



Disability Stigma and COVID-19 Response: Impact of Early Resource Allocation Policies and Recommendations for Countering Stigma in Public Health Crisis

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ABSTRACT

This paper examines the intersection between disability stigma and early responses to the COVID-19 pandemic in the United States. We begin with a key text, the Department of Human Services Office of Civil Rights's Bulletin, the document which provided initial guidance on an inclusive response to crisis, and analyze the central role of disability stigma in the creation of disability-conscious pandemic management. Next, we discuss several early stigma-based resource allocation policies, and note ways that disability stigma negatively affected disabled people at the onset of the pandemic. Finally, we suggest three interventions to reduce disability stigma on an individual, organizational and system level.

Keywords: Disability stigma, COVID-19, crisis response, countering stigma, social model of disability

INTRODUCTION

As a biosocial phenomenon, disability presents a particular challenge to the management of a national crisis and global pandemic. In a biomedical sense, disability may be understood as a medical condition that requires medical resources, which are often scarce during a pandemic. From a socio-political perspective, disability may be conceptualized as a set of culturally determined circumstances impeding the well-being of an individual or group. This second conceptualization of disability is known as the social model of disability. Employing this notion of disability, this paper analyzes the early response to the COVID-19 pandemic in the United States in order to show that disability stigma has been an integral, if not the central, element of the early emergency response to the pandemic in the United States. Further, the paper engages the social model of disability as a framework for countering stigma in the present or future public health crisis.

Section I of the paper examines the intersection of disability and COVID-19 pandemic in the context of disability stigma. In this section, we first analyze a key document issued by the

Department of Health and Human Services Office of Civil Rights and thereby establish that stigma was central in the government's framing of its early guidance on the management of the pandemic. We then show how rationing policies established by several states in the early months of the public health crisis institutionalized disability stigma. Section II introduces the social model of disability as a framework for countering stigma and proposes three evidence-based practices as preventative actions for future national health crises. In this paper, we use the terms "disabled people" and "persons with disabilities" interchangeably to honor both the identity-first and the person-first language preferences.

DISABILITY STIGMA AND COVID-19

Definition of Stigma

Stigma has been defined, variously, as an attribute, as a process, and as a form of social categorization that has a cognitive/affective and behavioral element (Brown, 2013). Goffman (1963) defined stigma as "the phenomenon whereby an individual with an attribute is deeply discredited by...society [and] is rejected as a result of the attribute" (p. 3). Although the concept of stigma has undergone significant shifts since its initial articulation, Goffman's definition continues to be foundational in contemporary stigma research, across disciplinary, cultural, and national boundaries (Blundell et al., 2016; Gormley, 2015; Grue, 2016; Parker & Aggleton, 2003; Thoits & Link, 2016; Werner, 2015). Link and Phelan (2001) criticize the original conceptualization of stigma, on the basis that it is excessively vague and obscures the lived experience of people with

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disabilities. This study considers these critics' views and expands Goffman's definition to include both the process of social marginalization and rejection and the lived experiences produced by exclusionary cultural practices. In this paper, stigma is considered to be a psychosocial condition based on the cultural privileging of certain individual traits and group identities. With this definition in mind, we turn to an analysis of early national and local policy responses to the crisis. We first review the effects of stigma on disabled people as a minority group, in light of the formal guidance, policies, and practices of resource allocation which were to take place at the onset of the pandemic, in the spring of 2020.

Centrality of Disability Stigma in COVID-19 Response

Disability stigma is often rooted in the belief that the lives of persons with disabilities are less valuable than the lives of non-disabled persons. This notion is particularly salient in the early hospital triage policies and practices that promoted disability-based exclusion from life-saving treatments in several U.S. states (Godfrey, 2020; Sabatello et al., 2020). Following many complaints from disability rights advocates, and recognizing the need for disability inclusion in the time of emergency, the Department of Health and Human Services (DHHS) Office of Civil Rights (OCR) issued a Bulletin "to ensure that entities covered by civil rights authorities keep in mind their obligations under laws and regulations that prohibit discrimination" (p.1). The bulletin further reminded the public that the emergency care must be: *Guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else. (p.1)*

Next, the bulletin laid out several practices intended to guarantee the dignity of all people, and that "as resources allow, government officials, health care providers, and covered entities should not overlook their obligations under federal civil rights laws to help ensure all segments of the community are served" (p.2), through provisions that accommodate the needs of the diverse groups of people who may require care during the crisis. For example, the bulletin recommends ensuring that all emergency-related recommendations are delivered in accessible forms and that religious accommodations in treatment are in place.

At the same time, the bulletin points out that there can be restrictions on accommodations - if they "may fundamentally alter the nature of a program, pose an undue financial and administrative burden, or pose a direct threat" (p.2). Further, the bulletin refers to the Public Readiness and Emergency Preparedness (PREP) Act, an act providing immunity from liability for emergency counter-measures that result in a mismanagement of crisis, to highlight that, in the case of private claims, there may be "immunity from certain liability under civil rights laws" (p.2). With these limitations in mind, the bulletin concludes the following: *Being mindful of all segments of the community and taking reasonable steps to provide an equal opportunity to benefit from emergency response efforts, including*

making reasonable accommodations, will help ensure that the emergency response is successful and minimizes stigmatization. (p.2).

Although the bulletin recognized human dignity and the power of civil rights law to uphold that dignity, it also called upon the PREP Act in order to set limits on the implementation of civil rights laws. The bulletin thereby sent a mixed message about the DHHS's commitment to the enforcement of civil rights laws and policies. Nonetheless, in its concluding remark, the OCR endorsed equal opportunity to accessing care and sent a clear message that the minimization of stigma is central to the practice of fundamental principles of fairness, equality, and compassion in COVID-19 response. In other words, the OCR recognized that one of the goals of a just response to the pandemic would be the weakening of stigmatization. In this way, the bulletin recognized stigma, including disability stigma, as an essential barrier to equal access to care and to inclusive emergency management.

Disability Stigma in Early COVID-19 Management:

Rationing

Although the rationing or allocation of medical resources is a common occurrence in contemporary healthcare systems, the global pandemic has highlighted its significance in health care management (Emanuel et al., 2020). Broadly speaking, rationing involves "denying a potentially beneficial treatment to a patient on the grounds of scarcity" (Scheunemann & White, 2011, p. 1625), which may occur on a macro — societal — level and on a micro — individual — level. Macro-allocation includes socio-political decisions on funding a range of public goods, such as education, public health, and healthcare. Micro-allocation decisions occur bedside and involve deliberations on resource allocation for a particular patient in a particular circumstance (Scheunemann & White, 2011).

While conceptually distinct, these two types of allocation are interconnected, particularly in the sense that macro-allocation decisions determine the availability of funds and resources to particular patients. For example, at the onset of the pandemic in the U.S., there were approximately 62,000 ventilators capable of treating complications of COVID-19 (i.e., "full-featured" ventilators) and 684,000 ICU beds for adult use. Neither quantity was satisfactorily meeting the needs that resulted from the growing pandemic. Additionally, the number of trained respiratory therapists and skilled critical care nurses was critically below the number anticipated to be required for a comprehensive response to the growing numbers of patients (Emanuel et al. 2020).

This scarcity of resources can be attributed to both the macro-allocation decisions made prior to and following the pandemic. For example, a 2018 study conducted by Harvard T.H. Chan School of Public Health, the Harvard Global Health Institute, and the London School of Economics, suggests that "many of the policy efforts in the U.S. have not been truly evidence-based" (p.1), and shows that the U.S. spends too much on health administration costs, pharmaceutical costs, and medical staff salaries (Datz, 2018). In addition to such misplacing of the funds, or perhaps because of it, at the onset of the pandemic, the U.S.

was experiencing a serious lack of essential supplies in the Strategic National Stockpile, which is intended to supplement state and local supplies during public health emergencies. This meant a critical deficiency of protective personal equipment for healthcare workers and citizens (Dall, 2020). Similarly to the pre-pandemic context, the onset of the pandemic both magnified the shortcomings of the macro-level health care governance and exacerbated the effects of new restrictions on individual access to scarce resources. For example, the White House's reluctance to use the Defense Production Act to motivate production, centralize purchasing, and coordinate the distribution of full-featured ventilators and PPE deepened the supply crisis, leaving nearly two-thirds of healthcare workers without a sufficient supply of masks (Bernstein & Safarpour, 2020), and leaving most U.S. states, hospitals, and physicians to grapple with micro-allocation decisions on their own (Ranney et al., 2020).

Under the pressures of such a climate of micro-allocation, states and hospitals began to self-regulate the rationing of medical resources as early as April 2020. Their allocation plans, rationing guidance policies, and day-to-day health service practice perpetuated—and exacerbated—the harms that disability stigma causes. For example, early rationing plans in the states of Tennessee, Alabama, and Washington State (Godfrey, 2020; Singh, 2020) explicitly allowed for prioritization based on anticipated or documented duration of need in the case of initial allocation or subsequent recommendations to re-allocate the resource when a patient is expected to use the resources for a greater than initially anticipated period of time. This clause was particularly pertinent to the allocation of full-feature ventilators, which were the first choice in managing COVID-19 symptoms at the onset of the pandemic. Given that persons with respiratory disabilities are likely to a) use ventilators for management of medical symptoms of their disabilities and b) require additional time on them in case of COVID-19 infection, it is fair to say that these rationing plans, at minimum, highlight the importance of disability awareness in resource management. Additionally, when such awareness is lacking, or when the plans disregard the well-being of disabled people, these plans create a pathway for the institutionalization of disability stigma in healthcare policy and medical practice. Unlike policies and procedures that may change in response to the activist and lobbying efforts of disability advocates (as was the case of state policies named above), once institutionalized, stigma is much harder to challenge. Yet its effects are insidious. Through its scope and persistence, stigma may spread fear and heighten anxiety in targeted populations.

We find one example of the extend of the consequences of persistent stigma in a complaint filed with the Office for Civil Rights U.S. Department of Health & Human Services on behalf of the Disability Rights Center of Kansas and the Topeka Independent Living Center, and their constituents. A complainant, Tessa Goupil, a 49-year-old woman with a neuromuscular condition who uses a ventilator, communicated anxiety about the ventilator re-allocation policies, and the fear that “she may even face preventable death” (Disability Rights

Center of Kansas, 2020, p.3). What is more, in their approach to ventilators as mere technological commodities, these re-allocation policies and practices disregard the crucial fact that, for a chronic user, a ventilator is an integral part of their being, and should be viewed as an corporeally integrated technology, rather than as a piece of medical equipment (Reynolds et al., 2020). As disability activist Alice Wong put it in an interview with Ari Ne’eman for his *New York Times* Op-ed, “My vent is part of my body - I cannot be without it for more than an hour at the most due to my neuromuscular disability. For clinicians to take my vent away from me would be an assault on my personhood and lead to my death” (Ne’eman, 2020, p.1). Elaine Godfrey (2020) further documented the commonality of the terrifying fear among persons with disabilities through a number of interviews with persons with disabilities in the early months of the pandemic. A summary of their experience is expressed in the words of one of her informants, Daniel Florio who said that, “It’s exhausting to balance the fear of contracting a deadly virus with the fear that the people who are supposed to care for you may not do so... The stress that we’re under really is a more extreme version of what we already experience... in terms of being undervalued by society” (Godfrey, 2020, para.17). Testimonies like these clearly show that when healthcare management is based on the devaluation of disabled people’s lives, their sense of well-being is deeply endangered, particularly if their lives typically require medical care.

Thus, in rationing policies like these, disability stigma is an integral, if never stated, element of resource allocation priorities which prioritize the securing of adequate resources for non-disabled people, while instilling fear into disabled people. Such policies thereby exacerbate the pandemic-related hardships experienced by people with disabilities and distort disability identity. Both macro-level allocation decisions (made by federal and local government) and micro-level rationing decisions (made by hospitals and medical staff) institutionalized disability stigma into the emergency response to the national crisis, from the very onset of the pandemic. We suggest that such an institutionalization is preventable and that more balanced policies and practices are achievable by adopting strategies for inclusion based on the social model of disability.

COUNTERING DISABILITY STIGMA THROUGH SOCIAL MODEL OF DISABILITY

Stigma and the Social Model of Disability

Disability is often defined in relation to the so-called “models of disability.” The distinction between different models of disability originated from the concept of disability presented by the Union of the Physically Impaired Against Segregation (UPIAS), a disability advocacy group from the United Kingdom which sparked the international disability rights movement in the early 1970s. The idea that there are distinct models or definitions of disability was introduced to the academic audience by the British sociologist Michael (Mike) Oliver.

In the first edition (1983) of his book *Social Work with Disabled People*, a textbook that brought up the need for

disability definitions in human service professionals' education, Oliver presented the two models of disability: the individual and the social. The divergence between the models reflects the conceptual distinction between impairment and disability put forth by the UPIAS. In their view, impairment is a biological characteristic of the body, while disability is a social response to people with impairments. Emphasizing the difference between the biological (or organic) and the social (or constructed), Oliver posited that “disability is a social state and not a medical condition.” (Oliver, 1990, p.3). Based on this proposition, social scientists have since the 1980s been examining disability as primarily a socio-political phenomenon and positing that social change must occur for the environment to become less disabling (Barnes et al., 1999; Barnes & Mercer, 2001). Further, disability advocates have been positioning the politics of disability at the center of public discourse on disability. Stigmatization of disabled people and the effects of disability stigma on each person with a disability are central to these advocacy efforts and a common topic in research informed by the social model of disability.

In this section, we draw on the social science research which prioritizes countering stigma both as a way to highlight the social character of disability and to achieve disability inclusion. We review three tools for stigma reduction under the social model of disability and suggest how these tools may be used to prevent or diminish disability discrimination during a pandemic at a) an individual level through personal interaction between a person with and without disabilities, b) an organizational level through institutionalizing regular disability awareness training for hospital administrators and staff, and c) a national level through the inclusion of disabled people in the creation of the social and political structures that support their participation in the political decision making, including the management of public health crisis.

Personal Interactions

Personal interaction between persons with and without disabilities can reduce disability stigma (Angermeyer & Matschinger, 1996; Corrigan et al., 2001; Couture & Penn, 2003; Gormley, 2015; Kolodziej & Johnson, 1996; Pettigrew & Tropp, 2006). These interactions offer an opportunity for people without disabilities to hear life stories of persons with disabilities and to then recognize the differences and similarities of experiences. These stories need not be illustrations of ‘overcoming’ disability but an opportunity for a non-disabled person to see a person with a disability beyond the negative stereotypes, to relate to them as a person with a life similar to their own (Kolodziej & Johnson, 1996; Gormley, 2015). This strategy is particularly applicable to reducing stigma about persons with psychiatric disabilities (Pettigrew & Tropp, 2006).

It is important to note that the circumstances and conditions in which an interaction is carried out plays an important role in the success of this intervention. Contact attributes that influence attitudes and stigma include frequency, duration, type and purpose of the activity, closeness, power and status differentials, the degree of collaboration, and context (Blundell et al., 2016;

Cerully et al., 2018). Based on their medical needs, persons with disabilities may have frequent interactions with medical staff. These encounters, however, occur in medical settings and are professional in nature and therefore restricted to the types of contact characterized by high power differentials, low degrees of collaboration, and limited closeness. These characteristics are exacerbated in times of pandemic-related resource scarcity and discriminatory allocation practices.

Based on the research on the efficacy of personal interactions to reduce disability stigma, we suggest that during periods of relative stability in public health status, healthcare workers should make concerted efforts to expand the range of interactions with their disabled patients. Through personal interactions that foster closeness and equalize the patient-staff power relations, health care administrators and medical staff can learn about how policies and practices can be made inclusive and respectful of disabled people's experiences. Further, we recommend that medical staff will regularly encourage patients to share their stories detailing their experiences with the systems of care, hospital procedures, and national healthcare policies, particularly during the current pandemic. These stories are likely to lead decrease in disability stigma during pandemic and non-pandemic.

Training Interventions

Training interventions are specific programs that aim to replace myths and stereotypes of people with disabilities with accurate information. Training usually includes presentations, classes, in-service training, and workshops, aimed at changing attitudes. The impact of training interventions has been extensively investigated in the literature. A meta-analysis of 79 studies involving more than 38,000 research participants addressing stigma related to mental health disabilities indicated that education and training programs generate a significant change in both attitudes and behaviors toward people with mental health disabilities (Corrigan, et al., 2012). Psychosocial perspectives or trauma-related explanations that challenge common myths about mental health disabilities have resulted in a more tolerant attitude, more empathy and less desire for social distance than training than training compared to training programs that emphasize biological or genetic explanations of mental health disabilities (Cook et al., 1995; Griffiths, et al., 2013; Haslam & Kvaale, 2015; Kvaale et al., 2013; Lebowitz & Ahn, 2014). Additionally, there is evidence of a positive impact of such training interventions to reduce stigma toward people with developmental disabilities (Seewooruttun & Scior, 2014), stigma relating to people with physical disabilities (Krahe & Altwasser, 2006; Lindsay & Edwards, 2013), and stigmatization of people with HIV/AIDS (Frye et al., 2017).

Given the variety of evidence of the positive influence of training interventions on reducing disability stigma, we suggest that training that aims to dispel disability myths and offer accurate information about disability experience should be regularly carried in hospitals. Such practice would likely normalize an understanding on the part of hospital administration and staff about the equal value of disabled and non-disabled lives in both the times of public health stability and crisis.

Structural Inclusion

Stigmatization and discrimination are social processes that can only be understood in relation to broader notions of power and domination (Gabel & Peters, 2004; Sabatello & Schultz, 2013; Shakespeare, 2006; Williams, 2001). Stigma is linked to the workings of social inequality. When we trace the sources of stigmatization we can identify forces that create and reinforce exclusion of different groups of people in different social settings (Gabel & Peters, 2004; Link & Phaeln, 2001; Sabatello & Schultz, 2013; Shakespeare, 2006; Williams, 2001).

In the context of disability, stigma occurs in a variety of cultures and is characterized by the exclusion of disabled people in participating in society (Gabel & Peters, 2004; Sabatello & Schultz, 2013; Shakespeare, 2006; Williams, 2001). Therefore, it is important to approach countering disability stigma as primarily an advocacy project aimed social, economic, and political change which requires a re-visioning of the hierarchical structures in the broader society, re-structuring social service delivery, and re-valoring social roles of persons with disabilities (Gabel & Peters, 2004; Sabatello & Schultz, 2013; Shakespeare, 2006; Williams, 2001). Further, as Meekosha and Shuttleworth (2016) argue, given that the oppression of persons with disabilities is deeply structural and systematic and efforts towards a social change must go beyond re-designing of legislation and policy. Instead, a society should structure itself to provide equal support and access to all institutions and social practices (e.g., healthcare, education, employment, housing, and recreation) for persons without disabilities ((Hinshaw et al., 2007). A main driver for the creation of this high level of inclusion is parity in power relations with disability service providers. As Brennan (2020) points out, contrary to this well-supported recommendation, the lack of such parity may have been at the root of the exclusionary character of the early pandemic response. In his recent article, he writes, *One of the most common faults has been the failure to genuinely include persons with disabilities in the collective response [to the pandemic]... Policymakers at many levels appear to have reverted to treating person with disabilities as objects of care or control, under mining many of the gains of recent years to enhance citizenship, rights, and inclusion.* (p.7).

We suggest that the inclusion of persons with disabilities and disability advocacy organizations in the policymaking is central to any effort to reduce and eliminate disability stigma on a societal level. Notably, this idea is not novel to this pandemic: to signal the importance of disabled people's participation in establishing social structures, the U.S. disability rights movement has coined the motto "nothing about us without us" over a decade ago (Carlton, 2000). Policy makers regard for this demand would be good starting point for the inclusion of disabled people at the structural level.

CONCLUSION

Disability is often defined as a complex bio-social phenomenon characterized by personal and group experience of stigmatization. Although it is widely present during the time of relative public health stability, disability stigma is particularly

prevalent during public health crisis, such as COVID-19 pandemic. In the United States, in its early response to this national emergency the Department of Health and Human Services Office of Civil Rights has endorsed the central role of stigma in preventing disability discrimination. Nonetheless, many States 'enacted resource allocation policies that were grounded on disability stigma. Although the policies were eventually corrected, stigmatization of disabled persons in the context of resource rationing continued to raise fear in persons with disabilities, particularly those seeking medical care at the onset of the pandemic. In this paper we argued that stigma-based emergency response is reducible and preventable. We suggested three strategies based on the social model of disability – conceptualization of disability primarily as a social construct – which could reduce disability stigmatization in the case of public health stability and national public health crisis, like the one recently caused by the global outbreak of COVID-19. Based on the scientific evidence on strategies for countering stigma, we proposed that at minimum these three interventions should be adopted by governmental and healthcare authorities, hospital administrators and staff, and medical personnel: inclusion of disabled people in political decision making, institutionalizing regular disability awareness trainings, and increasing personal and professional interactions between persons with and without disabilities. Introducing these interventions at the time of stability may reduce stigma-based response at a time of a public health emergency.

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