resources and fewer barriers to accessibility (Mental Health America, 2017). In speaking to the disconnect between policy and the effectiveness of implementation the same can be said for the National Alliance on Mental Illness (NAMI), the nation's leading grassroots organization dedicated to improving the life quality of individuals living with mental illness (National Alliance on Mental Illness, 2021). Complimenting the nation's two greatest authorities and governing bodies on mental health, countless non-profits and clinical settings work tirelessly to affect change and bridge substantial gaps. Yet with the demand for mental health services being higher than ever, the same inadequacies barriers persist.

GAPS IN SERVICES AND RESOURCES

Historically, the policies and legislation surrounding individuals with mental illness have fallen short in lending the population socioeconomic or sociopolitical power; policy design and legislature have hardly been inclusive or empowering. Social work practice looks at systems and the individual as a compilation of those systems. Social work models are traditionally person-first oriented (CSWE, 2015; NASW, 2021). In speaking to disability accommodation standards, interventions rely heavily on the medical model, a model that often pursues "fixing" rather than accommodating. Stigma prevails and the opportunities for individuals with mental illness to be part of the conversations pertinent to their needs remain thin. So does accessibility to effective resources such as treatment- a resource that should be considered a human right for one with a mental illness. The scope of treatment in application to individuals with mental illness must continue to advance and include hybridized models to not only treat pathologies that present secondarily to diagnosis but highlight the positive attributes of what one can do successfully notwithstanding the diagnosis they carry. The societal understanding of mental illness must change as well. Accurate and comprehensive information for laypersons not affected by mental health challenges must improve, as ignorance and inaccurate information are pervasive and perpetuate stigma. Many continue to suffer without treatment because of the social stigma attached to mental illness, and the subsequent shame in taking those first steps to pursue treatment creates internal barriers.

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ASSISTED OUTPATIENT TREATMENT (AOT)/KENDRA'S LAW

Successful policies such as Kendra's Law have positively impacted mental health treatment for individuals with more acute needs, yet services offered under Kendra's law are often underutilized and not accessed until something catastrophic has happened. Implemented in November 1999, New York State law affected Assisted Outpatient Treatment (AOT), granting the courts the authority to require individuals meeting certain mental health criteria to adhere to court-ordered medication management. Championed by the parents of Kendra Webdale, the victim of a crime perpetrated by an untreated and acutely mentally ill individual, Kendra's Law was implemented in effort to reduce the recurrence of such crimes. Kendra's Law proposed to increase the safety and life qualities of individuals living with more acute mental illnesses and the civilians they share community settings by assisting in treatment management. Whether reforms dictated under Kendra's Law have achieved their goal of improving life quality and increasing safety vs. providing patchwork over a damn that will inevitably break, remains a conflict of spirited debate between doctors, policymakers, and auxiliary mental health providers. Concurred by both critics and supporters alike, the legislature outlined by Kendra's Law is underfunded and underutilized, leaving both those afflicted by acute mental illness, and the residents they share community settings with vulnerable. Currently, 46 out of 50 states have some type of AOT program, and whereas parole officers and doctors can initiate the proceedings, the onus of care and initiating such processes is frequently on family, who commonly report not knowing about such programs. Furthermore, AOT can only be implemented after an individual has been deemed by the courts as non-compliant with treatment, and most often non-compliance is substantiated by an act of crime secondary to mental illness, and/or a history of criminal behavior secondary to mental illness, i.e., too little, too late in several cases (Perlin, 2003). New York has been innovative in providing resources and programs consistent with policy and legislation. New York, the greater metropolitan area, in particular, boasts several community centers, clinics, and hospitals where consumers can have their needs met in dignified settings, yet the broader and mercurial issue of an individual finding themselves on an AOT order, is often an individual that has previously been failed by the system.

DISPARITIES OF RACE IN MENTAL HEALTH DIAGNOSIS AND TREATMENT

The history of racism remains ubiquitous within all American systems. Mental healthcare services are no exception and remain even more dire and inaccessible for black Americans, and the broader black, Indigenous, people of color (BIPOC) community. Throughout history, black Americans have been attached to more severe (thus more stigmatizing) diagnoses than their white peers such as sociopathology, schizophrenia, and other Axis 1 pathologies. For example, during a time when homosexuality was recognized as a mental illness, it was more likely for a black American or an individual identifying with the BIPOC community to carry the diagnosis which at the time was one of the more stigmatizing pathologies (Russell & Fish, 2016; American Psychological Association, 2013). The stated history is part of the foundation that has contributed to the systemic racism that prevails to this day. Inequities of racism are further compounded by a lack of socioeconomic and sociopolitical power- resources that those with more serious diagnosis attachments are less likely to have. In comparison to white peers, findings from recent research through the Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Survey on Drug Use and Health (NSDUH) found that close to 40% fewer adults identifying as part of the BIPOC community with mental health needs received services within the timespan of a year, while the Center for Disease Control and Prevention's (CDC) Youth Risk Behavior Survey supports a close to 50% increase in attempted suicide for youths identifying as BIPOC by comparison to white youths (Center for Disease Control and Prevention, 2020; Substance Abuse and Mental Health Services Administration, 2021).

Mental health advocacy groups within the public, private, and non-profit sectors are beginning to take a closer look at the historical context of mental illness and racism to engender change and improve equity surrounding mental health services and accessibility (Aneshensel, 2009). One cannot overlook historical racism, as it must be addressed to effectively analyze mental health through a critical disability policy lens. It is paramount for equality and equity to be the greatest engines of policy design and amendment surrounding disability. For example, amending policies to be consistent with current social movements surrounding equity, diversity, and inclusion by recognizing the position oppression and inequity have held within our culture for far too long, confronting the disenfranchisement the stated has caused, and declaring through new and more importantly, advanced policies and legislature to allocate power and resources equitably. Within educational, healthcare, and community settings, the just treatment of individuals with mental health conditions is a public health and civil rights issue that must be responded to on a national level. The path to true equity and equality will be arduous. Education with a focus on mental health intersectionality and policy amendments surrounding mental health as a disability are paths to eradicate systemic disparities. Furthermore, enough cannot be said about the advocacy of allies in lending their power to vulnerable groups.

IMPACT OF COVID-19

COVID-19, a global crisis, has created a nationwide state of emergency and a high demand for mental health services. Mental health and services linked to treatment that could once be placated and held with moderate at best importance can no longer be ignored or treated with the lowest effort possible. In the wake of COVID-19, it has become apparent that healthcare providers cannot keep their focus solely on physical illness, mental health needs must be held with the same weight and mental healthcare providers must be

held with the same esteem. Equality of importance within the healthcare community alone is hardly enough. Education paradigms must expand as well to incorporate mental health education into the physical education/health curriculum. During the global shutdowns, such knowledge and resources would have been a tremendous benefit to children and adolescents experiencing isolation, significant mental health challenges, and dealing with the traumatic losses many endured. Without question, adults would have benefited from such knowledge and resources as well. In speaking to COVID-19, long-COVID and disability benefits are something to consider. Long-COVID presents as chronic symptoms of COVID-19, surpassing traditional periods when viral symptoms abate. Tests may or may not support a negative result, though symptoms persist, with severity being individualized. Whereas long-COVID is not a mental health issue (although cognitive impairment is consistent in many cases) it is becoming a prevalent enough health condition and one that presents with a significant amount of conflict in accessing disability benefits. Because COVID-19 and its subsequent long-term effects are ills being dealt with for the first time, relevant policy and legislature surrounding protocols and disability benefits have been fluid and unclear (Haque & Stein, 2020). What appears to be consistent, are the traditional barriers surrounding access to benefits and services, and the perpetuation of the afflicted party, often one in dire need, having to go without care or relegation to poor care.

SUMMARY

The policies and legislature surrounding disability are comprehensive and designed to protect and empower individuals living with disabilities. They are designed to create fuller life experiences abled peers are privileged by and can be edifying (and humbling) for abled peers in providing insight into what living with a disability means. Accessibility and reasonable accommodations provide modifications to standard practice intending to create inclusive experiences and equal opportunities for those with diverse needs. Ability is fluid and establishing a sense of sameness for individuals with diverse needs through macro-level policy interventions is where and how sustainable change is generated. It is in implementation that the intentions outlined in policy and legislature are lost. Moreover, continued comprehensive analysis of what constitutes a disability and what constitutes accessibility must be frequently revisited and amended. For example, barriers highlighted such as cost, insurance disparities, and the dearth of skilled clinicians accessible to those suffering from acute mental illnesses.

Preparing future healthcare providers to understand mental illness through a critical disability lens, must begin by incorporating such content into their baseline curriculum. For example, employing clinical faculty that has experience with the population, required reading inclusive of case studies on the population, and patient/clinician simulated exchanges. An ambitious but attainable objective would be to have such content incorporated into the health curricula within general education school settings. Mental health curriculum must begin at the grade school level (taught with consideration to age and comprehension) and would be an innovative way to bridge gaps and standardize diversity. To lay the foundation of true inclusion and normalization, it is paramount for neurotypical and otherwise typically abled students to understand the plight and needs of their diversely abled peers from as early an age as possible. Despite demand, lack of mental healthcare accessibility persists in engendering the American mental health crisis, the impetus of which is often found in failed policy and legislature; a shameful truth for a developed nation that righteously prides itself on justice and equal opportunity.

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