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Politics of (dis)ablement: The state of disability in the United States of America after the Americans with Disabilities Act of 1990 (ADA)

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Master's in Sociology

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SOCIOLOGIA
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Sociology Department

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Thank you for making this thesis possible.

Alexandre Miedzir

Note to text

2020 marked the 30th anniversary of the passage of the ADA. As a disabled person, this thesis was more than just a research project; it was a discovery and understanding of those who came before me and of a shared struggle that people with disabilities face that is transversal to the spectrum of disability.

I hope this thesis presents itself useful to all those interested in the topic of disability, especially to those trying to make sense of their disabled identities and lives in a non-disabled world.

Finally, I wish that the injustices and inequalities of today continue to press activists, scholars, politicians, public policy, etc., for a brighter and more inclusive future free of misconceptions and prejudices.

While disabilities are invariably physical, a (dis)abling society is a social product.

> *Disability only becomes a tragedy when society fails to provide the things needed to lead one's daily life.*
>
> Judith Heurmann

Resumo

A presente tese é um estudo demográfico e socioeconómico da deficiência nos Estados Unidos da América (EUA), onde os dados são analisados para perceber se as pessoas deficientes ocupam uma melhor posição estrutural na América do século XXI do que no século XX.

Esta tese é composta por três partes. Em primeiro lugar, uma discussão teórica sobre a deficiência como objeto de investigação, bem como sobre a sua construção social e a produção cultural. Em segundo lugar, uma breve contextualização da lei federal de 1990 *Americans with Disabilities Act (ADA)*, Pub. L. 101-336, 104 Stat. 327, a mais importante peça legislativa para as pessoas com deficiência na história americana. Por último, uma análise quantitativa de dados demográficos e socioeconómicos pré-COVID-19 (2008-2018) para melhor compreender a posição atual das pessoas deficientes nos EUA três décadas após a promulgação da ADA.

Pode-se dizer que a ADA alterou a posição estrutural das pessoas deficientes nos EUA, ou será que a lei não correspondeu às expectativas e objetivos? Apesar de alguns avanços significativos, principalmente nas áreas da acessibilidade e mobilidade, os dados analisados na última secção deste estudo mostram que as pessoas com deficiência nos EUA continuam a estar desproporcionalmente sobrerrepresentadas na parte inferior da maioria dos indicadores estatísticos, tal como acontecia antes da promulgação da lei *Americans with Disabilities Ac of* 1990.

Palavras-chave: Deficiência; Pessoas com deficiência; Americans with Disabilities Act; ADA.

Abstract

The present thesis is a demographic and socio-economic study of disability in the United States of America (U.S.), where data is analyzed to understand if disabled people occupy a better structural position in twenty-first-century America than they did in the twentieth century.

This thesis consists of three parts. First, a theoretical discussion of disability as an object of research, as well as disability's social construction and cultural production. Second, a brief contextualization of the Americans with Disabilities Act of 1990 (ADA), Pub. L. 101-336, 104 Stat. 327, the most important piece of legislation for disabled people in American history. Lastly, a quantitative analysis of pre-COVID-19 demographic and socio-economic data (2008-2018) to better understand the current position of disabled people in the U.S. three decades after the passage of the ADA.

Can it be said that the approval of the ADA changed the structural position of disabled people in the U.S., or has the Act failed to live up to its expectations and purpose? Despite some significant advancements, mainly in the areas of accessibility and transportation, reviewed data in the last section of this study shows that disabled people in the U.S. continue to be disproportionally overrepresented at the bottom of most statistical indicators, much as they were before the Americans with Disabilities Act's enactment in 1990.

Keywords: Disability; Disabled people; People with disabilities; Americans with Disabilities Act; ADA.

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1. Disability Theory and Problematics: Its Social and Cultural Dimensions

> We confront historical practices giving particular significance to traits of difference.... Why do we encounter this dilemma about how to redress the negative consequences of difference without reenacting it? (Minow 1990, pp.47-48).

1.1 The social construction of disability

The 2006 United Nations Convention on the Rights of Persons with Disabilities in Article 1 defined disabled people as individuals with "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UN General Assembly 2007, article 1). However, this needs to be broken down and discussed, for not everyone partakes in the same framing of disability[1].

Generally assumed as a stable, unchanging, and concrete category, history, however, reveals disability as a "highly mutable" and "dynamic" evolution of social identities and roles (Longmore 2003, p.239). As with all identities, the construction of disability and a 'disabled identity' is not a stable process. A distinct heterogeneous minority group, disabled people share, however, a common history and experience of oppression that is unique to disabled people (e.g., Oliver 1990, p.70; Richard & Hennekam 2021, p.2; Santuzzi & Waltz, 2016; Schur et al. 2013, p.2)[2]. It is only natural then that our research starts by defining disability, dissecting its material and social aspects, and discussing existing analytical models capable of studying disability at the intersection of these dimensions. In that sense, the object of disability

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[1] Throughout this thesis 'disabled people' will be the preferred term over 'people with disabilities'. Although it cannot be said one is right, I agree with Michael Oliver when he states that the term 'people (or person) with disabilities' misrepresents the experience of being disabled. While the term 'people with disabilities' attempts to assert the value of the person before the individual disability, the reality is that disability, "far from being an appendage" is "an essential part of the [disabled] self". In this view, separating the person from the body "flies in the face of reality" as it dissociates experience from identity in a harmful idealization of what being disabled and having a disabled identity implies. The term 'disabled people' will thus be used to characterize the group of people that because of their disability (as opposed to having a disability), and societal attitudes towards disability, experience the world in a particular way that is unique to disabled people (Oliver 1990, p.xiii).

[2] Without going into detail defining what identity consists of, as that is not within the scope of this research, identity is approached as a multi-layered product resulting from the intersections between "traits and characteristics, social relations, roles, and social group memberships" in their interpersonal, organizational, and societal factors (Oyserman et al. 2012, p.69).

studies is not the many disabilities per se, targeted by the many medical disciplines/sciences, but instead *disability* as a social phenomenon. It implies not just the recognition of a particular history but also the understanding of disability as a multi-level (individual, household, community, and institutional), multi-dimensional (social, historical, cultural, and political), dynamic (social relations and their change over time), relative (concrete time-space contexts), subjective (particular histories), and objective (measurable activity) experience that determines (regulates and controls) the way society frames disability (see Gordon et al.'s study on stigma and social exclusion Gordon et al. 2017, pp.16-17; see also Davis 1995, p.17)[3]. As Thomson said, "disability is a reading of bodily particularities in the context of social power relations" (Thomson 2017, p.6).

One of the major problems when dealing with disability comes from framing disability as a 'personal tragedy'. Understanding disabled people as tragic victims of nature, accidents, or circumstance reduces the scope of disability and disabled people in the medical sciences to patients, dehumanizing, marginalizing, and ultimately excluding disabled people from the public sphere and society. In this thesis, I will adopt an alternative model of disability that has been developing since the late twentieth century. Capable of addressing in its analysis the several dimensions of disability, as well as of addressing the material and non-material aspects of disability in the dialectical intersection of nature and society, the social model of disability frames disability as a social construction and as a cultural production more than a defect of the body or an individual problem (for epistemological debates of disability see e.g., Finkelstein, 1980; Oliver, 1990; Barnes & Mercer 2010, ch.2; Russell & Rosenthal, 2019)[4].

The advancement of social models of disability in the latter decades of the twentieth century came with important structural changes happening at the macro level in the Western

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[3] Agency likewise plays an active part in socially determining disability. The creation and maintenance of structures or mechanisms that are responsible for disability reproduction turn stakeholders into active actors. While disabled people's self-stigmatization is observable, one should not qualitatively equate voluntary exclusion with social exclusion. Whereas social exclusion is an enforced lack of participation, self-stigma is a coping mechanism to stigmatization and social exclusion, being a consequence of the social organization of disability, not a cause (for more on self-stigmatization see pages 21-23).

[4] I consider it to be relevant to make the distinction between disabled lifestyles and bodies, for even if one's body is not at all times disabled, the anticipation of a possible crisis or manifestation of one's disability can result in limiting one's daily life. The emotional bearing of disability and the anxiety it creates can be as disabling as the disability itself. In this sense, disability is not simply a 'violence of the self' but also the result of structural violence that passively limits one's life (e.g., lack of accessibility or proximity to adequate health centers). Disabled people live thus within permanent structural violence of the body and society, regardless of the active or passive presence of one's disability.

world-system where new epistemologies (post-modernism and critical frameworks), new ways of doing politics (identity politics), the civil rights campaign, new economic models (the rise of the welfare state and neo-liberalism), the rise of communism and labor oriented policies, the outcomes of the World Wars (WWI[5] and WWII[6]) and increasing awareness to war-veterans and disability, the technological development of the media, etc., all impacted in a qualitatively distinct way the socio-cultural and economic fabrics of society. With a growing body of literature and disabled-led activism that pointed at society as a disabling cause, far more than the physical, sensory, psychological, or intellectual restrictions/limitations of the body (Westerholm et al., 2006b, p.1507), Disabled People's Organizations (DPOs) focused instead on a praxis of contentious politics directed at transforming social perception and lobbying for the maintenance of the welfare state. Aware that it was the public perception and collective attitudes that established the limits to care provision, as well as the acceptable demands of those cared for, and the limits of state intervention and service provision —services that up to mid-twentieth century were either inexistent, precarious or profoundly inadequate to comply with disabled people's needs—, disabled people increasingly sought to influence the public debate by de-stigmatize and turning disability visible (Nielsen 2012, ch.4; Susser & Watson 1971, p.35; see also Beatty et al, 2019; Santuzzi & Waltz 2016, p.1118).

Historically, disability rose as a social category with capitalism and industrial society[7]. Institutionalized in the United States by the Revolutionary War Pension Act of 1818 (Nielsen

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[5] For examples of how WWI impacted disability legislation in the U.S., see the National Defense Act of 1916, Pub. L. 64-85, 39 Stat. 166 (https://uslaw.link/#q=Pub.%20L.%2064-85%2C%2039%20Stat.%20166), and the Smith-Hughes Act of 1917, Pub. L. 64-347, 39 Stat. 929 (https://uslaw.link/#q=Pub.%20L.%2064-347%2C%2039%20Stat.%20929), which led to the Federal Board of Vocational Education that later administered veteran and civilian vocational rehabilitation programs. See also the Vocational Rehabilitation Act of 1918, Pub. L. 65-178, 40 Stat. 617 (https://uslaw.link/#q=Pub.%20L.%2065-178%2C%2040%20Stat.%20617). For more on disabled veterans' history and rehabilitation, see e.g., Carden-Coyne, 2007; Gelber, 2005; Hickel, 2001; Linker, 2007; 2011; Stevens & Mettler, 2012.

[6] Wartime efforts during WWII resulted in a unique employment opportunity for disabled people, which positively impacted poverty rates and disability stigma by displaying disabled people as contributors in times of "national crisis" (Nielsen 2012, p.161). For examples of how WWII impacted disability legislation in the U.S., see the Servicemen's Readjustment Act of 1944, Pub. L. 78-346, 58 Stat. 284 (https://uslaw.link/#q=Pub.%20L.%2078-346%2C%2058%20Stat.%20284%20). For more on the not-so-clear relationship between disability and the 1944 Servicemen's Readjustment Act, see Rose, 2012.

[7] While scholars mention that disability as a social category rose with modern societies, this does not mean that disability or disability stigmatization was nonexistent before the eighteen or nineteenth centuries (see e.g., Schur et al. 2013, p.1. See also Braddock & Parish 2001, p.16; Bogdan, 2009; Chemers, 2006) but rather that only with the rise of industrialization did disability become a coherent legal construct as noted by, e.g., Nielsen 2012, p.71; Oliver 1990, p.32-34; Stone 1984, pp.40-41.

2012, p.71)[8] and in the United Kingdom by England's Poor Amendment Act of 1834, which distinguished between the 'deserving poor', those who were unwillingly unable to work, and the 'undeserving poor', those who refused to work, disability was set in relation to production and the productivity capacity of the human body. Being disabled was thus measured in the ability, or lack thereof, to productively partake in the productive process of the emergent urban industrial capitalist society (Oliver 1990, p.32-34; Stone 1984, pp.40-41). This notion, however, has been increasingly contested by disabled authors and DPOs for its narrow reductionism of human value to production, denouncing the detrimental impacts that the capitalist logic of surplus accumulation implies to all those whose bodies fail to comply with the standard physical requirements of machine work, industrial production, efficacy, and profitability. Disabled authors have instead pushed for a redefinition of disability where disability is framed not as a product of a defective body but instead as the result of society's structural organization, its lack of accommodation to non-conforming bodies, and its poorly devised public policies, consequently transferring the onus of disability from the individual to society. In other words, disability is not an individual problem but a political problem (e.g., Oliver 1990, p.60; Russell & Rosenthal 2019, p.133). The formulation of an intersectional social theory of disability aims not only to critically expose the ideological character of Western society in its discriminatory ableist epistemologies, discourses, and practices but also to denounce its collective institutions and organizations for the reproduction of discriminatory social structures that perpetuate disabled people's exclusion from society[9].

By the early 2010s, it was estimated that around one-sixth of the global population was disabled, with the tendency being for it to increase "in all countries" as median ages and lifespans increase, regardless of the level of development of the country (WHO/World Bank 2011, p.35). When more than 1 billion people are disabled, disability stops being a personal problem to become a relevant, albeit silent, social issue, and only with an analysis that deconstructs disability in its social construction, cultural production, and economic constitution

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[8] The first American "disability-specific institution", the American Asylum for the Deaf, was created in 1817 in Hartford, Connecticut. These and other early disability institutions in the U.S. were "part of the wave of evangelical Protestantism that flooded the United States in the early nineteenth century, guided by the mission of using sign language to share Christianity with those formerly isolated from its blessings". As Nielsen said, by the 1850s, deaf culture was "rich and growing" with deaf literacy, education rates, and economic success rates rising significantly (Nielsen 2012, pp.83).

[9] With policy impacting structural elements like built environment, workplace safety, access to welfare and medical care, educational opportunities, etc., framing disability as a bodily consequence necessarily and wrongly eliminates central elements to the conceptual constructions of disability (Schur et al. 2013, p.26).

it is possible to understand the 'nature' of disability (Schur et al., 2013, p.26). As Minow said, "the right to be treated as an individual ignores the burdens of group membership" (Minow 1990, p.48). The social model intersectional plural-disciplinary approach to disability is therefore fundamental since it problematizes the ideological charge of mainstream discourses that would otherwise pass unnoticed, displaying with it the contested field that is disability.

When analyzed historically, it is easy to perceive the "unstable" ideological character of disability as a category (Davis 1995, p.9)[10]. While capitalism did not create impairments or disabled people, there is, however, a qualitatively unique framing of disability that rose in the late eighteenth and nineteenth centuries. The need for a new type of social control that came with the development of new productive dynamics of industrial capitalism and the rapid urbanization rate that followed it, together with a growing bureaucratization, the development of institutions and institutionalization, and the professionalization of society that characterized the expansion of the Western State, turned disability into a social category and 'new' social phenomenon that did not exist before the late eighteenth and nineteenth centuries when disability tended to be cared for by the family and community (e.g., Foucault, 1988; Schur et al. 2013, p.2; Scull 2005, p.29. For a more extensive historical review see Nielsen 2012, ch.4)[11].

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[10] With socio-cultural constructions of disability varying culturally (geographically) and historically (temporally), cross-cultural studies of disability are not always feasible, weakening, if not undermining, the reliability of comparative analysis. This is true not just for international but also for national contexts where a change of categories/definitions can have profound impacts on data collection and interpretation (Barnes & Mercer 2010, p.21, 40; Oliver 1990, p.22; Schur et al., 2013, p.14, 119; Westerholm et al., 2006b; WHO/World Bank 2011, p.209) — for an in-depth discussion of disability models and measurements see Altman 2001; Altman et al., 2006.

[11] In American history, the end of the American Civil War (1861-1865) is considered the tipping point for disability as a social category. This resulted from a conjunction of factors, with some of the most relevant being the solidification of the federal government with the end of the Civil War, the rapid technological development from the Second Industrial Revolution (1870-1914), and the fast-paced urbanization that followed the Industrial Revolution. As cities and the urban population grew from around ten million to about fifty-four million between the 1870s and the 1920s (Nielsen 2012, p.104), so did the concentration of disability and poverty previously dispersed. Overcrowding, poor sanitary conditions and diseases, lack of infrastructure, disabled Civil War veterans, and the dangerously high number of work accidents from the ill-regulated booming industries were far more impactful than the disabling effects of the War (see Witt 2004, p.24), turning disability visible and into a public issue for which the states and the federal government were ill-equipped to deal with. Since post-Civil War disability pensions often failed to cover industrial workers, who composed the majority of the disabled population in America as they were "disproportionately likely to have immigrated into the United States after the Civil War" (Skocpol 1993, p.88), many had no option but to become beggars and or vagrants. Even though the nineteenth century saw a growing development of disability-related institutions in its latter half (1860s-1890s), the reality remained that most disabled people were still living in terrible conditions in institutions like asylums, prisons, and almshouses (Nielsen 2012, p.111). For more on the impacts of the Civil War on disability policy, see e.g., Black, 2001; Black & Song, 2003. For more on homelessness in American history, see Kusmer 2002, especially chapter 3 concerning the 1860s-1880s, the period of rapid urbanization after the post-Civil War America.

The qualitative transformations that American society passed through between the eighteenth and the late twentieth century could be said to have transformed the link between disability and capitalism, as disability passed from being a financial burden to a multi-billionaire business in the late twentieth and twenty-first centuries (Grinker 2020, p.60).

It is this historical and contextual qualitative transformation that turns disability into a social fact (Durkheim, 1982). A complex interaction between structural elements and contingent events, as a social phenomenon, disability surpasses the limits of the personal or the micro. Demanding a framework of analysis capable of framing its social nature without reducing it to a medical sub-discipline, or erroneous ahistorical readings that assume unaltering definitions, disability cannot be studied abstractedly from its historically particular bio-psycho-social and cultural contexts. Narrow abstract and or ahistorical readings simultaneously erase not only the rich diversity of disability as a category but also fail to contextualize the multiple 'disabled experiences' within more general contexts that are fundamental for a proper understanding of the socio-cultural implications of disability, be it from first-hand or second-hand accounts[12]. It is not by chance that the unequal geographical distribution of disability follows a similar trend to the unequal economic relations of the present world-system order. With around 80% of all disabled people being in the underdeveloped areas of Africa and Asia (Westerholm et al., 2006b, p.1508), or the fact that despite having a higher disability incidence, women are generally less likely to receive disability benefits in most countries where disability benefits exist (OECD 2010, p.73), it becomes clear that disability is not independent of the structural consequences of the existing economic order (Oliver 1990, pp.12-13). Even within

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[12] This thesis is framed within the epistemological framework of critical realism, framing the issue of disability in a way that necessarily transposes the limits of the individual (the empirical) to understand the structural position of disabled people as a somewhat shared existence rooted at the intersections of biological and social causal mechanisms that characterize human collective agency (the actual), posing, therefore, disability as a social issue, and, as realized collectively (causal chain), at the intersection of disabled experiences of the world and of a (dis)abling society of sorts (the real). The study of disability is thus more than the collection of individual narratives. It is the clarification of concrete bio-socio-historical here(s) (time(s)) and there(s) (place(s)). This recognition of social models does not imply that disability is not simultaneously micro but that depending solely on micro analyses, an entire dimension, which is fundamental to understanding disability, is lost. Simultaneously, as the study of structures and mechanisms is necessary for the understanding of disability as a category, so too it is equally important to avoid the growing trend of reality's "semiolization" in which the many ontological levels of existence are conflated with language when so is not necessarily so. Disability as a social fact surpasses interpretation or attitudes to be rooted in causal chains which, if ignored or left unstudied, result in theoretical and political heavy prices (For more on critical realism, its ontological organization of the world, and realist interpretation of causation, see e.g., Bhaskar, 1998; Archer et al., 1998; Sayer, 2000. For more on the "semiolization" of reality, see Paulo Netto's class https://www.youtube.com/watch?v=jmAv65ilwwE. See also Sayer 2000, Part I & II).

the United States, it is possible to correlate disability prevalence with poverty incidence, with poorer communities tending to concentrate, despite being underdiagnosed, when compared to healthier communities (for the correlation of disability and poverty incidence, see statistical analysis below; see also Davis 1995, p.24. For the underdiagnosis of disability in impoverished communities, see Grinker 2020, p.61). Disability studies, like other minority studies and current social sciences in general, have thus paid a heavy theoretical price in their "neglect of capitalism and political economy" (Hetland & Goodwin 2013, p.102) — a structural relation that is too obvious to be ignored.

Central to this critical social perspective of disability is the distinction between 'impairment' and 'disability', not only because of its powerful analytical insight into the causes of disability stigmatization and discrimination but also by its utility in determining appropriate targets for collective political action (Schur et al. 2013, p.10; see also Davis 1995, p.25). A distinction that resulted from the political work of organizations like the Union of the Physically Impaired Against Segregation (UPIAS), a central organization for the development of new critical perspectives and contributor to contemporary disability politics, UPIAS was a vocal party in establishing a critical narrative that translated disabled people's experiences (Rice, 2018; see also Schur et al. 2013, p.9). By defining impairment as "lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body" and disability as "the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities", UPIAS explicitly dissociated disability from a personal burden to frame it instead as a social consequence, and the result of the interaction of an impaired body with specific organizations of the environment and society, rather than a defect of the body (UPIAS 1975, p.4). Denouncing the oppressive ableist classical conception of (human) value and its implicit assumption of valuation by the body's productive capacities[13], the social model of disability exposes the classical ableist Western thought of disabled people as those whose non-conforming bodies fail to satisfy productive demands (e.g., Grinker, 2020; Oliver, 1990; Oliver & Barnes 2012; Russell & Rosenthal 2019, p.133). Although it is not always clear-cut the difference between the impacts of body impairments from the impacts of

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[13] Classical economists define value as socially necessary labor time (Marx, 1887). This implies that lower productive outputs result in lower profits, making the employment of non-conforming bodies problematic from a managerial perspective. This, of course, stands in a reasoning that assumes profits as the crux of the capitalist mode of production, accumulation, and business cycles (e.g., Marx, 1887), a hypothesis that more recent statistical and econometric studies have confirmed, e.g., Mitchell, 1913; Tinbergen, 1939; Tapia, 2017.

society in the causal effects of disability production, we must nevertheless strive to evaluate these separately since disability and impairments are not coterminous despite being often impossible to separate both (Schur et al. 2013, p.11).

Western liberal culture often highlights notions of human value on independence, autonomy, individualism, and hard work, positioning disabled people "in direct contrast to American ideals" (Nielsen 2012, p.9), disabled people have been confronted with the challenge of facing a systematic devaluation by design, and of finding meaning in other aspects of their lives than production and productivity. And, while it is not necessarily wrong to point out one's body when speaking of disability, it is the non-recognition of disability as a social circumstance that, in the end, turns bodily impairments into disabilities and impaired people into disabled people when such is not necessarily so. According to the social model of disability, being disabled or unable to participate in society, productively or otherwise, happens when society fails to accommodate impairments, limitations, and/or needs. Disabled scholars and activists have thus pushed for the narrative that disability is a *social experience* derived not from one's impairments but instead from "the specific ways in which society organizes its fundamental activities" (Russell & Rosenthal 2019, p.119)[14]

It was in the wake of this critical understanding of disability, benefitting from a new contentious political paradigm influenced by a new wave of political actors such as the New Left and what came to be known as 'new social movements'[15], together with the crucial influence of disabled-led activist organizations, especially in the late twentieth century, that many disability rights organizations adopted the slogan '*Nothing About Us Without Us*' (Charlton, 1998). Chronically left at the receiving end of policy design and service provision, disabled people pushed in the late twentieth century for inclusion in policy design, research[16],

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[14] A recent case that shows how much disability and its stigmatization is a social relation is the framing of autism. Autism and other aspects of neurodiversity, once stigmatized, are today becoming increasingly valued precisely because of the specificities it implies. As Grinker noted, the stigma of certain impairments, conditions or illnesses varies significantly according to their productivity and economic usefulness, showing how much of a relation, and relative, the social and cultural productions/constructions of disability are (Grinker 2020, p.55). Despite this, social models of disability do not imply that one's body has no impact, for it would be naïve to assume that society is the sole factor of disability. Nevertheless, it is important to recognize the limiting consequences of disabling politics, policies, and design (Schur et al. 2013, p.11; Scotch & Schriner, 1997).

[15] For more on the New Left, see Davis, 2017. For a characterization of 'new social movements', see Taylor & Van Dyke, 2004.

[16] As with other minorities, research has been a contested area within the disability rights movement. With many studies having dubious benefits for the disabled, disabled people face a research paradigm and context in which the benefits do not always compensate for the emotional distress of exposure (Oliver 1990, pp.7-9). With the researcher assuming a privileged position of power over disability narratives, the power asymmetry between the researcher and the object of research has had an

and service provision as a way of tackling the negative stigma of disability dependency, as well as influencing the promotion of better policies and services capable of satisfying disabled people's needs and interests (see e.g., Blanck, 2004; Longmore, 2009; Oliver 1990, p.120; Schur et al., 2013, p.xiii; Scotch, 2001; Shapiro, 1993)[17]. As Nielsen said, disability rights activists sought to "extend the full exercise of citizenship, democracy, and self-determination" that had been continuously denied until the late twentieth century (Nielsen 2012, p.172)[18].

Like other minorities and Indigenous peoples, disabled people and DPOs have in the re-framing and re-telling of disability one of their fundamental challenges and 'weapons' (Nielsen 2012, p.17). The deconstruction of their stigmatized identities and past became an essential

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important historical role in social control and structural violence. From portraying non-conforming bodies and races from savages to second-class citizens, to using minorities and disabled people in unsanctioned experiments, as well as reinforcing the submissive role of disabled people as dependents (e.g., Davis 1983, ch.12). Although researching ethics have evolved (e.g., Milan, 2014; Smith, 2012), the underlying question remains: does disability research satisfy disabled people needs and interests?

[17] American federal policy has historically insufficiently met disabled people's aspirations and needs. Defining disability as the inability to engage in "substantial gainful activity (SGA)", the accessibility to disability benefits is rooted in the understanding that disabled people cannot work. With a historically low hard cap on monthly income ($200 for the better part of the 1970s, $300 for the 1980s, $500 for the 1990s, crossing the $1,000 mark for the first time in 2010 for the non-blind disabled) (https://www.ssa.gov/oact/cola/sga.html), state aid comes with the price of systemic dependency. Today, for one to be qualified for Supplemental Security Income (SSI), one must comply with the requirements of being disabled and having simultaneously "limited income" and "limited resources" not surpassing the monthly threshold of $2,000, or $3,000 for a couple (https://www.ssa.gov/ssi/text-eligibility-ussi.htm). This 'means-test requirement', as Tenbroek and Matson said (Tenbroek & Matson, 1966), prohibits disabled people who need access to public aid from future planning or savings, creating a dependency *by design* and a dependency stigma that is hard to break down when resource accumulation in cash or kind is, by law, impossible. Furthermore, as noted by Morton, the countable resource limit for SSI eligibility ($2,000 for individuals and $3,000 for couples) was set in 1989 and is not inflation-indexed, leading to a progressive decline of the value stipulated by SSI eligibility criteria, resulting in a tightening of the program's eligibility requirements (Morton 2014, p.6). It was not until the 1980s that Congress ordered the elimination of most work disincentives from SSI under the Social Security Disability Amendments Act of 1980, Pub. L. 96-265, 94 Stat. 441, Sec. 1619 (https://uslaw.link/#q=P.L.%2096-265%2094%20stat.%20441; for Sec. 1619 see https://www.ssa.gov/OP_Home/ssact/title16b/1619.htm#ft66; Longmore 2003, p.249). For more on the historically complicated relationship between disability and welfare, see Tenbroek & Matson, 1966).

[18] As noted by Schur et al., the late twentieth century was a tipping point for disabled people, with important landmarks achieved worldwide. A few examples of these are the Americans with Disabilities Act of 1990, the Law of the People's Republic of China on the Protection of Disabled Persons of 1990, the Disability Discrimination Act in Australia of 1992, the Disability Discrimination Act of 1995 in the United Kingdom, the Employment Equity Act in South Africa of 1998, and the Equal Rights for People with Disabilities Law of 1998 in Israel. Finally, by 2006, the United Nations adopted the UN Convention on the Rights of Persons with Disabilities, an important international recognition that has been signed by at least 153 countries (Schur et al. 2013, p.3) — as of August 2023, the U.S. had not yet ratified the UN convention (https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Treaty.aspx?Treaty=CRPD).

political tool and an important element for disabled people's activism in their challenge to orthodox ableist disabling narratives of disability. Aware of this, disabled people and the disability rights movement have highlighted the connection between political activism and social inclusion, stressing the need for disabled people to lead the struggle against their own oppression, segregation, and social exclusion (Schur et al. 2013, p.123). Interestingly, the re-framing and re-telling of disability is not simply a change from biased or derogatory terms to inclusive and/or positive language. A central aspect of redefining and reclaiming language for disabled people is historically including it. With disability being "everywhere in history (…) but conspicuously absent in the histories we write" (Baynton 2017, p.31), either purposefully by elimination or by ignoring it as an irrelevant characteristic/element not central to the story, an important task for disabled scholars and activists lays on 'enlightening' history to the presence of disability, a process that often requires being "creative in (…) keyword searches (…), as well as reading between the lines of discussions of illness, social welfare, activism, vagrancy, and health" (Nielsen 2012, p.17). As Hobsbawm said, in the end, "words are witnesses which often speak louder than documents" (Hobsbawm 1996, p.1).

1.2 Eugenics, social Darwinism, and the disabled: from exclusion to castration, from castration to extermination

> Any person who is diseased, maimed, mutilated or in any way deformed so as to be unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in this city, shall not therein or thereon expose himself to public view, under a penalty of not less than one dollar nor more than fifty dollars for each offense (Chicago 1911, #2028)[19].

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[19] 'Unsightly beggar ordinances' or "Ugly Laws", as popularized by Burgdorf & Burgdorf Jr., 1975, can be found as early as 1867 in San Francisco (Schweik 2009, p.3). Having developed quickly from the 1880s, and in effect until the late twentieth century —despite the municipal enactment having ceased by World War I, the last known "unsightly beggar" was however arrested in 1974 in Omaha, Nebraska (Schweik 2009, p.6)—, the 'unsightly beggar ordinances' were not only a response to disability's growing stigmatization, they were also a response to the economic depression of the 1870s, the worst to date, which had worsened the condition of disabled people and strengthening the correlation between disability and poverty (the post-war economic contraction between October 1873 to March 1879 is described by the U.S. National Bureau of Economic Research (NBER) as the longest-lasting contraction in American history with a 65-month economic contraction (https://www.nber.org/research/data/us-business-cycle-expansions-and-contractions). Although not commonly enforced despite their proliferation, as is usual with city ordinances (Schweik 2009, p.8), the 'unsightly beggar ordinances' remain by their simple approval into law a powerful symbol of disability's institutional discrimination and criminalization, as well as an entry door to nineteenth's

Eugenics (from the Greek εὖ *(eû)* 'good, well', and -γενής *(genḗs)* 'come into being, growing'), a term coined by Charles Darwin’s cousin Francis Galton (1822-1911), is a set of beliefs currently disproven as having no scientific standing (Lifton 1986, p.24). Derived from a combination of social Darwinism, scientific racism, and a combination of proposals based on the new field of genetics, eugenics promoted the idea of race improvement through genetic cleansing of the national genetic pools to promote desirable hereditary traits. Although eugenic practices existed throughout history, it was in the first half of the twentieth century that it enjoyed “its greatest influence” (Spektorowski & Ireni-Saban 2013, p.24).

Eugenics and bio-racial discourses were not just present in authoritarian states or regimes such as Nazi Germany but also in ‘progressive’ countries such as the UK or the U.S. where it strongly impacted society (e.g., Russell & Rosenthal 2019, ch.19; Hawkins, 1997; Hofstadter, 1971). Regarding its impacts on disabled people, the history of eugenics and disability can be overly simplified as *exclusion* from social life since the late eighteenth century with the rise of modern urban societies and their increased regulation of the individual, ‘shutting away’ “those considered not fit for public life” (Nielsen 2012, p.104); to *castration* of the insane, of the ill and of the disabled, of the unfit and the immoral, and those considered to be “degenerates” (see e.g., Laughlin 1922, p.452)[20]; to *extermination*, with Nazi Germany being the paradigmatic case[21]. Eugenics and social Darwinism marked thus, in their (un)‘natural selection’ for a

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century and early twentieth’s century American thought (for a detailed analysis of the ‘unsightly beggar ordinances’ see Schweik, 2009). A previous version of the same ordinance that opens this section had been passed in Chicago in 1881: “Any person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in this city, shall not therein or thereon expose himself to public view, under a penalty of one dollar for each offense. On the conviction of any person for a violation of this section, if it shall seem proper and just, the fine provided for may be suspended, and such person detained at the police station, where he shall be well cared for, until he can be committed to the county poor house.” (Chicago City Code 1881, #1612). The modifications from the 1881 to the 1911 versions show well how disability was increasingly criminalized by public policy with the 1911’s ordinance language being far more radical than the one in effect in 1881.

[20] Laughlin classified the following classes of people as “socially inadequate classes” whose society would benefit from their sterilization: “(1) Feeble-minded; (2) Insane, (including the psychopathic); (3) Criminalistic (including the delinquent and wayward); (4) Epileptic; (5) Inebriate (including drug-habitués); (6) Diseased (including the tuberculous, the syphilitic, the leprous, and other with chronic, infectious and legally segregable diseases); (7) Blind (including those with seriously impaired vision); (8) Deaf (including those with seriously impaired hearing); (9) Deformed (including orphans, ne’er-do-wells, the homeless, tramps, and paupers)” (Laughlin 1922, pp.446-47). For the importance of Laughlin’s contributions to eugenics, see note 22.

[21] Nazi extermination followed five stages: coercive sterilization; infanticide of impaired children in hospitals; killing of impaired adults with carbon monoxide gas, mainly collected from mental

purified national genetic pool[22], the need for disabled people to "justify our very existence" in contemporary society (Russell & Rosenthal 2019, p.223). As Russell said, while capitalism heightened "the production dynamics that devalued the less exploitable or non-exploitable bodies (…) Social Darwinism theorized their disposability" (Russell & Rosenthal 2019, p.36).

Not wanting to expand into the history of eugenics, being it outside the scope of this thesis, it is however impossible to study disability history in the U.S. without contemplating the effects that such philosophies and policies had on stigmatizing and excluding disabled people. Being the climax of a long history of discriminatory disability policies (Schur et al. 2013, pp.1-2), eugenics can also be seen as the rationale that justifies resolving the 'disabling problem' of non-productive bodies. Being presented as a more efficient scientific rationale than the institutionalization of sickness, indigency, and dependency (Russell & Rosenthal 2019, pp.212-213; Nielsen 2012, p.129), bio-racist practices became the highest form of institutionalized violence against disabled people and the 'natural' outcome to the new social control needs of the late nineteenth/early twentieth urban industrial societies. Eugenics and social Darwinism can thus be seen as the sublimation of the late eighteenth and nineteenth centuries' rapid development of urban industrial capitalism. While industrialization "actively generated

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institutions; killing of impaired inmates; and finally, expanding on previous experiments, mass killings in extermination camps (Lifton 1986, p.21).

[22] An example of a pro-Eugenic influent report containing an overview of the chronological list of laws, practices (type of operation and manner of its performance), and data of performed sterilizations up to 1922, as well as suggestions on how to implement, and of the importance of "the right of the state to limit human reproduction in the interest of race betterment" see Laughlin, 1922. Laughlin's report, was the base for the *Model Eugenical Sterilization Law*, a model act for compulsory sterilization that directly influenced the Virginia Sterilization Act of 1924, a state law that strongly influenced the development of eugenics in the U.S. For more on the life and importance of Harry H. Laughlin for the development of eugenics, see Eugenics Record Office's archives https://www.eugenicsarchives.ca/connections?id=5233cfc65c2ec500000000ae.

disability" (Nielsen 2012, p.105)[23], policy actively segregated (institutionalized) and criminalized its victims[24].

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[23] Nielsen's claim that industrialization "actively generated disability" is two-fold: i) industrial work required specific physical standards that were often restrictive as a result of machinery standardization, leading people who did not fit the physical requirements for fast-paced repetitive tasks to be effectively separated from the 'able', to be classified according to the new category of 'disabled' which rose with the capitalist industrial revolution. These new physical requirements effectively narrowed the understanding of physical normalcy to bodies able to participate in the economic process of capital accumulation, reducing disabled people's social roles, resulting in increased stigmatization and segregation of disability (e.g., Finkelstein, 1980; Morris 1969, p.9; Oliver 1990, p.47; Russell, 1998; Russell 2001, p.89; Russell & Rosenthal 2019, p.133; Topliss 1979, p.11). And ii) industrialization, especially American industrialization, came with a high rate of disabling and mortal industrial accidents rates resulting from low labor protection laws (for examples of the precarious conditions of industrial work and life in the nineteenth century, see e.g., Witt 2004, ch.1; Engels 1969). This historical trend persisted well into the late twentieth century, especially in industries like the mining industry or railroads, with more miners dying in Southern West Virginia during WWI than U.S. soldiers on the battlefront (Nielsen 2012, p.169). Similarly, due to WWII war efforts' increasing production speed, the rising rate of disabling and mortal accidents resulted in more than 2 million workers suffering from temporary to permanent disability and/or death, making it "safer for Americans to be on the battlefront than it was for them to work on the home front of the arsenal of democracy" (Kersten 2006, p. 166, see also tables presented in pages 167-168 and ch.6). The heavy industrial disabling accidents rates help as well to explain the growing phenomenon of homelessness in American cities starting in the late nineteenth century. With work-accident compensations being "often woefully inadequate" (Kusmer 2002, p.103), it was hard for families and victims to meet the long-term income loss and increased expenses that disabled households incurred.

[24] Racist ideologies were predominant in institutions making the institutionalization of Afro-Americans, Native Americans, other minorities, and women significantly worse and less regulated when compared with white male-hetero disabled people, with non-white disabled people having greater chances of illness and death after admission (for examples of African-American racist institutionalizations see Hughes 1992, p.456; for examples of ill-treatment of Native Americans see the paradigmatic case of the Canton Asylum (Silk, 1929; 1933; see also Spaulding, 1986); for examples of racist discourses on civilization and insanity in Asian populations see (Shin, 2021). With disability being "a significant factor in the three great citizenship debates of nineteenth and early twentieth centuries: women's suffrage, African American freedom and civil rights, and the restriction of immigration" (Baynton 2017, p.18), it is impossible to ignore how 'disability' and "the power to define bodies as disabled" was used throughout U.S. history as justification for subjugation and oppression (Nielsen 2012, p.191; Baynton, 2017). Not only was disability used to legitimize pro-slavery or the different racialized treatment of "uncivilized" races, but it was equally used to criminalize sexuality, as well as female's socio-political aspiration by deeming the female body and motherhood incompatible with voting or education (see e.g., Pitts, 2012; Baynton 2017, p.24-26). When freed slaves were considered "insane" as a result of their freedom (Robertson, 2020; see also e.g., Grossi, 2021; Hughes, 1992), or that insanity was absent from Asian populations due to "the long-lasting belief that the uncivilized rarely experienced insanity" (Shin 2021, p.146), it should make us, as Nielsen noted, "seriously question the means by which people were committed to insane hospitals as well as educational institutions" (Nielsen 2012, p.109). Finally, the notion of disability as undesirability was firmly applied to immigration by limiting entry to undesirable races and bodies deemed incompatible with the physical and moral ideals of the model American citizen. As a result of eugenics' growing influence, and of a generalized fear over "the decline of the national stock" (Baynton 2005, p.33), the U.S. passed, starting in the late nineteenth century, a series of increasingly restrictive Immigration Acts restricting the right of entry to all those considered disabled, criminals, physically and/or sexually deviant, as well as politically radicals. Starting with the Page Act of 1875, Pub. L. 43-141, 18 Stat. 477 Ch.141, §5 (https://uslaw.link/#q=Pub.%20l.%2043-

> The question of how to maintain the nation has dominated all eras of U.S. history. In the Progressive Era, perhaps more than in any other, however, that meant surveillance and containment of bodies considered deviant or degenerative. Policies were put in place to carefully monitor the bodies of those entering the United States and sterilize the deviant bodies of those already within the nation's gates. Sexuality, class, race, gender, and ethnicity forcibly intersected with notions of disability and quality citizenship. (Nielsen 2012, pp.142-143)

What started with workhouses, asylums, prisons, colonies, special schools, etc., many of which contributed to the aggravation of physical and psychological disabilities/illnesses as a result of harsh, poor, and inadequate service provision (Morris, 1969; Oliver 1990, p.28; Russell & Rosenthal 2019, p.133; Schur et al. 2013, p.2), especially true for those with cognitive or mental disabilities, whose institutionalization "often meant isolation and abuse" (Nielsen 2012, p.143)[25], ended up with castration of the impaired and unfit in the 'progressive West' and, in the more extreme cases like those of Nazi Germany, with infanticide and the mass killing of disabled people[26].

141%2C%2018%20Stat.%20477%20Ch.%2014), and the Immigration Act of 1882, Pub. L. 47-376, 22 Stat. 214. Ch. 376 §2 (https://uslaw.link/#q=ch.%20376%2C%20%C2%A7%202%2C%2022%20Stat.%20214) that restricted access to any "lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge" (Baynton 2005, p.33), followed by the highly restrictive Immigration Act of 1924, Pub. L. 68-139, 43 Stat. 153 (https://uslaw.link/#q=Pub.%20L.%2068-139%2C%2043%20Stat.%20153) that further restricts immigration of undesirable people like southern and eastern Europeans and Asians (Baynton 2016, p.1; Baynton 2017, pp.28-29), "virtually termina[ting] the immigration of all Asians" (Shin 2021, p.148). Other restrictive Acts are the Chinese Exclusion Act of 1882, Pub. L. 47-126, 22 Stat. 58. (https://uslaw.link/#q=Pub.%20L.%2047-126%2C%2022%20Stat.%2058), the Immigration Act of 1907, Pub. L. 59-96, 34 Stat. 898 (https://uslaw.link/#q=Pub.%20L.%2059-96%2C%2034%20Stat.%20898), the Immigration Act of 1917, Pub. L. 64-301, 39 Stat. 874 (https://uslaw.link/#q=Pub.%20L.%2064-301%2C%2039%20Stat.%20874), and the California Alien Land Law of 1913 (Shin 2021, p.152. For more on disability and immigration, see Baynton, 2016; Dolmage, 2018). Disability policy historical reviews continuously reveal the impacts that non-medical aspects like class, gender, race, ethnicity, or sexuality, have on discourses and framings of disability, with social standing radically altering disability experiences and outcomes. With this said, it is impossible to ignore the central role that disability has played in U.S. institutional designs as an umbrella term to justify exclusions of citizens and civil rights (Nielsen 2012, p.67).

[25] For historical reviews of disability institutionalization's sub-human conditions in the U.S. that endangered and contributed to the development of illnesses, often turning disabled people's institutionalization into imprisonment, see Dix, 1843 for a detailed description of nineteenth century's sub-human conditions; and Deutsch, 1948; Wright, 1947; Taylor, 2009, or the disturbing photographic exposé of Burton Blatt & Fred Kaplan (Blatt & Kaplan, 1966) for twentieth century's examples.

[26] By 1920, twenty-five states had enacted policies that made sterilization compulsory for the "criminally insane" and the "genetically inferior" in the U.S. American sterilization programs were so developed that, in 1923, Fritz Lens, a German physician-geneticist and later a leading ideologue in the Nazi programs of "racial hygiene", considered the U.S. an example (Lifton 1986, pp. 22-23). By the 1960s, around sixty thousand Americans had been subjected to forced sterilization, with the

The twentieth century, the century of institutions, was also the period of discriminatory socio-biological evolutionary science (Carey 2009, pp.52-82; Rimmerman 2013, pp.18-19; Shakespeare 2006, p.1136; Trent 2006, p.1501). A rationalization of socio-economic interests, racism, ableism, and classism, the history of bio-racism, eugenics, and social Darwinism cannot be dissociated from the "Manchester economics of Ricardo and Smith and the dog-eat-dog world of the mid-nineteenth-century British capitalism" (Proctor 1988, p.16). These theories ended up working as the theoretical and moral legitimization of predatory practices of capital accumulation, often coated as scientific conclusions rather than policy (Russell & Rosenthal 2019, p.231). Associating "defects" of the body with hereditary mental and moral faults or deficiencies, eugenics offered a moral justification for the rampant economic disparities as "deficiencies" of the poor, ever more narrowly defining 'the ideal citizen' not only by class but also under "increasingly specific physical terms" (Nielsen 2012, p.115)[27]. Bio-racism became to the liberal bourgeoisie of the nineteenth and early to mid-twentieth century what blood had been to royalty, with bio-racist pseudo-sciences being to industrial society what the bible and the Church had been to pre-industrial western societies: a moral justification of an unequal and increasingly disparate social, productive, and cultural 'natural' order of things. Elevating inequality to a "natural law" (Hofstadter 1971, p.98), these discourses of 'non-correctability' of the 'inferior' population had the practical effect of halting or dismantling the creation or development of Western social security and health systems, institutionally legitimizing the growing socio-economic inequalities that marked the unstable period of the late nineteenth and early twentieth centuries —instability and growing inequalities which were only reverted with the post-WWII development of the welfare state[28].

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vast majority having no sound medical justification (Stern 2005, p.106). In the words of Justice Oliver Wendell Holmes, in one of the most high-profile cases regarding sterilization (Buck v. Bell), "it is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind… Three generations of imbeciles are enough." (Buck v. Bell, 274 U.S. 200 (1927), p.274 U.S. 207. https://supreme.justia.com/cases/federal/us/274/200/#207).

[27] Eugenic beliefs and practices are not without logical financial benefits for both capitalist and non-capitalist societies. Populational bioengineering, often justified by mystic, religious, or cultural discourses of evil and punishment from angry/displeased gods or mythological entities has been a method of resource management that is not rare in human history (e.g., Schur et al., 2013, p.1; Rimmerman 2013, p.13; Braddock and Parish 2001, p.15-17, 25; Chemers, 2006; Bogdan, 2009). What is, however, today proved as nonscientific is the conclusion that from genetic cleansing one eliminates undesired bodies, especially considering that most disabilities are "acquired" with age, by sickness, or accident (Davis 1995, p.23).

[28] Although the history of the welfare state and the neo-liberal transition are not in the scope of this thesis, as its complexity demands a study of its own, it is impossible to understand present-day disability politics without an understanding of the structural and categorical transformations that disability passed through during this period from dependent to consumers. Benefitting from a period

1.3 The cultural production of disability

> Beliefs about sickness, the behaviors exhibited by sick persons, and the ways in which sick persons are responded to by family and practitioners are all aspects of social reality. They, like the health care system itself, are cultural constructions, shaped distinctly in different societies and in different social structural settings within those societies (Kleinman, 1980, p. 38).

The cultural representation of disability is one of the major struggles for disabled people. Ill-portrayed misrepresentation of disability in the media and other forms of cultural production harms the disabled community by stigmatizing instead of normalizing disability and non-conforming bodies. While it is still rare today to find disabled characters in ordinary contexts/actions, the opposite is not. Portraying disability in television, movies, or cartoons as a token of 'the extraordinary', this quasi-mythological cultural restriction of disability to either sub-human or super-human characters, together with ableist beauty standards and usual negative portrayals of disability, creates a representational void that conditions identity building, particularly impactful for disabled youth that grows up with unfavorable stereotypes in a crucial period of identity formation (e.g., Diefenbach & West, 2007; Nitsch 2023, p.269; Oliver 1990, pp.61-62; Quinn & Earnshaw 2013, pp.41-42; Schur et al. 2013, p.120; Thomson 2017, p.9-12; Wahl, 2003; Westerholm et al., 2006a, p.1504), especially when considering that most disabled people 'move' within social networks where most actors are not disabled themselves, further isolating the impaired body and its unique identity (Santuzzi & Waltz 2016, p.1115). Furthermore, media, in its underrepresentation, inaccuracy, and exaggeration of illnesses and disability coverage, by linking disability with socio-economic dependency, crime,

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of post-war state expenditure (welfare state) allied with medical technological innovation, and later neo-liberal public disinvestment, shortage of public service, and subsequent services privatization, disabled people passed from having no available social role in the early phases of industrial capitalism, to integration through dependency via state services provision, to consumers with the privatization of previously public provided services. The twentieth's century dissociation from community and Church care to state institutionalization, together with the professionalization and technological development of health and pharmaceutical industries and the growing marketization of health, especially from the post-WWII, all transformed disability from a financial black hole into a multi-billion industry (Grinker 2020, p.60). Late post-WWII twentieth century's material conditions of existence transformation led disabled people to gain a new consumerist role inexistent in early industrial settings. A 'useful' social role gain that can be said to have helped explain why neo-conservative monetary and fiscal policies stopped being accompanied by the discourses of disposability that characterized nineteenth and twentieth centuries public discourse.

violence, and deviant behaviors, reinforces stigmatizing attitudes (e.g., Reifegerste & Wiedicke 2023, p.184; see also McGinty et al., 2014).

Efforts have been made to revert this tendency in the last decades by increasing healthy representations of disability. Nevertheless, despite these efforts, media coverage and disability representation continue practically nonexistent (Ma, 2017; Kingsbury, 2021). The Cooperative Children's Book Center of the University of Wisconsin-Madison, which has been since 2018 documenting the number of books it receives for children and teenagers representing disabled identities, reported that, from all books received in 2019, only 126 or 3.4% had a primary character with disabilities, a clear indication of disability as being abnormal[29].

Lee & Low Book's publisher has likewise reported the lack of disability representation in the publishing industry with its Diversity Baseline Survey, the largest study ever done to examine diversity among publishing staff[30]. The Diversity Baseline Survey surveys publishing houses and review journals regarding the racial, gender, sexual orientation, and ability makeup of their employees every four years[31]. The 2015 Diversity Baseline Survey showed that only 4% of the employees contemplated in the survey were disabled. The second Diversity Baseline Survey, published in 2019, reported that 11% of the publishing workforce had disabilities, an increase that, according to Lee & Low Book, is likely to represent no real growth but instead the result of rephrasing questions, together with the de-stigmatization of mental health and mental illness in the U.S.[32].

As explained by Alaina Lavoie, communications manager for We Need Diverse Books[33],

> Literary agents and editors often turn down books with disabled main characters because they explain they 'can't connect to the story' or don't think the book has marketing potential (…) Once disabled creators do get a book deal, they often face ableism at other levels throughout the process. It may be that they're challenged on book jacket copy, or not given a large promotional budget, or assumed to be a niche book for just a niche audience that isn't seen as 'mainstream.' A lot of the ways that ableism shows up in publishing are subtle microaggressions, and disabled creators often have to continue to advocate for themselves and their work: To get printed ARCs [advanced review copies] made for accessibility reasons, to request accessible event

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[29] https://ccbc.education.wisc.edu/the-numbers-are-in-2019-ccbc-diversity-statistics/.
[30] https://www.leeandlow.com/about-us.
[31] https://blog.leeandlow.com/2020/01/28/2019diversitybaselinesurvey/.
[32] https://blog.leeandlow.com/2020/01/28/2019diversitybaselinesurvey/.
[33] https://diversebooks.org/.

> venues for their in-person readings and events, to push for accessibility for online events, to have their work submitted for awards and to the media for promotion" (Alaina Lavoie interviewed in Kingsbury, 2021).

Sidelined, disability representation in literature tends to follow ableist stereotypical perspectives on disability under penalty of not being material worth publishing. In this sense, as Kingsbury noted, most literary representations of disability represent disability as burdensome, equating disability with death or rehabilitation experiences, situations that fail to represent the diversity of outcomes and experiences that is the disability spectrum, the reason why having disabled authors and workforce is crucial for a distinct representation of disability. This becomes even truer when we speak of disabled people who are equally minorities, people of color, and/or LGBTQ+ (Kingsbury, 2021).

As mentioned already, the problem with these discourses of disability that position disability as either a personal tragedy or as a medical affair mask other fundamental elements in the disabled body that may deserve equal attention when defining a disabled person like ethnicity, cultural background, gender, or sexuality, etc.; elements that often are unproblematized when discussing the disabled body, turning disabled people rhetorically disabled deepening the invisibility of non-conforming bodies as well as their stigmatization (Prendergast 2001, p.45). And, while new communication and meeting tools like the internet provide new accessible and safer spaces for the interaction and construction of a 'disabled identity' (Grinker 2020, p.63; Blanck, 2014), it would be naïve to understand that disability is no longer stigmatized by ableist and relative socio-cultural constructions of normalcy[34].

The problem of disability misrepresentation and non-representation does not end with the disabled person/body. It also affects those who, despite their able-body, coexist with disability, having part of their identity intertwined with it, be it professionally, socially, or due to family ties with disabled people. Known in psychology as 'concealable stigmatized identity(-ies)', that is, "identities that can be kept hidden from others but that carries with it social devaluation" (Quinn & Chaudoir 2015, pp.36-37), non-disabled people associated with disability may thus equally suffer from disability's stigmatization and lack of representation, with the individual impacts of labelling and othering varying accordingly to the actors' psychoemotional experiences of disability (Santuzzi & Waltz 2016, p.1114; see also Reeve, 2002; Reeve, 2004).

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[34] As noted by Davis, the present concept of 'normalcy', 'normal', 'average', 'normality', etc., meaning non-deviant or conforming, only entered the English around the 1840s and 1850s. As he said, "if the lexicographical information is relevant, it is possible to date the coming into consciousness in English of an idea of 'the norm' over the period 1840-1860." (Davis 1995, p.40).

The more conscious one is of existing stigmas, also known as 'stigma consciousness', the more one is psychoemotionally affected by its stigmatization, concealable or not. Especially true for concealable identities, the stressful factor of anticipating stigmatizing behaviors by disclosing a stigmatized identity negatively impacts the experience of disability, conditioning disabled people's behaviors in a self-harmful way (e.g., not requesting accommodation at work or poorer mental health —more on this below). Anticipated negative reactive behaviors or stigmatization has thus a particularly negative impact on shaping disabled identities, private, and social practices of disability (e.g., Chaudoir & Quinn, 2010; Galvin, 2005; Livneh, 2009a; 2009b; Quinn & Chaudoir, 2009; Quinn & Earnshaw, 2011; Quinn & Earnshaw, 2013; Santuzzi et al., 2014; Santuzzi & Waltz 2016, p.1118; Westerholm et al., 2006a, p.1505). As Clare said, "disability has been soaked in shame, dressed in silence, rooted in isolation", effectively decreasing disabled people's organizational efforts for "without pride, disabled people are much more likely to accept unquestioningly the daily material condition of ableism (…). Without pride, individual and collective resistance to oppression becomes nearly impossible." (Clare 2015, p.107)[35].

Stigma has historically been classified into three types: physical, of character, and race, culture, and/or religion (Westerholm et al., 2006a, p.1502; see also Goffman, 1963), and of two dimensions, "public" (stereotypes, prejudice, and discrimination) and "self-stigma" or private (self-reflexive or internalized) (Corrigan et al., 2009, p.75; Westerholm et al., 2006a, p.1503). In what concerns disability stigmatization, it varies according to certain macro contextual structural factors like the cultural history of stigmatization in that culture, as well as the disabled body's visibility, severity, and controllability; that is, with how salient the disabled body is to the public eye (Richard & Hennekam 2021, p.1; see also Mik-Meyer, 2016; Sabat et al., 2019). Regardless of the combination of macro and micro factors in the stigmatizing process, the reality is that, despite efforts otherwise, stigmatization reached such drastic proportions in contemporary American society that the U.S. Department of Health and Human Services has recognized on several occasions stigmatization as one of the central obstacles to progress in the areas of health and mental illness (DHHS 1999, 2001). Stigmatized people are often blamed for their suffering, deemed incompetent, marginalized, dehumanized, and ultimately excluded

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[35] While disposition does impact the experience of disability, and while the micro does have an impact on the meso and macro, I believe attitudinal transformation is not the central element when understanding disability's history and politics. While important for one's personal and social well-being, attitude transformation without structural change accounts for little and rarely a long-lasting solution, as will be demonstrated next.

from society (e.g., Corrigan & Kleinlein, 2005; Goffman 1963, p.3; Grinker 2020, p.55; van Beukering et al., 2021), ending up thus suffering a qualitative transformation of status, to have their public, private, and collective identities, transformed (stigmatized) into "deviant" identities in which their disability(-ies) overrides most personal attributes/characteristics (Westerholm et al., 2006a, p.1503), with society collectively denying non-conforming bodies the requirements to "carrying on the routines of everyday life" (Becker 1963, pp.31-35); a tendency that characterizes most of modern and contemporary socio-cultural and legal history of disability[36].

Albeit much reduced and significantly ameliorated throughout the twentieth century, stigmatization still profoundly impacts disabled people. Not only in social dimensions such as education or employment, where the negative stigma of disability influences attitudes from employers and other stakeholders in rejecting disabled people as valid workers (e.g., Biggs et al., 2010; Foitzek et al., 2018; Janssens et al., 2021; Krupa et al., 2009; Mik-Meyer, 2016)[37], but also in accessing health care or housing, as well as by profoundly impacting self-esteem and disabled people socialization, with stigmatization isolating, demoralizing, and ultimately leading to rejection and reclusion from social life (Hipes et al. 2016, p.17; van Beukering, et al., 2021).

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[36] Just because society erases characteristics when faced with impaired bodies, the same experience necessarily reflects disabled people's understanding of their own identities. The generalization of the disabled label can lead to wrongful assumptions about what aspects one considers central to identity construction (Galer, 2012). Identity generalization necessarily implies the risk of oversimplification. Identities can vary from and within the individual, across time and by place. Similarly, not all impaired people understand themselves to be disabled. A disabled identity is, in the end, fluid and not necessarily linked to having/being impaired (Santuzzi & Waltz 2016, p.1115).

[37] Previous research has pointed out that people with mental illnesses are three to seven times more likely to be unemployed, and those with physical disabilities are twice as often when contrasted with the non-disabled population (OECD, 2012; van Beukering et al., 2021). However, despite disabled people's chronic unemployment rate, historical evidence suggests its causes may be unfounded and determined primarily by social and economic contexts rather than individual characteristics or impairments/disabilities. A significant contemporary example was the high employability of the disabled workforce during WWII when disabled people's placements between 1940 and 1950 almost reached the two million mark (Nielsen 2012, p.160). Not only that, disabled workers also "compiled impressive records of productivity" (Hahn 1986, p.127), making contemporary assumptions about the employability of disability questionable. This is especially true for today's job market, where technological development has mitigated impairments/disabilities' impacts on one's daily life and capacity to participate in employment. For more empirical evidence on disabled workers' productivity not being below average, see Greenwood & Johnson's study of 16 surveys that demonstrate disabled worker's productivity being comparable with non-disabled over a period of almost 40 years between 1948 to 1984 (Greenwood & Johnson 1985, p.80-90); see also Stein 2000, p.323.

Self-stigmatization or internalized stigma is another consequence of stigmatization that comes with the social experience of exclusion, leading to social reclusion as a way of escaping devaluation and resulting in grave consequences to one's mental health, self-esteem, and self-efficacy (e.g., Corrigan et al., 2006; Corrigan et al. 2009, p.75; Corrigan et al. 2015, p.10; Quinn & Earnshaw, 2013; Quinn & Chaudoir 2009; 2015)[38]. Particularly relevant to disabled people, self-stigmatization is distinctly reflected in what can be described as the 'why try' effect (e.g., Corrigan et al., 2009; Corrigan et al., 2015), affecting one's mental health and normal processes of socialization by limiting one's interaction (social avoidance), to restrict and avoid possible confrontations with antipathetic actors and dehumanization of the self, linked to the stressful event that disclosing a stigmatized identity implies (Corrigan et al., 2009, p.76; Quinn & Chaudoir, 2015; Quinn & Earnshaw 2013; Westerholm et al., 2006a, p.1504-1506)[39]. This self-refraining of engagement as a consequence of self-internalized stigma and eroded mental health significantly impacts important dimensions of one's life. Vocation, housing, education, health and wellness, relationships, wealth, recreation, etc. are but a few of the most central social relations that are negatively impacted by stigma and self-stigmatization (e.g., Corrigan et al., 2009, p.75; Corrigan et al., 2015, p.10. See also e.g., Beatty et al., 2019; Bricker-Katz et al., 2013; Chaudoir & Quinn, 2010; Hielscher & Waghorn, 2017; Madera et al., 2012; Ren et al., 2008; Rosenfield & Neese-Todd, 1993)[40]. Considering the connection between unemployment, psychological distress, depression, and the increased social costs of precarity is well-known to social scientists (e.g., Paul & Moser 2009; OECD 2010, pp.46-47; OECD 2014; Schur, 2002; Wanberg 2012), it is concerning how much more disabled people are disproportionally affected by systemic imbalances of power that keep disabled people at the

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[38] Self-stigmatization comprises three steps: "awareness of the stereotype, agreement with it, and applying it to one's self" (Corrigan et al., 2009, p.75), with its harms manifesting emotionally (low self-respect) and behaviorally ('why trying?' X) (Corrigan et al. 2015, p.13). It is thus not surprising that those who report having stigmatizing identities present lower levels of psychological well-being (Quinn & Earnshaw 2013, p.42), especially when the stigmatized identity assumes a preponderant centrality and salience to one's identity (Quinn & Chaudoir, 2009).

[39] Studies show that people with concealed identities are more likely to suffer from depression, anxiety, or suicidality than those who assume/disclose their stigmatized identities. Concealable identities live in a dilemma between the chance of a positive disclosure or risking social rejection (Bogart, 2015; Nario-Redmond et al., 2013; Quinn & Earnshaw, 2011; 2013; Westerholm et al., 2006a, p.1505).

[40] Recent scholarship has also shown how disabled workers create a positive work-related identity through in-group downward social comparisons contrasting one's disability to other disabled workers whose disabilities are more salient. As Richard & Hennekam show, disabled people paradoxically reinforce the stigmatized identity of disability rather than participating in non-discriminatory identity processes, further suppressing individuals with more stigmatizing identities/bodies and failing to promote destigmatization (Richard & Hennekam 2021, pp.2-3, 12). This phenomenon shows how disabled workers fail to compose a stable identity/class (Santuzzi & Waltz, 2016), a symptom of invisibility and a lack of positive disabled-led social networks.

bottom of most socio-economic indicators/markers (see subsequent data analysis). Even with a change of attitudes, stigma is not only the result of structural mechanisms, but also of a lack of disability knowledge (Domzal et al., 2008, p.13; Scior, 2011; van Beukering et al., 2021)[41], the structural harms of the current capitalist modes of production and accumulation, the individualistic and ableist ethos it produces, as well as the reduction of disability to medical contexts, disability's lack of representation in its cultural invisibility along with the retraction of disability from social life, and a 'personal tragedy' narrative of disability, all straitjacket disability into a stigmatized socio-cultural and economic ethos of exclusion, dependency, and neglect, that, on its turn, reinforces existing stigmas by forcing disabled people to conform to their structural position, risking further dehumanization and social exclusion. As Lawson concluded,

> people living in poverty are more at risk of having impairments and, at the same time, people who have impairments (which may not have been caused by poverty) are likely to be pushed into poverty by a multitude of disabling societal forces (Lawson 2011, p.49)[42].

Stigma, just like disability, needs thus to be analytically broken down and analyzed in its expressions as symptomatic of historically concrete embedded organizations of society[43]. With stigma being a direct consequence of society's organization, only a system that weights human and material factors could lift disabled people out of their chronic underprivileged position and "eliminate discrimination against disabled persons" (Russell & Rosenthal 2019, p.34).

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[41] The lack of knowledge on disability negatively impacts disabled people's employability, for it mystifies symptoms and needs, as well as abilities, subjecting disabled people to misconceptions about their disability and questioning the capacity to perform under stress or efficiently (e.g., Russinova et al., 2011; Scheid, 2005), as well as safety and predictability of the disabled person (e.g., Can Öz et al., 2019; Jacoby et al., 2005; Rao et al., 2010). Lack of knowledge on symptoms, re-occurrence, and recovery, lack of knowledge on possible accommodations, or the refusal to do so, as well as harassment and discrimination upon disability disclosure, all contribute to increasing and maintaining disabled people's chronic unemployment and underemployment (van Beukering et al., 2021).

[42] One must also consider the outstanding costs of disability exclusive to disabled people. With the tendency to earn below national average incomes but having disability-specific expenses, from disability-aid tools to inbuilt modifications, from personal assistants to physiotherapy, etc., disability poses a financial strain on already impoverished disabled households, resulting in increased hardship and higher poverty rates (e.g., Saunders 2007; Stapleton et al., 2008; Wilkinson-Meyers et al., 2010; Zaidi & Burchardt 2005).

[43] Autism stigmatization history exemplifies how stigmatized identities can change under their economic and structural valorization. As Grinker noted, with neurodivergent cognition's increased value, neurodiversity has become an example of how economics influences the stigmatization or destigmatization of identities and characteristics. Autistic people are now able to participate in the economy and succeed in the workplace "not despite their differences (…) but because of them" (Grinker 2020, p.56).

Understanding stigma's causal mechanisms does not suffice to destigmatize stigmatized identities and social relations. While knowing social processes and social relations meta-structures is a necessary condition for its transformation, only a combined political, legal, sociocultural, and economic response capable of transforming these structures could answer the problem of disability) stigmatization. The Americans with Disabilities Act of 1990 (ADA) exemplifies this discrepancy between attitudinal change and transformation enforcement.

2. Americans with Disabilities Act (ADA)

> The story of the ADA can be told in many ways—as a story of disability, as a story of civil rights, as a story of activism. (Nielsen 2012, p.191).

2.1 The Americans with Disabilities Act (ADA): An Unrealistic Demand?

The Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, 104 Stat. 327, passed by Congress in 1990, is a civil rights law that "prohibits discrimination against individuals with disabilities in all areas of public life, including jobs, schools, transportation, and all public and private places that are open to the general public" (ADA National Network 2017, p.1)[44]. The Act has 5 main titles: Title I – Employment, Title II – Public Services, Title III – Public Accommodations and Services Operated by Private Entities, Title IV – Telecommunications, and Title V – Miscellaneous Provisions[45].

The ADA, the most important landmark in disability politics in the U.S., was designed to be simultaneously a civil right and a labor economic bill to end employer discrimination and improve disabled people's overall socio-economic conditions (Russell & Rosenthal 2019, p.100). The result of a long movement that gained traction in the late 1960s, heavily influenced by the Civil Rights Movement and later identity politics, the ADA can be seen as the culmination of disabled people's activism (for more on disabled people's activism in America, see e.g., Barnartt & Scotch, 2001; Longmore 2003, ch.5; Longmore, 2020; Shapiro, 1993; Fleischer & Zames, 2011)[46]. Built on the Civil Rights Act of 1964, Pub. L. 88-352, 78 Stat.

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[44] https://adata.org/factsheet/ADA-overview.

[45] The ADA, as published in 1990, can be found at https://www.eeoc.gov/americans-disabilities-act-1990-original-text. For more information, see https://adata.org/. A culmination of a long struggle for disability recognition, the ADA can be seen as the culmination of twentieth-century disabled people's and disabled people organizations' activism.

[46] In the U.S., the tendency is to frame social issues as human rights issues, both in activism and constitutional history (Oliver 1990, pp.120-121). In the case of the disability rights movement, it was "energized by, overlapping with, and similar to" other civil rights movements like those waged by

241[47], especially Titles II and VII, the Architectural Barriers Act of 1968, Pub. L. 90–480, 82 Stat. 718[48], Rehabilitation Act of 1973, Pub. L. 93–112, 87 Stat. 355[49], of and its 'Section 504', as amended in 1974, the Education for all Handicapped Children Act of 1975, Pub. L. 94-142, 89 Stat. 773[50] (known since 1990 as the Individuals with Disabilities Education Act, Pub. L. 101-476, 104 Stat. 1103 (IDEA))[51], and two reports issued by the National Council on the Handicapped (NCH 1986; 1988), that became the basis and first version of the Americans with Disabilities Act introduced to the Senate in 1988[52] (Nielsen 2012, p.190; Colker 2005, p.17, 27; NCH 1986; 1988), "the ADA received much more detailed consideration by Congress than any other prior civil rights legislation" (Colker 2005, p.7)[53]. Despite this, the ADA was passed in a context where the "philosophical momentum for social justice" had considerably decreased (Russell & Rosenthal 2019, p.72). Not only had the social movements from the 1960s and 1970s lost much of their political relevance, new philosophical and politico-economic ideologies had emerged. The then-rising, now hegemonic, neo-liberal ideology profoundly impacted the disability rights movement and disability politics by shifting the discourse on state provision and attacking the welfare state (Hudson, 2003; 2005; Klein, 2007; Chase-Dunn & Almeida, 2020)[54].

African Americans, feminists and LGBT in the 1960s and 1970s, with disabled activists and DPOs affirming disabled bodies as "sources of political, sexual, and artistic strength", instead of root-causes of stigma, making disability pride a central political element in the disability discourse (Nielsen 2012, p.171; see also Clare, 2015).

[47] https://uslaw.link/#q=Pub.%20L.%2088-352%2C%2078%20Stat.%20241.

[48] https://uslaw.link/#q=Pub.%20L.%2090%E2%80%93480%2C%2082%20Stat.%20718.

[49] https://uslaw.link/#q=Pub.%20L.%2093%E2%80%93112%2C%2087%20Stat.%20355.

[50] https://uslaw.link/#q=Pub.%20L.%2094-142%2C%2089%20Stat.%20773.

[51] https://uslaw.link/#q=Pub.%20L.%20101-476%2C%20104%20Stat.%201103.

[52] The National Council on the Handicapped, an independent federal agency, is now known as the National Council on Disability. The agency's name changed under the Handicapped Programs Technical Amendments Act of 1988, Pub. L. 100-630, 102 Stat. 3289 (https://uslaw.link/#q=Pub.%20L.%20100-630%2C%20102%20Stat.%203289).

[53] "The ADA was considered by four committees of the House of Representatives, with each committee authoring a lengthy report [(H. Rept. 101-485, Parts 1,2,3, and 4, https://www.congress.gov/congressional-report/101st-congress/house-report/485)]. It was then reported out by the House Rules Committee [(H. Rept. 101-488, https://www.congress.gov/congressional-report/101st-congress/house-report/488)]. After different versions of the ADA passed in the House and Senate, it was also the subject of two conference reports [(H. Rept. 101-558; H. Rept. 101-596, https://www.congress.gov/bill/101st-congress/senate-bill/933)]" (Colker 2005, p.7, the references in between brackets correspond to Colker's notes 18-20, the links were added to the original text and notes).

[54] The 1980s disabled activist efforts can be said to have been an attempt to prevent the Reagan administration (1981-1989) from dismantling the rights gained during the preceding decades more than advancing existing legislation (Colker 2005, p.4).

Enacted under an unfriendly political context, its passage resulted from the watering down of the original document to get congressional consensus and Bush's presidential approval (Colker 2005, pp.28-29)[55]. This watering down restricted the ADA's implications and enforceability, jeopardizing its goals and failing to correspond to disabled people and disabled people's organizations' expectations. Contrarily to other civil rights and labor bills, the Americans with Disabilities Act was approved only when it was guaranteed the financial health of American businesses would be protected against excessive adaptability costs ("undue hardship") from its enforcement (Russell & Rosenthal 2019, p.64; 42 USC. §12112(b)(5)(a)). This compliance exemption, when its compliance would result in financial hardship, has, however, profoundly restricted its legal interpretation and enforcement, damaging the Act's purpose, enforceability, and protection.

In 1995, the Cato Institute, a conservative think tank, published an article, "Handicapping Freedom: The Americans with Disabilities Act", denouncing the harmful consequences of the Act, suggesting employers and private entities be compensated for any accommodation cost:

> If Congress is serious about lifting the regulatory burden from the economy, it must consider major changes in, if not outright repeal of, the ADA. And, if Congress is to undo the damages already done by the act, it should consider paying reparations to cover the costs that individuals, private establishments, and enterprises have suffered under the ADA's provision (Hudgins 1995, p.68)[56].

The United States of America Commission on Civil Rights findings on the Americans with Disabilities Act reported that the price for compliance in employment provision was one of the most persistent criticisms against the Act. However, as stated in the same report, most business accommodations (70%) fell below the $500 mark, proving it to be an irrational fear (Isler et al. 1998, pp.4-5). Even if subsidized, to avoid adaptability cost criticism from employers, ADA enforcement would still be cheaper and more advantageous than existing state or federal pensions since moving disabled people to active payrolls would remove them from state

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[55] The final version of the ADA, as approved in 1990, had only two major aspects stronger than the original draft bill presented in 1988: it recognized 43 million Americans as disabled, as opposed to the 36 million recognized by the 1988 bill (S. 2345 sec. 2(a)(1)), and secondly, it had a broader understanding of "public accommodations" (see 42 U.S.C. §§ 12181-12189) than the 1988 version that used the definition found in Title II of the Civil Rights Act of 1964. However, as will be shown later, despite recognizing 43 million Americans as disabled, the bill's final version had a narrower definition of disability, excluding people who could have otherwise benefited from its broader understanding (Colker 2005, p.29).

[56] For other examples of influential critical perspectives of the ADA's Title I, see e.g., Epstein R. A. 1995, pp.480-494; Epstein S. B., 1995; Barnard, 1990; Schuman, 1995; Willis, 1994.

benefits. If anything, the ADA, in terms of employment, has served to protect employers more than it has ever worked to protect disabled workers. Legal outcomes were so poor during the first decade of its enforcement that the American Bar Association's Commission on Mental and Physical Disability Law, in its 1998 report, patently stressed the inefficacy of the Act to protect disabled people in cases of employment discrimination:

> the facts strongly suggest the opposite: employees are treated unfairly under the Act due to myriad legal technicality that more often than not prevent the issue of employment discrimination from ever being considered on the merits (American Bar Association 1998, 403-404).

A significant part of this results from how the Supreme Court ruled its understanding of disability and the ADA. Understanding the ADA from an ahistorical perspective that failed to resolve the Act's literary ambiguities[57], the Supreme Court interpreted the statute "as narrowly as possible", failing to benefit from Congress's extensive reports that accompanied the passage of the bill (see note 54) that intended to help in resolving "the fine details of the bill" (Colker 2005, p.8). Supreme Court's overruling of lower court decisions that had ruled in favor of disabled plaintiffs, to side instead with the accused employers in what became known as the Sutton trilogy: Sutton v. United Airlines, Inc., 527 U.S. 471 (1999)[58], Murphy v. United Parcel Service, Inc., 527 U.S. 516 (1999)[59], and Albertson's, Inc. v. Kirkingburg, 527 U.S. 555 (1999)[60], significantly impacting the Act's reach, narrowing down the spectrum of disability and claims covered by the ADA to a "relatively narrow band of plaintiffs" (Colker 2005, p.2)[61]. By ruling that impairments that could be mitigated by lifestyles, devices, or medications, could not be considered disabilities, the Supreme Court's rulings led to lower courts disqualifying conditions like diabetes, heart conditions, epilepsy, cancer, and mental illness from ADA's protection under its Title I, technically disqualifying these as disabilities (Russell & Rosenthal 2019, pp.120-121; see also Colker 2005, p.16). These rulings were, however, in direct opposition to Congress's understanding of the Act and the people covered by it[62]. As stated in

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[57] Examples of this are: "disability", "reasonable accommodation", and "undue hardship" (Colker 2005, p.16).

[58] https://supreme.justia.com/cases/federal/us/527/471/.

[59] https://supreme.justia.com/cases/federal/us/527/516/.

[60] https://supreme.justia.com/cases/federal/us/527/555/.

[61] Toyota Motor Mfg., Kentucky, Inc. v. Williams, 534 U.S. 184 (2002) was another Supreme Court ruling contributing to a restrictive understanding of disability (https://supreme.justia.com/cases/federal/us/534/184/).

[62] As Colker said, "the judiciary has refused to consider the documents that Congress created to clarify its intentions. It has insisted that the plain language resolves all controversies rather than interpreting the ADA in the context of its two years of considerations." (Colker 2005, p.66).

the Committee on Education and Labor report (1990), the second and most complete report, it was suggested that disabilities be considered regardless of the effects of mitigating measures: “whether a person has a disability should be accessed without regard to the availability of mitigating measures, such as reasonable accommodations or auxiliary aids. For example, a person who is hard of hearing is substantially limited in the major life activity of hearing, even though the loss may be corrected through the use of a hearing aid. Likewise, persons with impairments, such as epilepsy or diabetes, which substantially limit major life activity are covered under the first prong of the definition of disability, even if the effects of the impairment are controlled by medication” (H. Rept. 101-485 Part 2, 52)[63]. Not only has the Supreme Court narrow the meaning of disability requiring plaintiffs to “demonstrate that they are disabled after a court takes into account the ameliorative effects of mitigating measures” (Colker 2005, p.2), it understood disability under the ADA in a narrower sense than it had under Section 504 of the 1973 Rehabilitation Act, which recognized as disabilities even those that could be mitigated with medication (Colker 2005, p.16). Supreme Court's decisions have thus restricted the ADA enforcement to those workers whose disabilities could not be mitigated through corrective aids or medicine (Russell & Rosenthal 2019, pp.84-86). This narrow understanding of disability led to extremely low winning rates for disabled plaintiffs at both trial (7% winning rate) and appellate (16% winning rate) court levels throughout the ADA's first decade, with disability discrimination rates being “worse than results found in comparable areas of the law”, with only prisoner rights cases faring as poorly (Colker 1999, pp.99-100). Of the 1200 cases filed under the ADA employment provisions from 1992 to 1998, only 8% were ruled in favor of disabled employees, with the percentage dropping to 5% by the year 2000 (Russell & Rosenthal 2019, p.101). This generated a “disturbing trend” of “hyper-technical, often illogical interpretations of the ADA”, where the Supreme Court’s precedents have harmed the very same people that the ADA was supposed to protect (Mayerson, 1997).

This created a dangerous blurred line where workers are either deemed too ‘able’ to benefit from the ADA’s protection or not ‘disabled’ enough to be covered by it and avoid discrimination (Russell & Rosenthal 2019, p.86), making it “difficult for individuals to be both ‘disabled’ and ‘qualified’ to bring successful ADA lawsuits” (Colker 2005, p.xiii). Too functional to be disabled but not able enough to be optimal workers, the Supreme Court’s decisions at the turning of the century have sentenced disabled workers to a new

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[63] The Judiciary Committee further legitimized this view on disability by agreeing to the definition of disability put forward by the Committee on Education and Labor (H. Rep. 101-485 Part 3, 28-29).

institutionalized fragile position where existing law, designed to protect them against discrimination, works solely to increase the discrimination, victimization, and alienation of the disabled worker (Mayerson, 1997, p.587). In the end, the Supreme Court's narrow understanding of disability has "turned the ADA on its head" (O'Brien 2001, p.195), leaving disabled people protected only formally, with the newly acquired but non-enforced rights serving only to reinforce existing status quo and discrimination (Young & Quibell 2000, p.757). As Russell said, summarizing the legal desert of disability legislation: "if one is disabled enough to sue, one is too disabled to work (…) since if one is able to work, one has no grounds to sue" (Russell & Rosenthal 2019, p.86)[64].

Despite this, it is undeniable that precarious legal protection is better than no law. In fact, as a federal law, the ADA has had considerable impacts on disabled peoples' daily lives, from environmental design to a series of social rights that were previously negated or not sufficiently regulated, changing disabled people's lives for the better. An example of this is ADA's Title II, which expanded the protection disabled people were given under Section 504 by stating that "no qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any public entity" (42 USC. §12132), extending hence Section 504 of the Rehabilitation Act of 1973 coverage to all public entities, regardless of federal funding. Finally, Title III states that "no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation"

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[64] It is important to mention that on September 25, 2008, Congress enacted the Americans with Disabilities Amendments Act (ADAAA), Pub. L. 110-325, 122 Stat. 3553 (https://uslaw.link/citation/us-law/public/110/325), in an attempt to overturn and correct the Supreme Court's rulings that had resulted in an interpretation that delimited and narrowed the understanding of disability, failing that way to respect Congress's intents while enacting the Americans with Disabilities Act (see pages 24-28 for context). By broadening the scope of disability, the ADAAA managed to include and protect people that, despite being disabled, were ruled to be uncovered by the ADA, as well as, much like other civil rights statutes, redirect the focus to whether discrimination occurred, rather than to an exhausting analysis of whether the plaintiffs have or not a disability, as had been the pattern set by the Supreme Court's early rulings. For more on the 2008 amendments, see https://web.archive.org/web/20201019083653/https:/www.eeoc.gov/laws/guidance/fact-sheet-eeocs-final-regulations-implementing-adaaa, see also https://www.eeoc.gov/laws/guidance/questions-and-answers-final-rule-implementing-ada-amendments-act-2008, and https://www.federalregister.gov/documents/2011/03/25/2011-6056/regulations-to-implement-the-equal-employment-provisions-of-the-americans-with-disabilities-act-as.

(42 USC. Subpart B – General Requirements. § 36.201 General), extending disabled people's protection for the first time to the private sector, changing not just discrimination but also, for example, accessibility (Colker 2005, pp.20-21). As shown by the historical contextualization of disability provided in this thesis, it is undeniable the progress American society has made regarding disability. However, like past civil rights legislation, the ADA has been "consistently tested and eroded in the courts" (Nielsen 2012, p.191). Despite the many positive signs of progress brought forward by the ADA, the reality remains one of inequality, poverty, dependency, and social exclusion that leaves disabled people overrepresented at the bottom of most statistical indicators, as shown in the next and last section of this thesis.

3. Data Analysis

Fast forward three decades after the Americans with Disabilities Act approval, can we say that disabled people's demographic and socio-economic condition in the U.S. has improved, or do disabled people remain today at the fringes of society as was the case in the late twentieth century? (e.g., Mudrick, 1997; Turpin, 1997; Russell & Rosenthal 2019, p.73). The following analysis reviews data between 2008-2018 in an attempt to answer this question.

The analysis is based on data collected from Cornell University's Disability Statistics Online Database[65]. I have opted not to include any data coincident with the COVID-19 pandemic since its data would compromise the 'normal' disability trends. COVID-19 data fluctuations deserve to be studied independently as a phenomenon of its own.

Disability prevalence, employment rate and types of employment (full-time or other), annual earnings, annual house income, poverty levels, supplemental security income (SSI), educational attainment, health insurance coverage, and service-connected disability are the indicators reviewed in this thesis. It is important to note that while there is not a single definition of disability, U.S. public authorities following Section 4302 of the Affordable Care Act of 2010, Pub. L. 111-148, 124 Stat. 119[66], define disability as being comprised of at least one of six disability types: hearing, vision, cognition, mobility, self-care, and independent living[67].

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[65] For data sources, see the statistical appendix. Cornell's database is available at https://disabilitystatistics.org/. Data was rounded to the hundreds.

[66] https://uslaw.link/#q=Pub.%20L.%20111-148%2C%20124%20Stat.%20119.

[67] For more information regarding the implementation guidance on data collection, see https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0.

With this said, do non-institutionalized disabled people fare better today in the U.S. than in the late twentieth century or has the Americans with Disabilities Act of 1990 failed to live up to its equality standards?

3.1 Disability Prevalence

Disability prevalence can be studied from many perspectives and sub-sections. Since the purpose of this study is to understand the impact a nationwide federal policy has had, I have opted for studying prevalence under general terms, excluding disability prevalence by age sub-sections, since it adds little to the analysis in question.

When studying disability prevalence per type of disability (Figure 3.1 and Figure 3.2), it is possible to verify that while the distribution is quite unequal, the evolution over time is consistent, with ambulatory being the largest category across the 11-year sample, followed by decreasing order by cognitive, independent living, hearing, self-care, and visual disability[68].

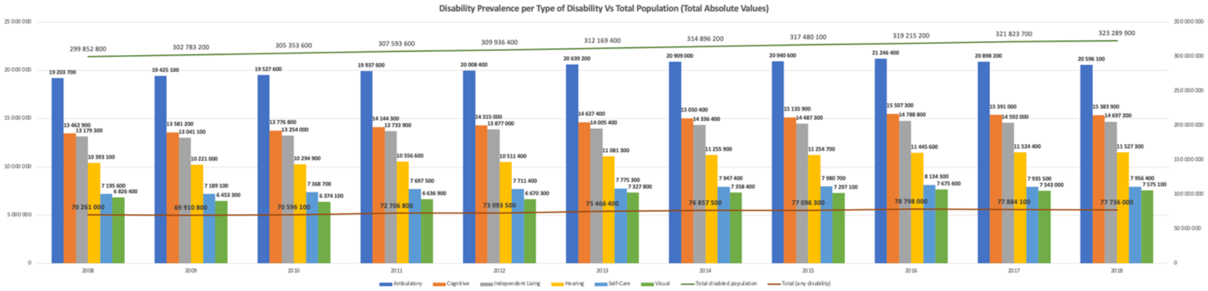

Figure 3.1: Disability prevalence per type of disability vs total population (total absolute values) 2008-2018.

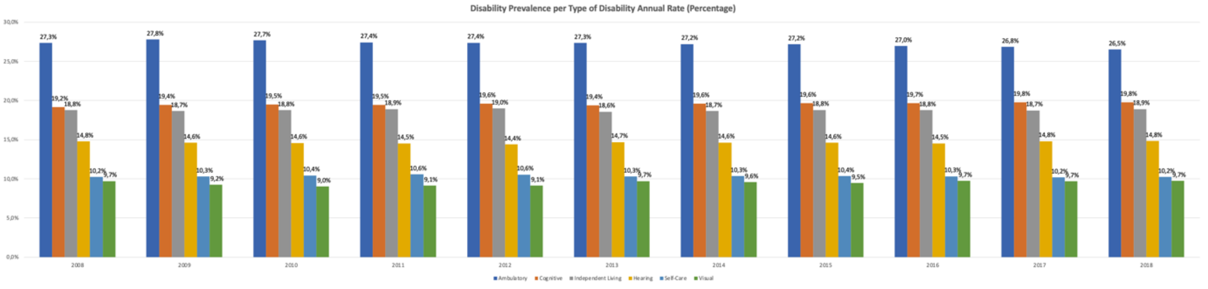

Figure 3.2: Disability prevalence per type of disability annual rate in percentage 2008-2018.

Regarding disability prevalence per gender (see Figure 3.4), women have a higher incidence rate. Despite this, gendered disability distribution remained relatively stable during

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[68] Children below 5 years old were only asked about Vision and Hearing disabilities. The Independent Living disability question was only asked of persons aged 16 and older (Erickson & Schrader 2020, p.10). Focused general trends discrimination by age group offers no relevant information for this study. For a more detailed breakdown, see https://disabilitystatistics.org/reports/acs.cfm?statistic=1.

the period under review, with it never varying more than 1% between the highest prevalence rate of 52.5%, registered in 2008 and 2009, and the lower prevalence rate of 51.4% in 2017. Despite its relative stability, the relative prevalence of disability in women dropped in 2018 (51.6%) when contrasted with 2008 (52.5%), falling -0.9%, leading to a -1.8% gender gap reduction from 5% in 2008 to 3.2% in 2018. Despite disability's prevalence gender gap reduction, the gendered distribution of disability has remained virtually unchanged over the years, with its variations not being expressive.

In absolute numbers (Figure 3.3), the increase has been steady but slow, with the total variation between year 1 (2008) and year 11 (2018) being +1,957,300 for the female gender and +2,459,200 for the male gender. As to the gender gap, the largest gap (5%) was recorded in both 2008 (1,804,600) and 2009 (1,829,300), with the shortest, 1,128,500, a 2.8% differential, being registered in 2017. As observable in Figures 3.3 and 3.4, the gendered distribution of disability was predominantly female in relative and absolute values throughout the period under review (2008-2018).

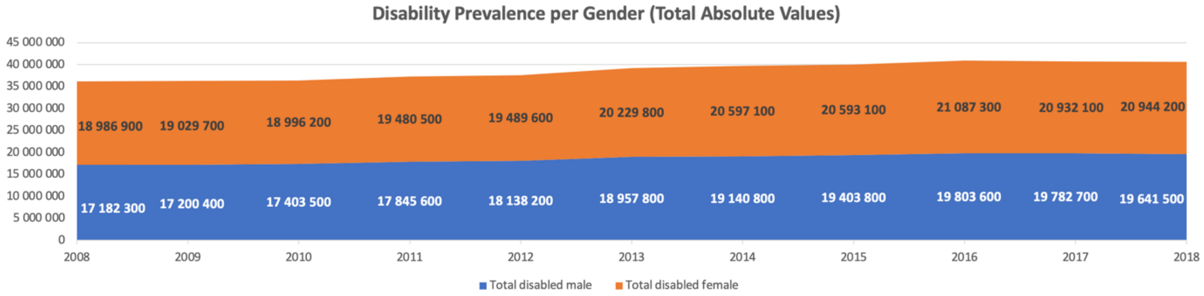

Figure 3.3: Disability prevalence per gender (total absolute values) 2008-2018.

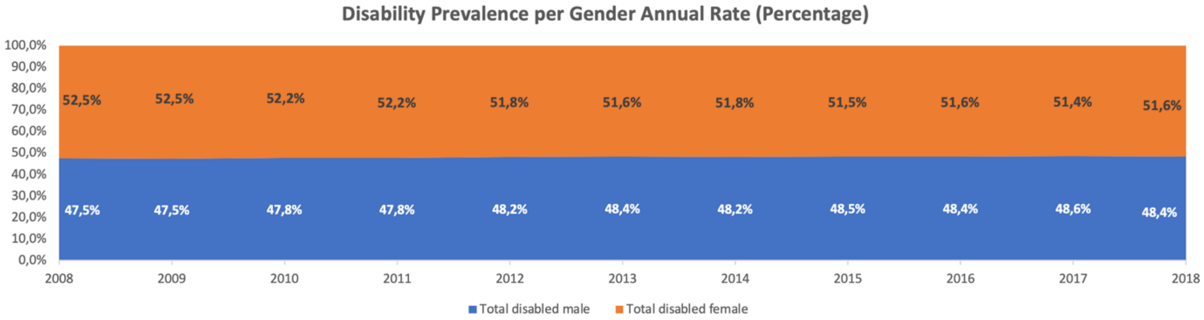

Figure 3.4: Disability prevalence per gender annual rate in percentage 2008-2018.

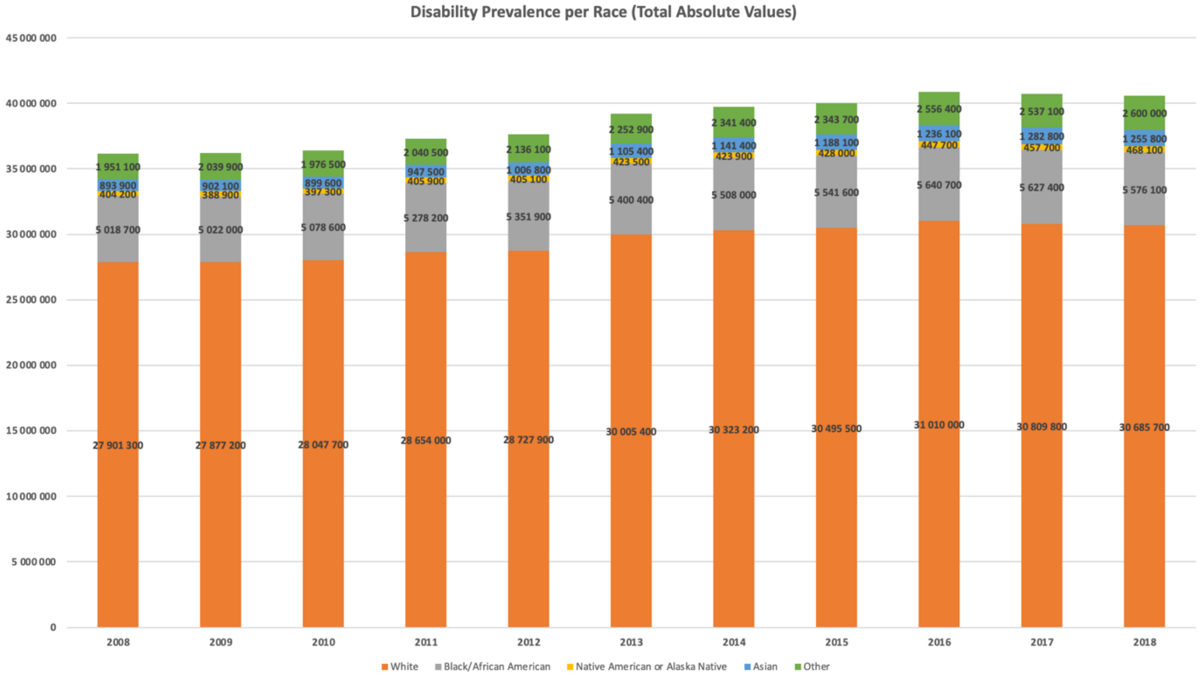

Figure 3.5:Disability prevalence per race (total absolute values) 2008-2018.

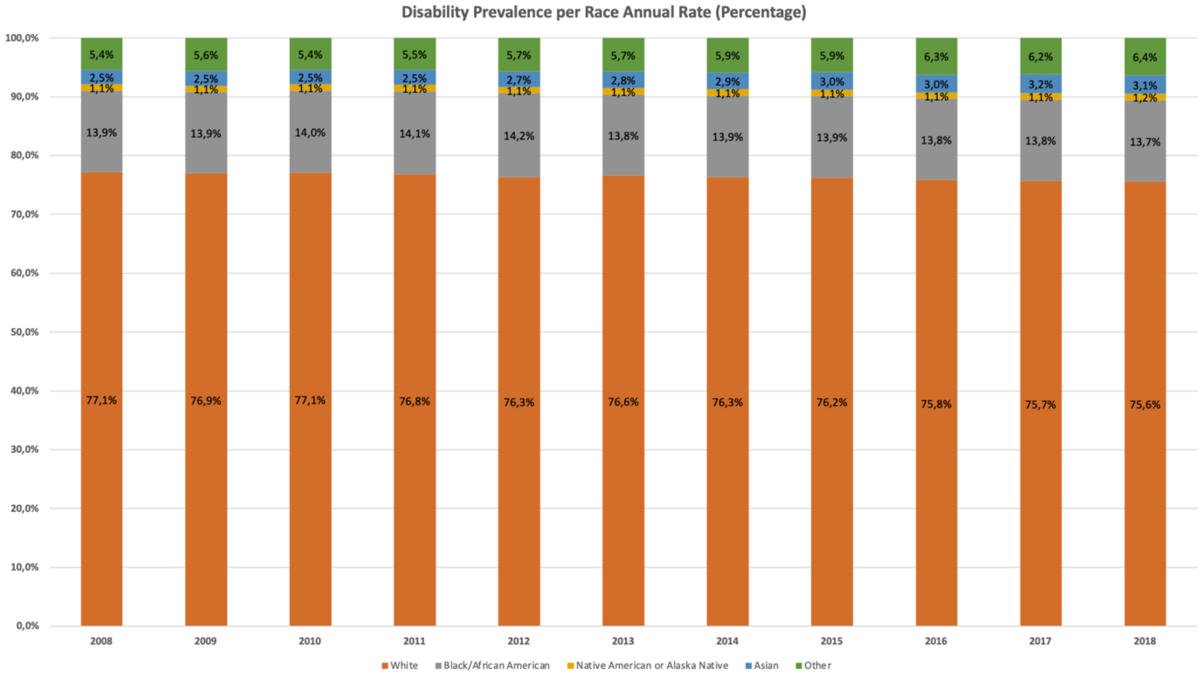

Figure 3.6: Disability prevalence per race annual rate in percentage 2008-2018.

The observable gender gap in Figures 3.3 and 3.4 is also verifiable across the multiple races recognized by the U.S. government. As seen in Figures 3.7 and 3.8 below, the female gender predominance is transversal to race with a few exceptions like the racial group ‘other’, which in 2012 had 17,500 more males than females with disabilities, and in 2017, 2,700 more males than females. The other exception, recorded in 2018, was the Native American or Alaska Native racial group, which recorded 500 more males than females with disabilities.

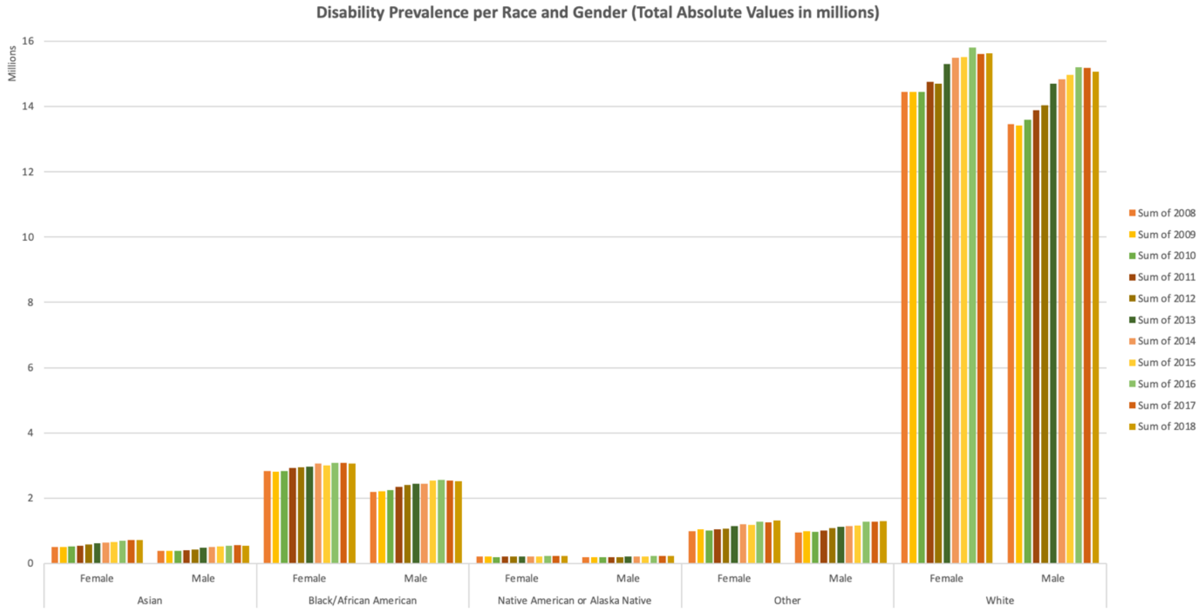

Figure 3.7:Disability prevalence per race and gender (total absolute values in millions) 2008-2018.

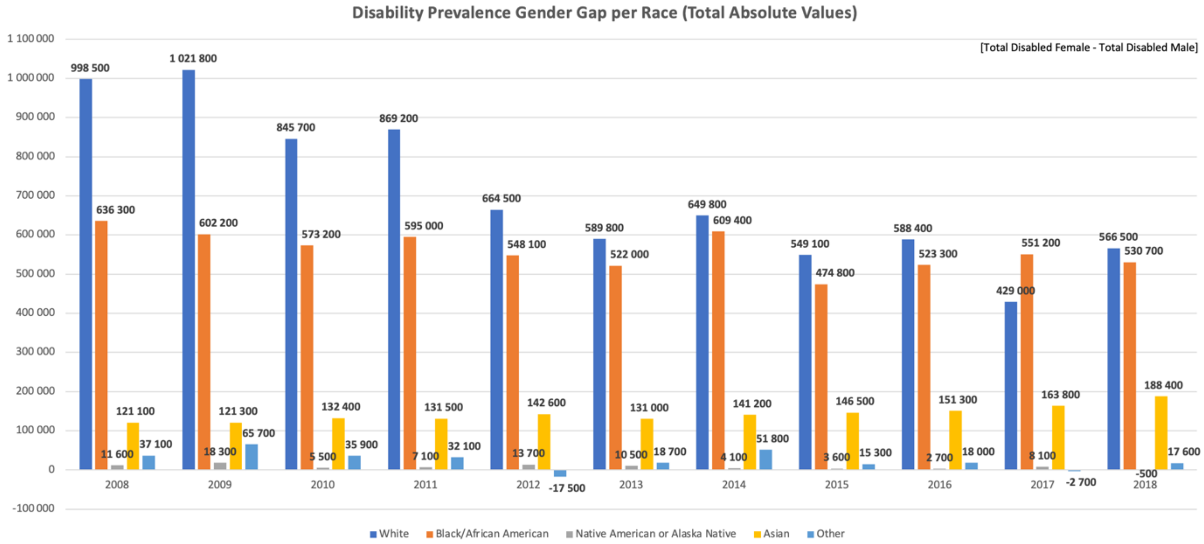

Figure 3.8: Disability prevalence gender gap per race (total absolute values) 2008-2018.

Overall, while none of the exceptions in Figure 3.8 is significant to alter the predominant gender, there are nonetheless significant changes in the gender gap composition of the different racial groups. As shown in Figure 3.9, the most noticeable change is in the white racial group, with the female gender gap decreasing by 11.8%, from 55.3% in 2008 to 43.5% in 2018. On the other hand, both the Black/African American and the Asian racial groups increased their gender gaps, with disabled women increasing their representation by 5,4% in the Black/African American, from 35.3% in 2008 to 40.7% in 2018, and by 7.8% in the Asian racial group, from 6.7% in 2008 to 14.5% in 2018. While the overall trend continued to be female, it is possible to verify that the disabled population's gender gap has been changing its composition. Although not in the scope of this study, it is important to understand the causes of such gender gap transformations. Is it a result of new data collection methods? Are males breaking through disability's stigma and self-stigma by reporting previously undisclosed disabilities? Are males disproportionately affected by the U.S. military's service-connected disabilities?

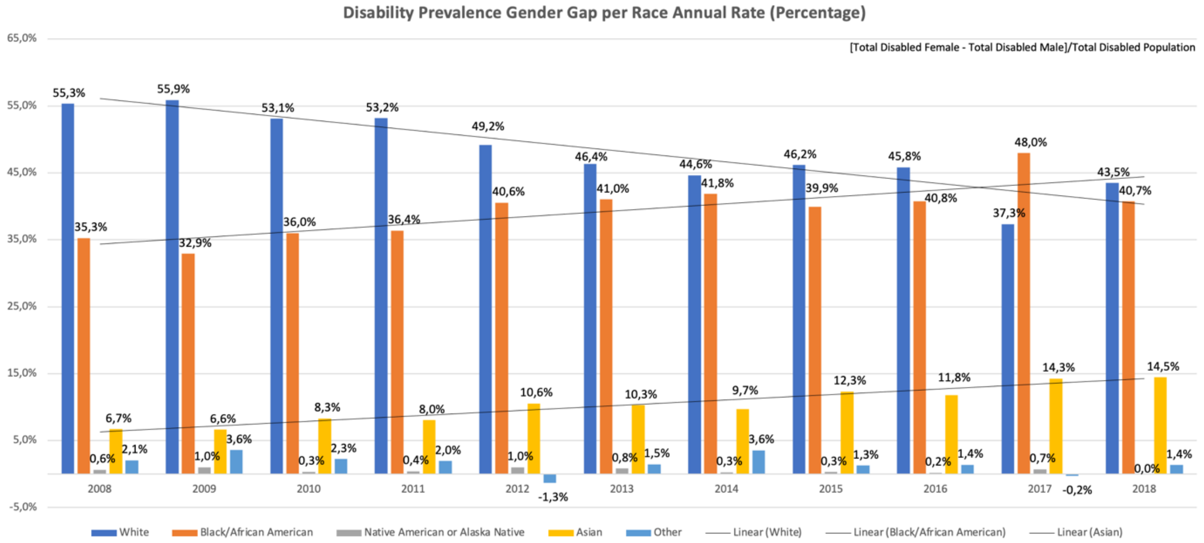

Figure 3.9: Disability prevalence gender gap per race annual rate in percentage 2008-2018.

3.2 Employment

Relatively to employment, it is also possible to verify stark differences not only between disabled and non-disabled but also within the disabled population. Not only are the disabled and non-disabled employment profoundly distinct in volume, as was expected considering their populations (see Figure 3.10), but these are also in clear contrast regarding employability. With disabled people's employment rate being around 35% and the non-disabled around 77% of their respective populations (see Figure 3.11), it is clear the wide employment gap. In this thesis, I will not just enumerate the peculiarities of the employment disability gap but also highlight some causes and issues that might explain this gap.

Although it is important to refer that the post-2008 employment decrease followed the Great Recession that occurred from December 2007 to June 2009[69], disabled employment levels, as shown in Figure 3.11, have failed to catch up with pre-crisis levels in the 11 years

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[69] As registered by the National Bureau of Economic Research (https://www.nber.org/research/data/us-business-cycle-expansions-and-contractions).

under review despite the longest economic expansion registered during this period[70]. Furthermore, while the non-disabled population employment rates in 2018 levelled with 2008's values (80,0% in 2018 vs. 79,9% in 2008), disabled people's employment rates failed to recover by 2018, with its value of 37.8% being below 2008's values (39.5%) by -1.7%. As seen in Figure 3.12, the annual employment rate difference between the disabled and non-disabled population shows a continuously increasing gap from 2008 to 2012 (+2.4%), followed by a slight gap reduction (-0.5%) in 2013, immediately followed by a new increase between 2014 and 2015 (+0.8%). The gap reduced again in 2016 (-0.4%) and 2017 (-0.6%), slightly increasing once more in 2018 (+0.1%), with the final differential being 42.2% in 2018, a +1.8% gap differential increase over the 11 years under review.

With this said, not only have disabled people relatively lost employment share (Figure 3.11), but the employment gap between disabled and non-disabled populations has also increased (Figure 3.12) despite the growing number of disabled people with employment (Figure 3.10) and the virtually uninterruptedly increase in the employment levels up to late 2018, further increasing until the COVID-19 crisis, as demonstrated by Figure 3.13.

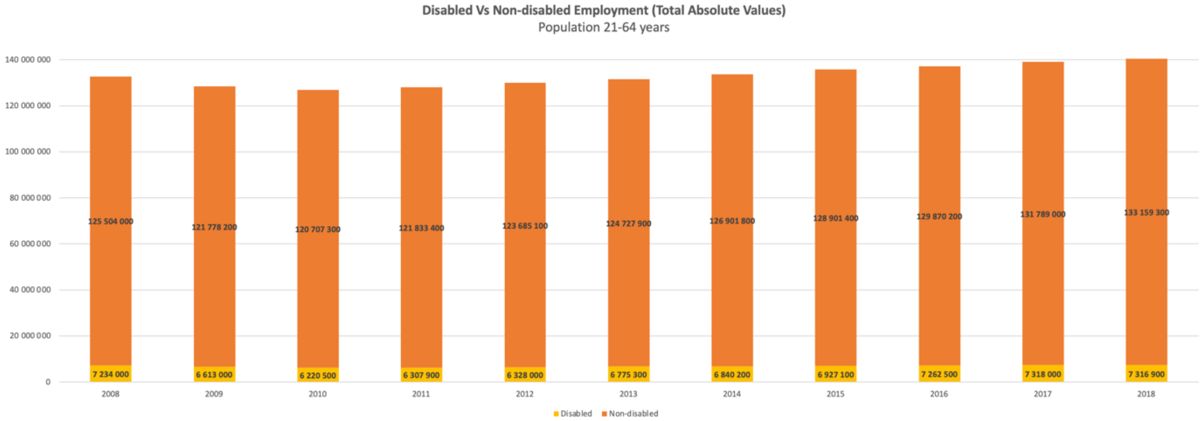

Figure 3.10: Disabled vs non-disabled population employment among people aged 21 to 64 years (total absolute values) 2008-2018.

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[70] As registered by the National Bureau of Economic Research, the period between the Great Recession of 2008 and the Covid-19 crisis represents the longest period between recessions (https://www.nber.org/research/data/us-business-cycle-expansions-and-contractions).

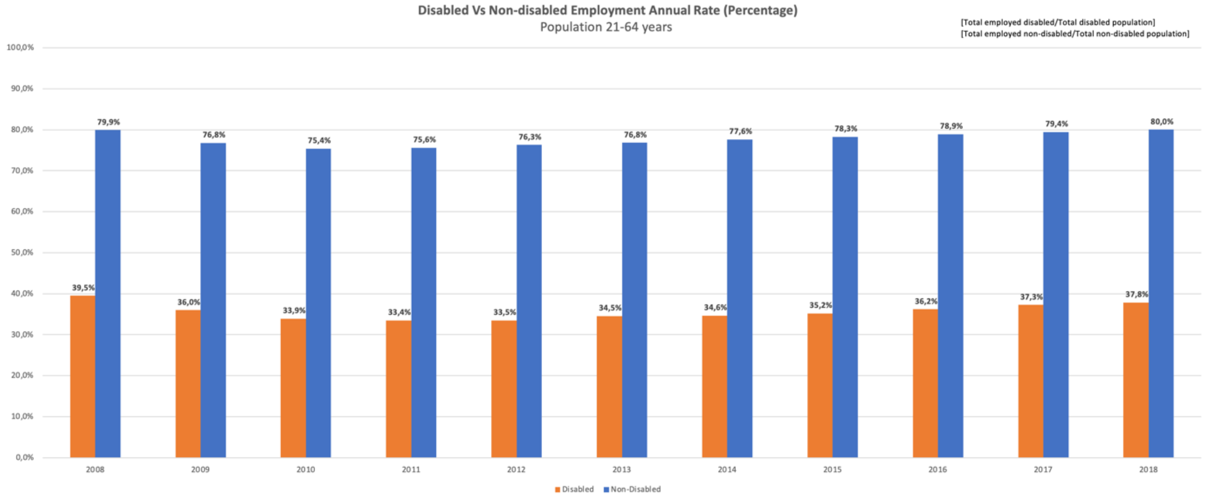

Figure 3.11: Disabled vs non-disabled population employment annual rate among people aged 21 to 64 years in percentage 2008-2018.

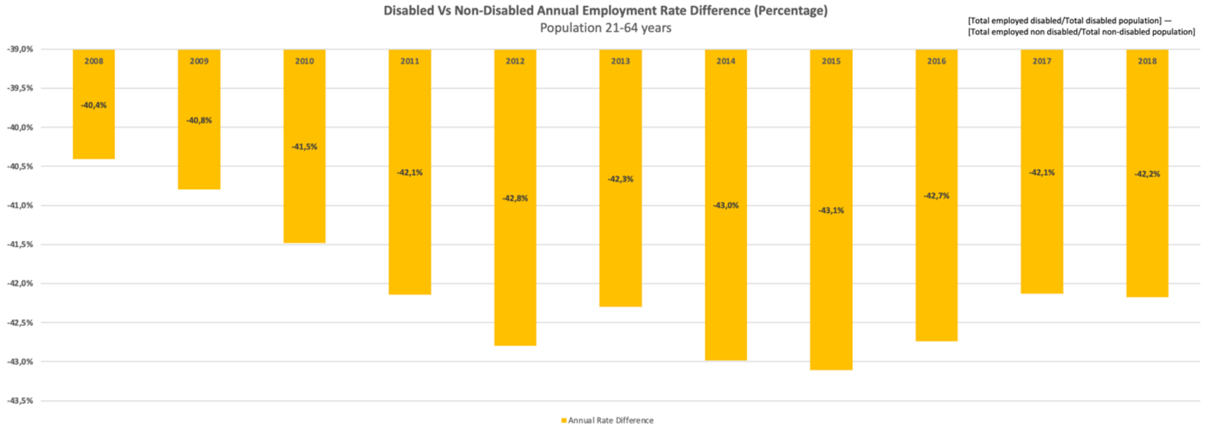

Figure 3.12: Disabled vs non-disabled population annual employment rate difference among people aged 21 to 64 years percentage 2008-2018.

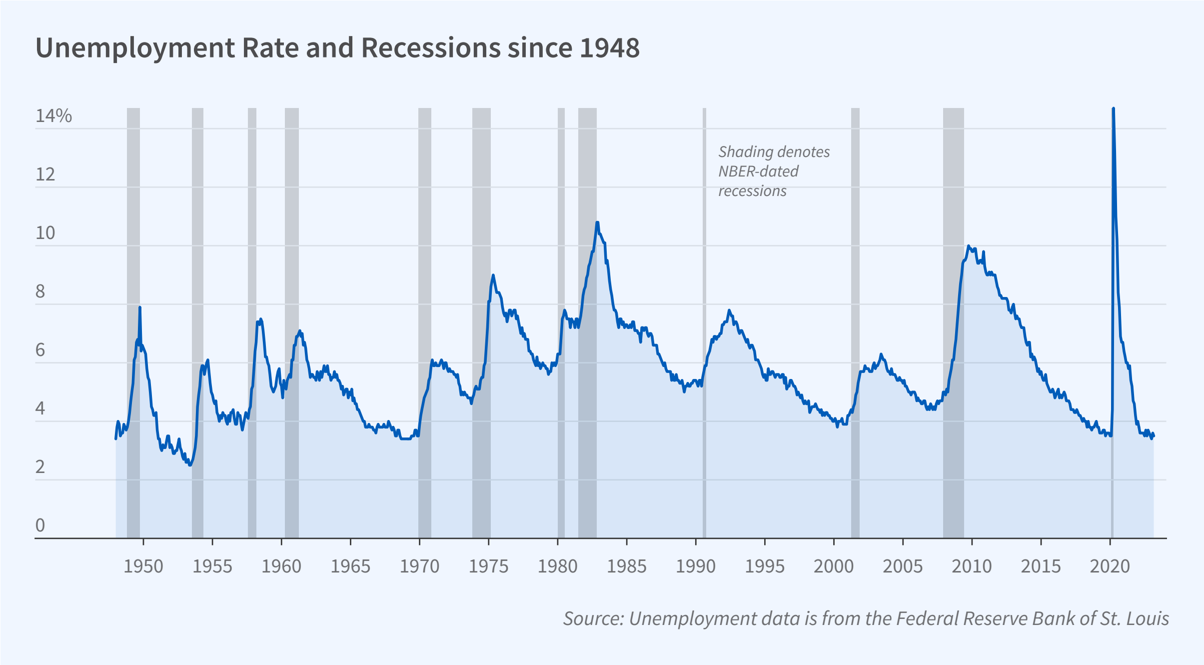

Figure 3.13: Unemployment rate and recessions since 1948 as registered by the U.S. National Bureau of Economic Research (https://www.nber.org/research/business-cycle-dating).

Regarding gender (see Figure 3.14), despite the gap among disabled workers, as with the non-disabled population, the gender gap is significantly less pronounced than the disability gap. Whereas disabled females score lower in annual employment rates every year by an average of -5.4% when compared to disabled males, when employment rates are contrasted by disability prevalence, the gap is significantly larger to the point where it can be argued that gender is secondary when characterizing disabled people's employment[71]. In addition, another piece of evidence that for employment disability status precedes that of gender, when contrasting the gender gaps between non-disabled and disabled employed workforce, it is verifiable that the non-disabled gender gap (11.2%) is almost double the existing gender gap within disabled workers (5.8%), showing that for non-disabled workers gender plays a much more central role than it does for the disabled workforce.

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[71] I do not mean that gender gaps are not relevant within the disabled community. Socio-economic and demographic gaps always have concrete and real consequences.

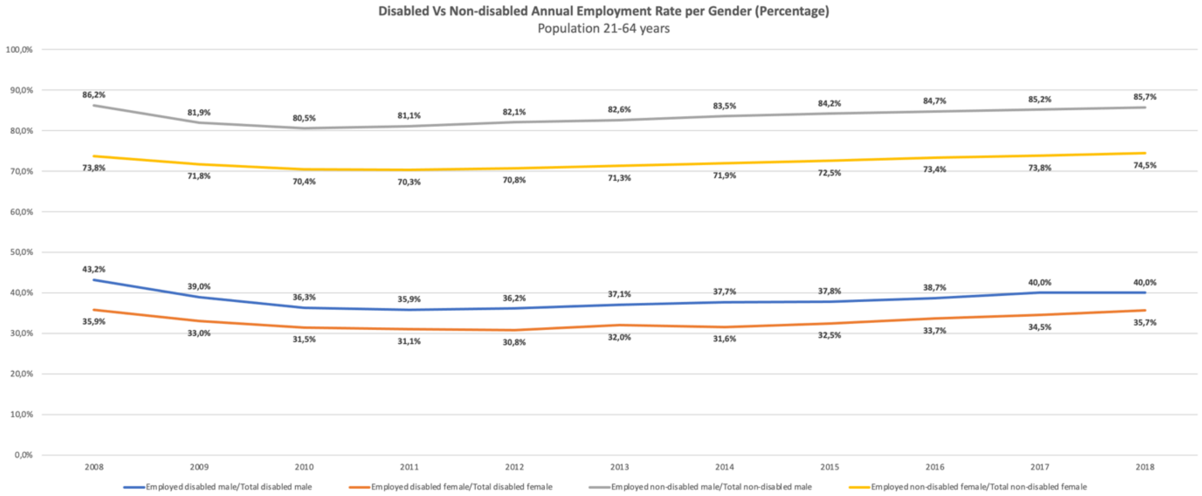

Figure 3.14: Disabled vs non-disabled population annual employment rate per gender among people aged 21 to 64 years in percentage 2008-2018.

One characteristic is, however, peculiar. When disabled workers' employment rate is studied by race and gender (Figures 3.15 to 3.17), it comes to light that despite the female gender having an overall lower employment rate in most racial groups, both Black/Afro-American and Native American or Alaska Native racial groups have, contrarily to the norm, a higher employment rate for the female gender, as is clearly observable in Figure 3.17. This thesis identifies thus a research gap relative to Black/Afro-American and Native American or Alaska Native employment rates disparate tendencies. This is especially significant in the Black/Afro-American racial group, where the difference between genders is the most expressive. With the largest gap recorded in 2011 (19%), most years present a stable gap of 14.3%, with it being the minimum gap. With an average rate of 15.11% across all years, the Black/Afro-American employment gendered gap is thus unique, contradicting expectations. As to the other races, only the White racial group comes close to matching the Black/Afro-American recorded averages, with white disabled males having a gap on average of 11.51% across the same period (2008-2018). As to the Native American or Alaska Native employment gendered gap, it follows a less stable pattern than the Black/Afro-American, since not all years present a positive female gap, with 2008 (7.0%), 2010 (2.1%), and 2011 (12.2%), being male predominant.

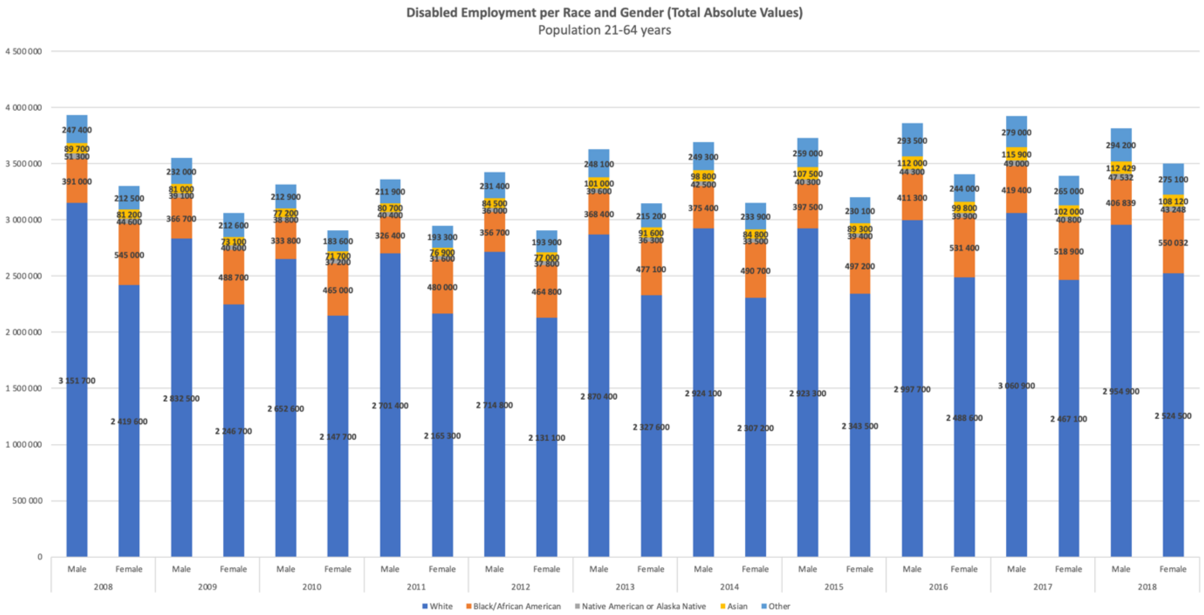

Figure 3.15: Disabled population employment per race and gender among people aged 21 to 64 years (total absolute values) 2008-2018.

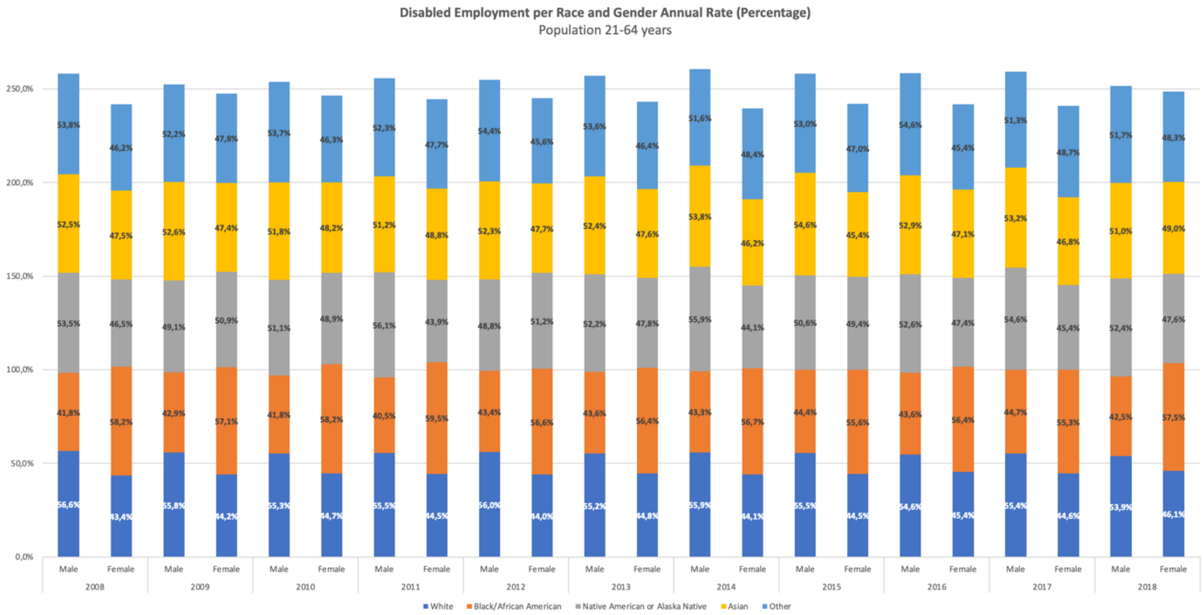

Figure 3.16: Disabled population employment per race and gender among people aged 21 to 64 years annual rate in percentage 2008-2018.

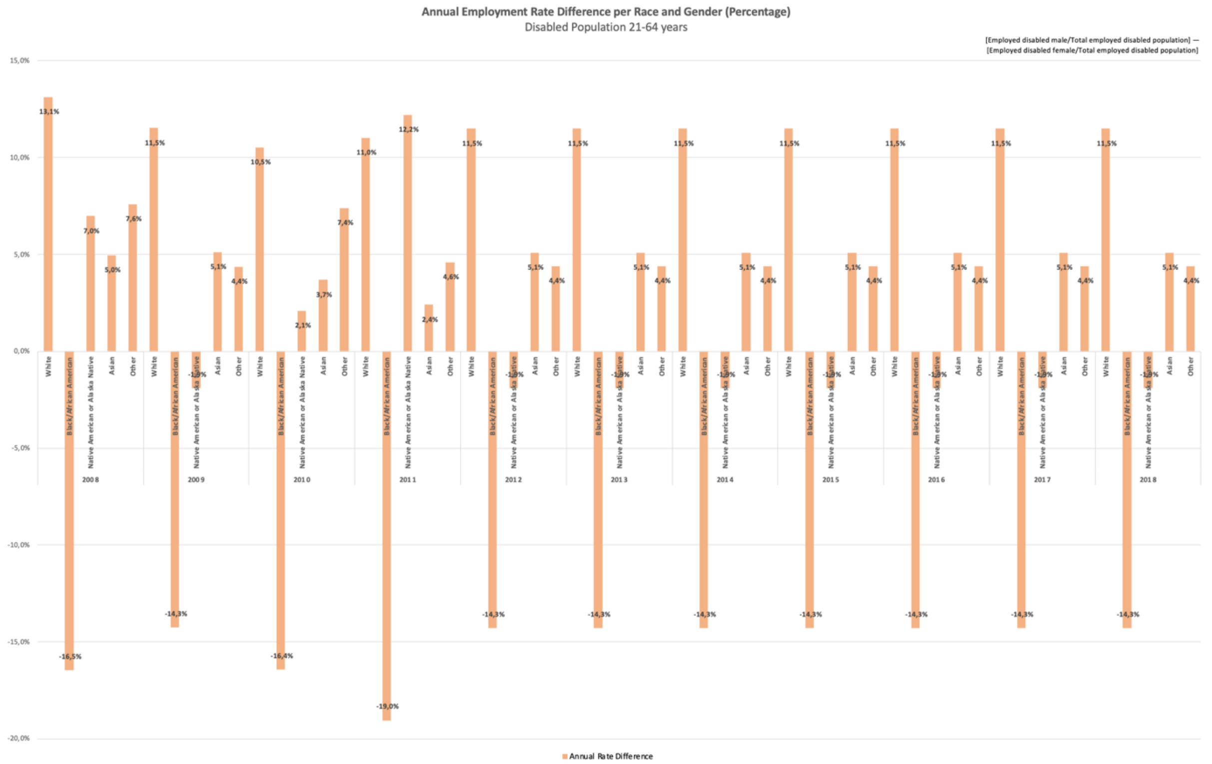

Figure 3.17: Disabled population annual employment rate difference per race and gender among people aged 21 to 64 years in percentage 2008-2018.

Finally, it is important to review employment by employment type (full-time vs. part-time) (see Figure 3.18).

Full-time employment follows the macroeconomic trend of post-crisis recovery (see Figure 3.13). As unemployment drops, full-time employment rises both for the disabled and non-disabled population alike. However, recovery rates differ, with the non-disabled falling less and recovering more and faster than the non-disabled. Both groups' full-time employment fell until 2010, with the disabled full-time employment rate declining by 2.4% from 64.2% in 2008 to 61.8% in 2010 and the non-disabled by 2.3% from 75.6% in 2008 to 73.3% in 2010. The non-disabled full-time employment rate has, since 2010, generally and continuously increased except for 2012 and 2013, where it was constant at 73.9% for both years. Finally, by 2018, non-disabled full-time employment recovered its pre-crisis levels surpassing 2008's full-time employment rate (75.6%) by 0.8% to 76.4%. On the other hand, for the disabled full-time employment rate, the evolution followed a similar pattern, however, at a slower pace. Contrary to the non-disabled rate, which started to improve by 2011, disabled people's full-time employment decline was longer, from 64.2% in 2008 to 61.8% in 2011, with both 2010 and 2011 having the same rates (61.8%). Relatively stable from 2012 to 2015, varying by 0.1%, from 62.5% in 2012 to 62.4% in 2013, to 62.5% in 2014 and 2015, it was not until 2016 that the disabled people full-time employment rate (63.4%) started going up. Despite continuous recovery from 2015-2018, it was only in 2018 that disabled people's full-time employment rate, 64.3%, surpassed its 2008 levels (64.2%), and only by 0.1% —a much shorter growth than the 0.8% registered by the non-disabled population. When compared to 2008 rates (75.6%), the non-disabled full-time employment rate had already surpassed its pre-crisis levels by 2017 (75.9%) by 0.3%, while disabled full-time employment rates in 2017, 64.1%, continued below 2008 levels by 0.1% (64.2%).

Regarding part-time employment, the evolution is inverted, with both disabled and non-disabled part-time employment rates increasing in the post-crisis years to later fall below pre-crisis levels by 2018.

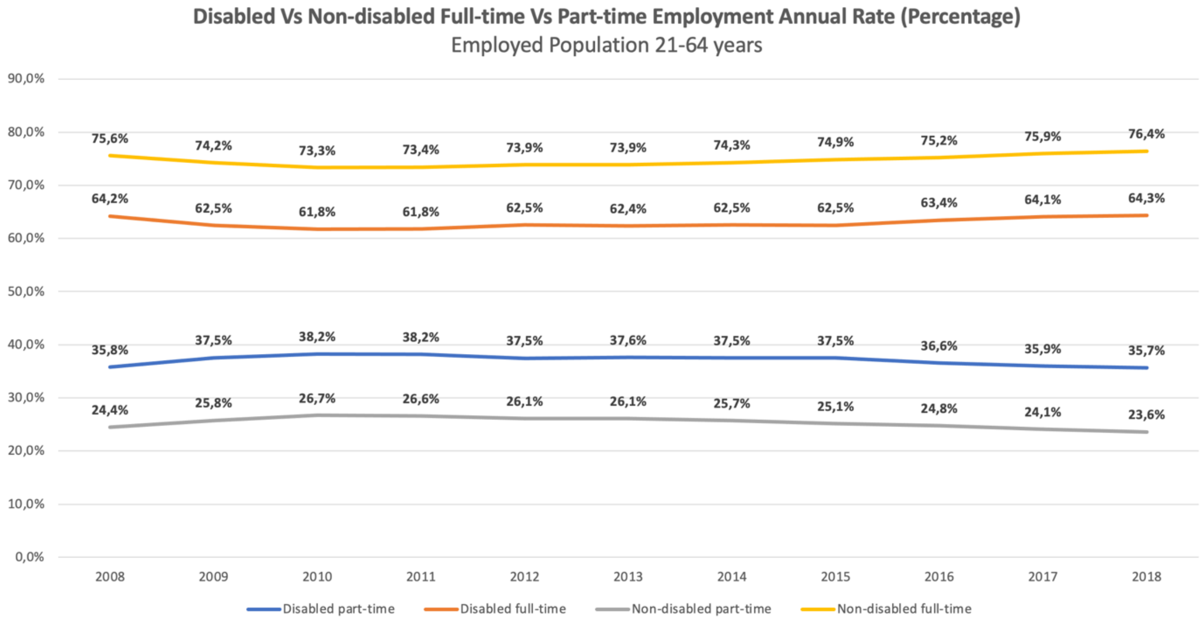

Figure 3.18: Disabled vs non-disabled full-time vs part-time employment among employed people aged 21 to 64 years annual rate in percentage 2008-2018.

As to causes that explain disabled people’s low employment rates, these are varied, complex, and interrelated. First, some scholars point to the ADA as having negative impacts on employment (Jolls, 2000; see also Acemoglu & Angrist, 2001; DeLeire, 2001; Stapleton & Burkhauser, 2003)[72]. More recent studies also point to the fact that disabled workers tend to be

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[72] Despite no study being able to demonstrate that the ADA has had positive impacts on employment or poverty rates in its first decade, it is important to retain that the ADA was thought of as an antidiscrimination statute, not as a promoter of employment (Colker 2005, p.69-70). While discrimination impacts employment rates, it was not the most cited factor regarding employment precarity. U.S. Bureau of Labor Statistics data from 2019 shows that discrimination was not the main barrier to disabled people's employment, with one's disability (79.0%), lack of education or training (12.2%), lack of transportation (10.6%), and the need for special features in place of employment

found in declining occupations (Kruse et al., 2010). Past estimates for the period 2008-2018, coincident with the years under review, had projected disabled people to be overrepresented in 19 of the 20 fastest-declining occupations while simultaneously underrepresented in 17 of the 20 fastest-growing occupations (Schur et al., 2013, p.46), a factor which can help explaining the higher rates of unemployment or of precarious employment that characterizes disabled people in the U.S. Educational attainment, as will be mentioned, is another factor influencing disabled people employment. With disabled people historically performing poorly in educational settings, which remains the norm today, the disabled workforce is less equipped to adapt to changing demands. This is true for both the U.S. and worldwide context (OECD 2010, 27-28)[73]. Finally, physical limitations and individual needs, which can impair the capacity to work at full-time rates, legal barriers to employment, where employment can result in disability benefits eligibility loss, or simply disability stigma and prejudice, all contribute to explaining disabled people's historically low employment rates. With “compelling evidence” that “employers have stigmatized attitudes” towards disabled people (Scheid, 2005), and with disabled workers reporting feeling “passed over”, “demoted”, or “fired” (Hipes et al. 2016, p.16), forgoing job applications to avoid discrimination (e.g., Brouwers et al., 2016; Üçok et al., 2012; van Beukering et al., 2021), or avoiding promotions that could potentially disclose their disability (Bricker-Katz et al., 2013), it is hard to ignore the impacts that stigma has on disabled people higher unemployment and underemployment (for more on stigma see pages 18-20).

Despite the multitude of factors involved, the most reasonable explanation to describe disabled people’s lower employment rates would be a combination of all the above-mentioned factors, with these varying from individual to individual.

3.3 Annual Earnings

Relatively to full-time employment median annual earnings, the disparities between the disabled and non-disabled populations are equally evident. As demonstrated in Figure 3.19, the full-time employment median earnings gap has increased in 2018 when compared to 2008

(9.9%), all weighing more than employer or coworker attitudes (7.6%) (https://www.bls.gov/opub/ted/2020/barriers-to-employment-for-people-with-a-disability.htm).

[73] Furthermore, it was estimated by the National Council on Disability, relying on data collected by the Department of Labor, that approximately 321,131 thousand disabled people were working under 14(c) certificates for subminimum wages (NCD 2018, pp.26-27). For more on disabled people working under 14(c) certificates for subminimum wages, see South Carolina Advisory Committee to the U.S. Commission on Civil Rights, 2021; see also U.S. Commission on Civil Rights, 2020.

levels. Whereas in 2008, the gap was 12.5% or $5,100, with non-disabled workers full-time median earnings being $40,700 and disabled workers $35,600, in 2018, the full-time employment median earnings gap increased from $5,100 to $8,700 or 17.7%, a $3,600 increase. Despite disabled workers earning more than +$4,900 on average in 2018 ($40,500) than in 2008 ($35,6000), the median earnings gap overall increase shows the impoverishment of disabled workers relative to workers without disabilities.

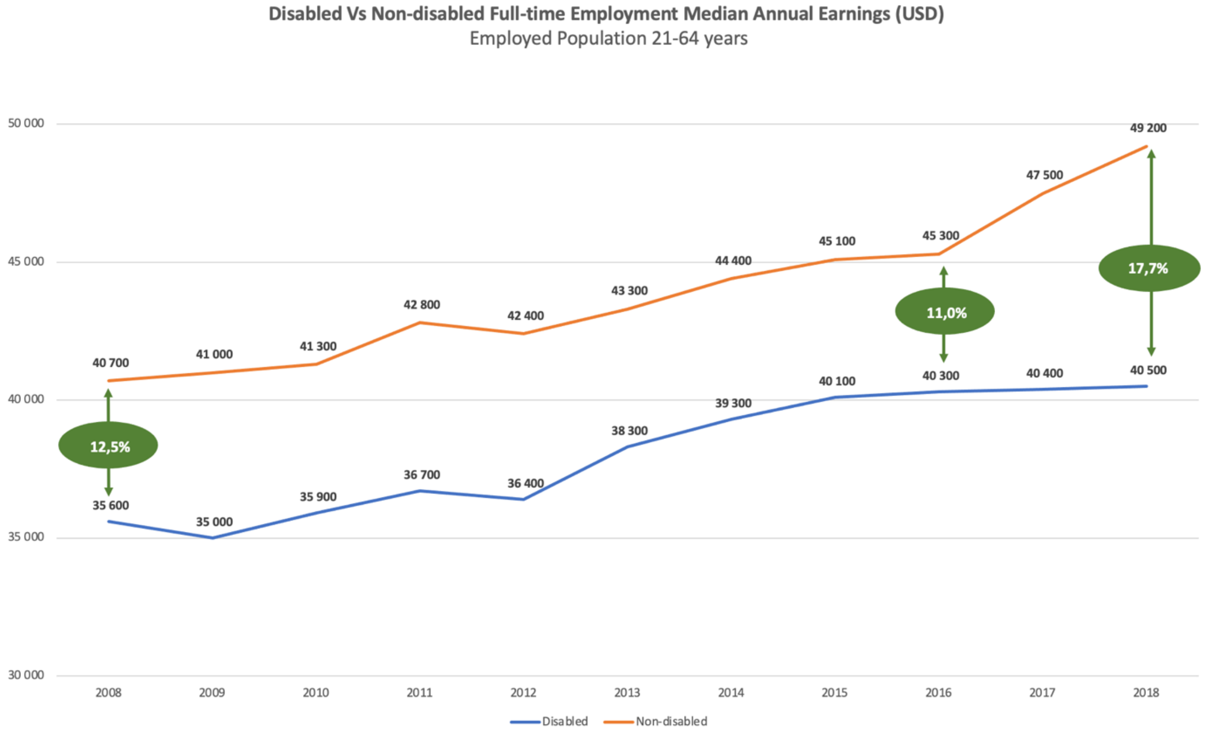

Figure 3.19: Disabled vs non-disabled full-time employment median annual earnings among employed people aged 21 to 64 years in USD 2008-2018.

Figure 3.19, above, shows that full-time employment median earnings had a positive albeit unequal growth for both disabled and non-disabled workers alike. Relatively to non-disabled workers' full-time employment median earnings evolution, it increased almost uninterruptedly from 2008 to 2018, with 2012-2018 having a more rapid growth than the post-crisis years of 2008-2011, especially between 2016 and 2018. Whereas from 2008 to 2010, non-disabled workers' full-time employment median earnings grew $300 per year, from $40,700 in 2008 to $41,000 in 2009 and $41,300 in 2010; in 2011, it increased $1,500, from $41,300 to $42,800, to then decrease $400 to $42,400 in 2012, an overall increase of +$2,100 from 2008 to 2011. Between 2012 and 2016, the overall median increase was $2,900, from $42,400 in 2012 to $43,300 in 2013, a $900 growth, subsequently increasing $1,100 in 2014 from $43,300 to $44,400, and $45,100 in 2015, a $700 growth. Finally, between 2016 and 2018, the overall full-time employment median earnings increased exponentially by $3,900, with both 2017 (+$2,200) and 2018 (+$1,700) being the years in which the median average grew the most to $47,500 and $49,200, respectively. It was in these last couple of years that the full-time employment median earnings gap between the non-disabled and disabled workers increased, with 2018 representing the largest gap, 17.7% or $8,700, and 2016 the shortest at 11% or $5,000. In 2008, the first year under review, the gap was 12.5% or $5,100.

Relatively to disabled workers' full-time employment median earnings, the evolution, albeit positive in absolute numbers, grew slower than the non-disabled averages, especially since 2015, with its values barely changing. Contrary to non-disabled workers, disabled workers' full-time median earnings declined in 2009 from $35,600 in 2008 to $35,000 in 2009, a consequence of the 2008 Great Recession, recovering in 2010 ($35,900) and 2011 ($36,700), with the 2010 values ($35,900) being already above the median values of 2008 ($35,600). Declining in 2012, much like it happened with non-disabled workers, disabled workers had in the next couple of years, from 2012 to 2015, the largest median full-time earnings increase from $36,400 in 2012 to $38,300 in 2013 (+$1,900), to $39,300 in 2014 (+$1,000), to $40,100 in 2015 (+$800).

This fast growth led to the median earnings gap between disabled and non-disabled full-time workers to fall to its minimum in 2016 (11% or $5,000). However, from 2015 to 2018, disabled workers' full-time median earnings stabilized, with its yearly increase being much shorter than in preceding years, from $40,100 in 2015 to $40,300 in 2016, a $200 growth, to $40,400 in 2017 and $40,500 in 2018, both years with a $100 growth. This stagnation, paired with non-disabled workers' 2016-2018 rapid earnings growth, increased the gap between disabled and non-disabled full-time earnings. Furthermore, when inflation-indexed (real earnings)[74], disabled workers' full-time median earnings declined in 2018 compared to 2008. Disabled workers' full-time median earnings in 2008 ($35,600) would be approximately $41,540 in 2018 if adjusted to inflation, a higher value than the $40,500 median earnings reported in 2018 by around $1,040. Disabled workers have, therefore, not only become relatively poorer than non-disabled workers, with a larger median earnings gap in 2018 than in 2008 but also objectively poorer with a lower purchasing power under sub-standard wages despite full-time earnings nominal increase.

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[74] Inflation's cumulative value from 2008-2018 is 16.69%. For data on inflation see, e.g., https://www.officialdata.org/us/inflation/2008?endYear=2018&amount=35600.

The same is verifiable when comparing Max & Min full-time employment earnings as depicted in Figure 3.20. Although slightly different in values, the overall trend is the same, with the Max earnings gap more unequal in 2018 ($8,350 or 16.9%) than in 2008 ($4,830 or 11.8%). Furthermore, whereas between 2008 and 2018, disabled workers' full-time Max earnings increased by $5,000 or 12.2%, from $35,970 to $40,970, non-disabled workers' full-time Max earnings increased by $8,520 or 17.3%, from $40,800 to $49,320, a $3,520 or 5.1% difference between both groups, showing once more the centrality disability plays for individual financial health.

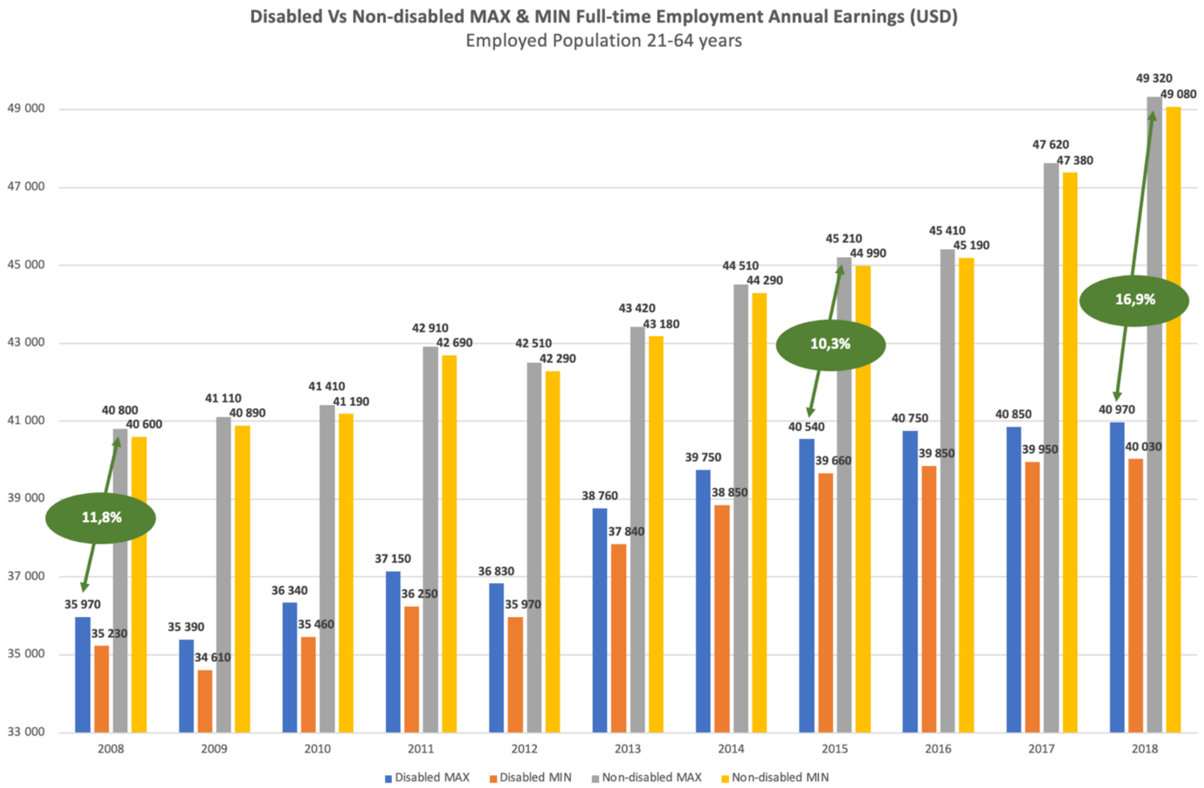

Figure 3.20: Disabled vs non-disabled Max & Min full-time employment annual earnings among employed people aged 21 to 64 years in USD 2008-2018.

Finally, regarding household median annual income (Figures 3.21 and 3.22 below), there is another verifiable large gap between disabled and non-disabled households. As to the post-2008 crisis recovery, Figure 3.21 shows that only in 2013 for non-disabled households, and in 2014 for disabled households, did the household median annual income recover its 2008 pre-crisis levels. Despite household median income recovery being initially slower than full-time employment earnings, when inflation adjusted, it is possible to verify, contrary to full-time employment median earnings' evolution, that both disabled and non-disabled households had a real median growth when comparing 2018 with 2008 values.

However, much like it happened with full-time employment median annual earnings, despite household median income increasing for both non-disabled (from $61,200 in 2008 to $74,400 in 2018, a $13,200 increase) and disabled households (from $39,600 in 2008 to $46,900 in 2018, a $7,300 increase), the income growth fell short of closing the gap between disabled and non-disabled households. Despite evolving uninterruptedly positively from 2013, disabled household median income failed to recover to its pre-crisis gap levels (35.3%), managing nevertheless to reduce the peak gap levels of 2011 (39.2%) to 37.0% in 2018.

Similarly to Max & Min full-time employment earnings analyzed above, so too do Max & Min household income present a trend that shows the same discrepancies and inequalities portrayed by household's median income evolution, displaying likewise the unequal growth between disabled and non-disabled household income over the 11 years under review (2008-2018). With this said, while disabled household income has grown both in median ($7,300 or 15.5%) and Max ($7,440 or 15.7%) income, the relative gap between disabled and non-disabled households increased, showing again, like in full-time employment earnings, that being disabled/having a disability is a likely indicator of relative poverty in present-day America.

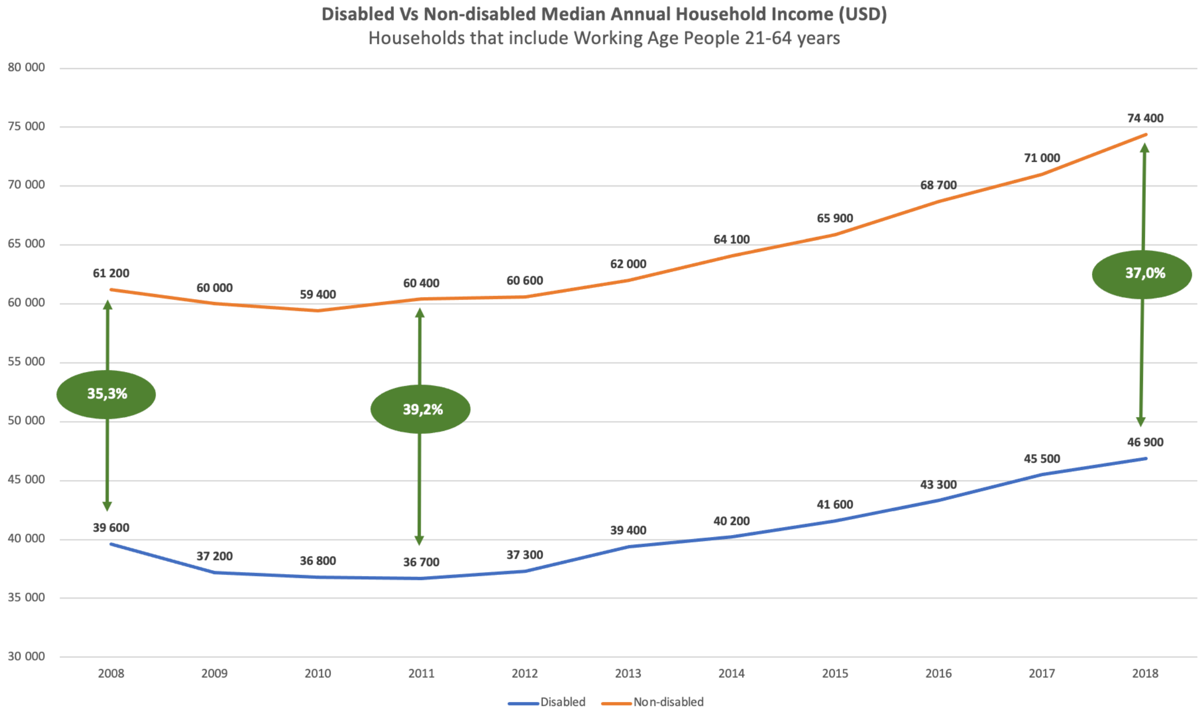

Figure 3.21: Disabled vs non-disabled Median annual household income among households that include working age people aged 21 to 64 years in USD 2008-2018.

Figure 3.22: Disabled vs non-disabled Max & Min annual household income among households that include working age people aged 21 to 64 years in USD 2008-2018.

3.4 Poverty

Following the pattern set by disabled people's lower incomes and earnings, it comes as no surprise that poverty incidence is higher among the disabled population than it is among the non-disabled. While in absolute values, the non-disabled population scores higher in poverty incidence (Figure 3.23), when analyzed in percentage rate (Figure 3.24), the reality changes, with disabled people faring far worse.

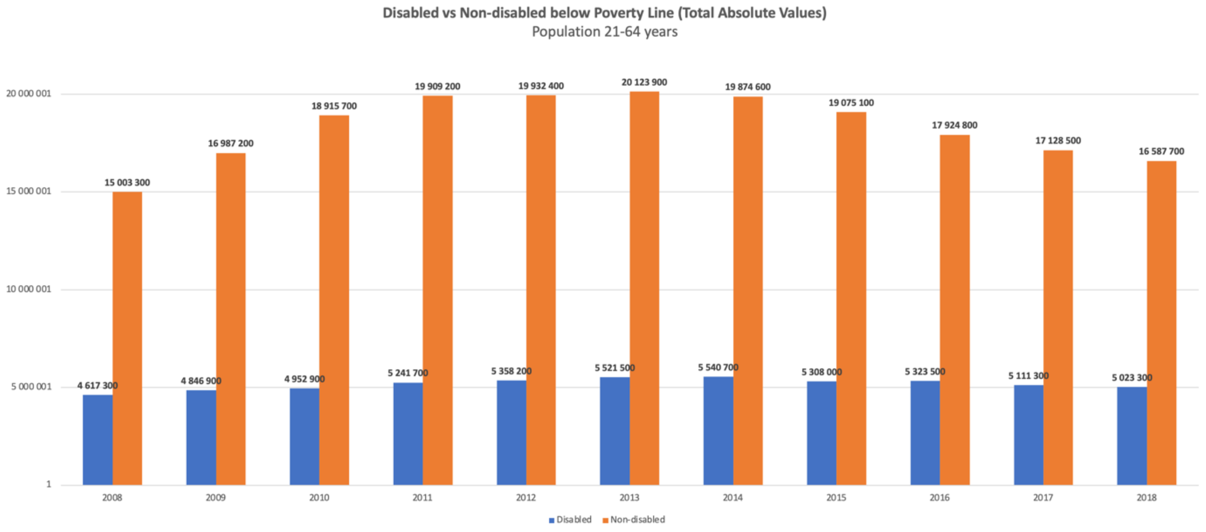

Figure 3.23: Disabled vs non-disabled population below poverty line among people aged 21 to 64 years (total absolute values) 2008-2018.

As expected, poverty incidence rates increased in the post-crisis years for the disabled and non-disabled populations (see Figure 3.24). Whereas the non-disabled rates peaked in both 2011 and 2013 with 12.4% of the non-disabled population below the poverty line, disabled rates peaked in 2012 with 28.4% of the disabled population below the poverty line. Despite the rates improving overall in the latter years from 2013-2018 for the non-disabled and from 2012-2018 for the disabled population, neither group managed to have their 2018 rates, 10.00% for the non-disabled and 26.0% for the disabled population, lower than their pre-crisis levels —a possible result from real wage decrease, as shown before.

When comparing disabled and non-disabled poverty peaks, 2012 with 2011/2013, respectively, vs. 2018 levels, it is possible to verify that both groups have improved, or reduced, their poverty incidence rate by the same ratio of 2.4%, with disabled people improving from 28.4% in 2012 to 26% in 2018, and non-disabled improving from 12.4% in 2011 and 2013 to 10% in 2018.

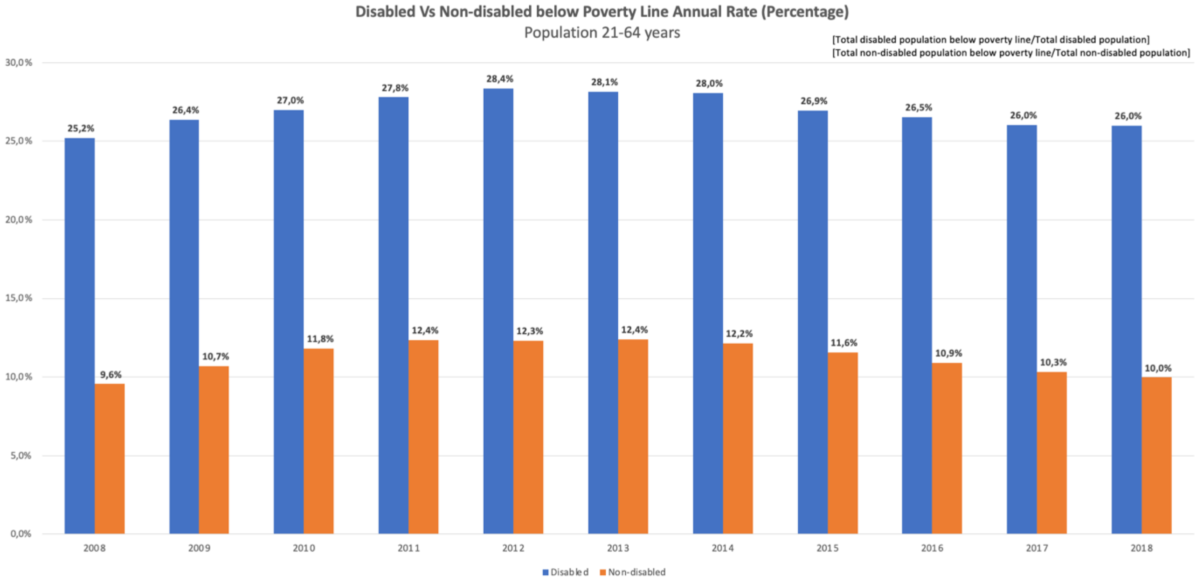

Figure 3.24: Disabled vs non-disabled below poverty line among people aged 21 to 64 years annual rate in percentage 2008-2018.

As to the poverty gap between the disabled and non-disabled population (Figure 3.25), it is observable that the gap increased throughout the period under review, with it being 16% in 2018, while in 2008, the gap was 15.7%, a 0.3% increase. Although it improved in the post-crisis years of 2010 (15.2%) and 2011 (15.4%), with both years scoring lower than 2008 (15.7%), this is not due to the disabled population's poverty reduction but instead to non-disabled population's rising poverty rates, making the gap reduction far from a positive indicator of welfare, but instead of general impoverishment. 2012 is the year with the worst gap. Disabled people had not only the worst year in terms of population below the poverty line (28.4%) but also the largest relative gap between disabled and non-disabled populations below the poverty line (16.1%) between 2008 and 2018. Not only did disabled people fail to improve their pre-crisis levels by 2018, the poverty gap between disabled and non-disabled below the poverty line increased. Like previous indicators, the annual rate of people below the poverty line shows the relative impoverishment disabled people face in present-day America.

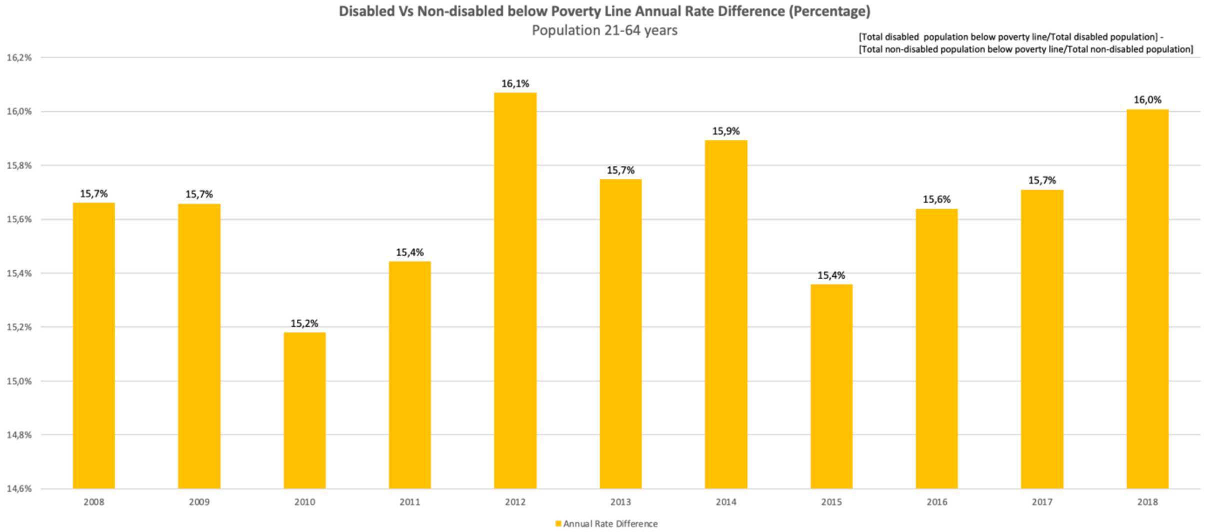

Figure 3.25: Disabled vs non-disabled population below poverty line annual rate difference among people aged 21 to 64 years in percentage 2008-2018.

3.5 Supplemental Security Income (SSI)

Supplemental security income is a supplement given to disabled people who have limited income or resources, not confined to institutions (hospitals or prisons) run on public funding[75]. As expected, the disabled population receiving SSI increased during the post-crisis years from 17.7% in 2008 to 19.9% in 2012, a 2.2% increase, decreasing to 19% (-0.9%) in 2018. As with other indicators, despite recovering in comparison to post-crisis years, 2018 values remain higher than 2008 values.

Considering that those who are qualified for it are disabled people whose accumulated income and resources fall below $2,000 a month for an individual and $3,000 for a couple, it is safe to say that a higher percentage of the disabled population between 21-64 years old is at risk of poverty and social exclusion, which resembles the findings in Figure 3.11, which shows

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[75] For an overview of the program, see Morton, 2014. As noted by Morton, the countable resource limit for SSI eligibility ($2,000 for individuals and $3,000 for couples) was set in 1989 and is not inflation-indexed, leading to the progressive decline of the real value stipulated by SSI's eligibility criteria, tightening the program's eligibility requirements (Morton 2014, p.6).

a decrease in disabled people employment from 39.5% in 2008 to 37.8% in 2018. As to the steep recovery in 2013, where the attribution of SSI fell by 1%, it can be attributed to the general economic improvement of disabled people in the U.S., both in employment earnings, which saw a $1,900 median increase from 2012 to 2013 (see Figure 3.19), as well as to a higher household median annual income with a yearly $2,100 increase from 2012 to 2013 (see Figure 3.21).

Further studies are needed to understand the exact causes of such a steep decline between 2012-2013, especially considering that from 2012 to 2018, the variation rate was only 0.9%. The abrupt 2012-2013 variation makes it an anomaly that deserves further study.

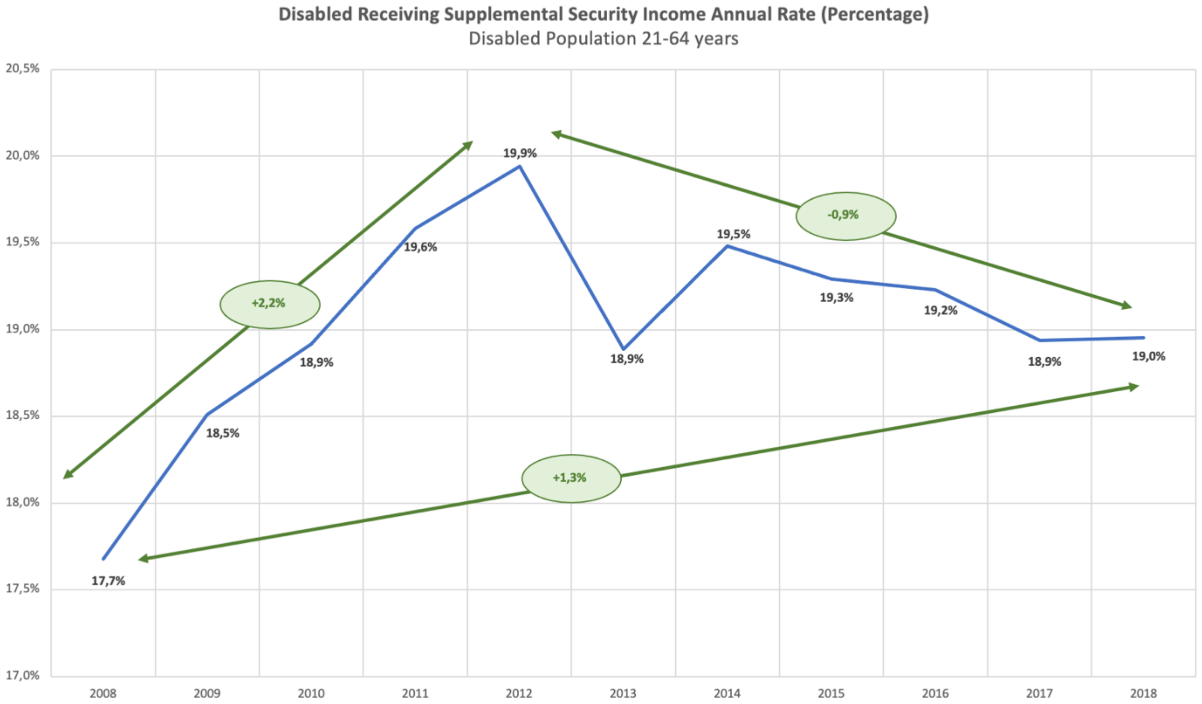

Figure 3.26: Disabled population receiving Supplemental Security Income (SSI) among people aged 21 to 64 years annual rate in percentage 2008-2018.

3.6 Educational Attainment

Regarding Educational attainment, I will focus mainly on highlighting the disability gap between both disabled and non-disabled populations (see Figure 3.31), showing that educational attainment is directly related to lower household income and higher poverty rates. These are not just consequences of a lower education but also causes. Considering the higher cost of education in the U.S., households with less financial possibilities and higher poverty rates tend to invest less in education. With this said, since absolute values tell us little about the impacts educational attainment has on the different groups under review, Figures 3.27 and 3.28 are included more as generalities than targets of analysis.

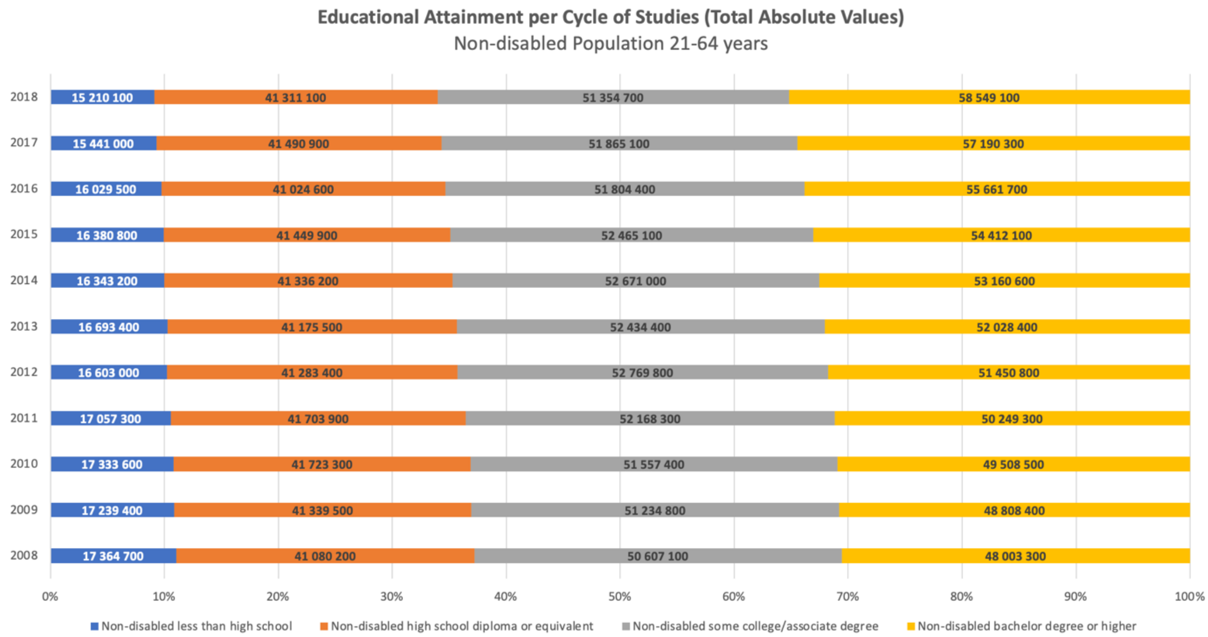

Figure 3.27: Non-disabled population educational attainment per cycle of studies among people aged 21 to 64 years (total absolute values) 2008-2018.

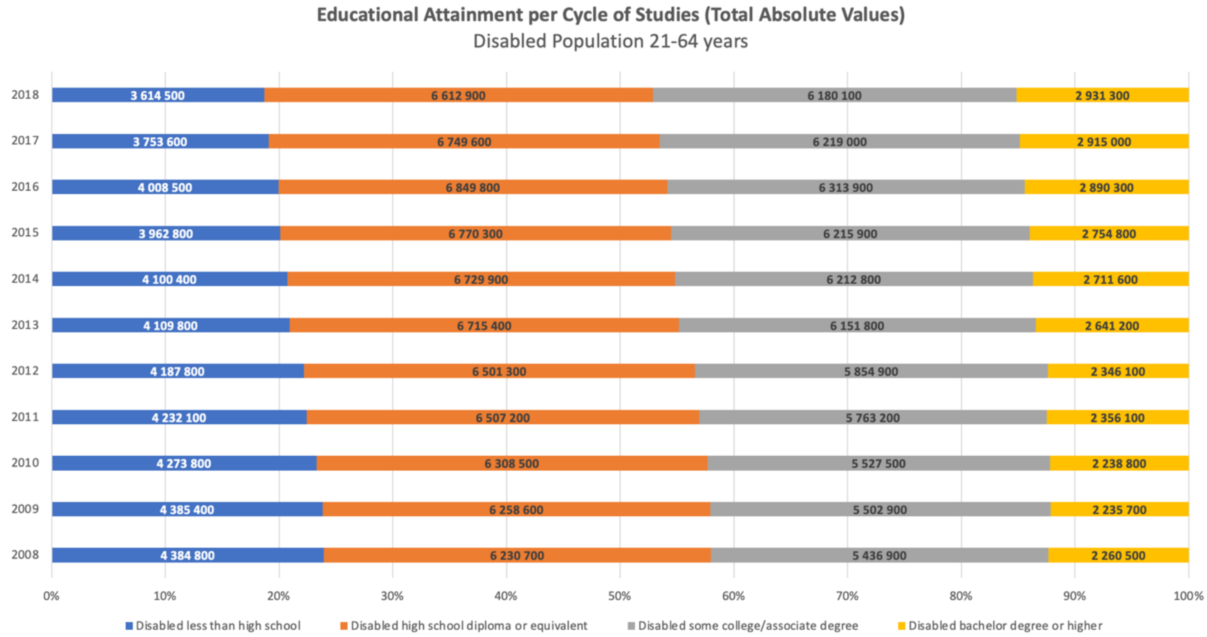

Figure 3.28: Disabled population educational attainment per cycle of studies among people aged 21 to 64 years (total absolute values) 2008-2018.

Focusing on Figure 3.29, a clear trend is observable: the increase in people with higher education. In comparison to 2008, those with a bachelor's degree or higher are the group whose value increased the most, from 30.6% in 2008 to 35.2% in 2018, a 4.6% increase. On the other hand, those with less than high school continuously reduced their weight from 11.1% in 2008 to 9.1% in 2018, a 2% decrease, coincidentally also the largest. To this, those with a high school diploma and some college/associate degree followed, with a 1.4% and 1.3% decrease between 2008 and 2018, respectively, from 26.2% to 24.8% (high school diploma or equivalent), and from 32.2% to 30.9% (some college/associate degree). Albeit relatively stable throughout the decade, it is possible to verify a positive trend within the non-disabled population, where more people (+3.3%) completed higher education degrees in 2018, 66.1% held some college/associate degree or a bachelor's degree or higher, than in 2008 (62.8%).

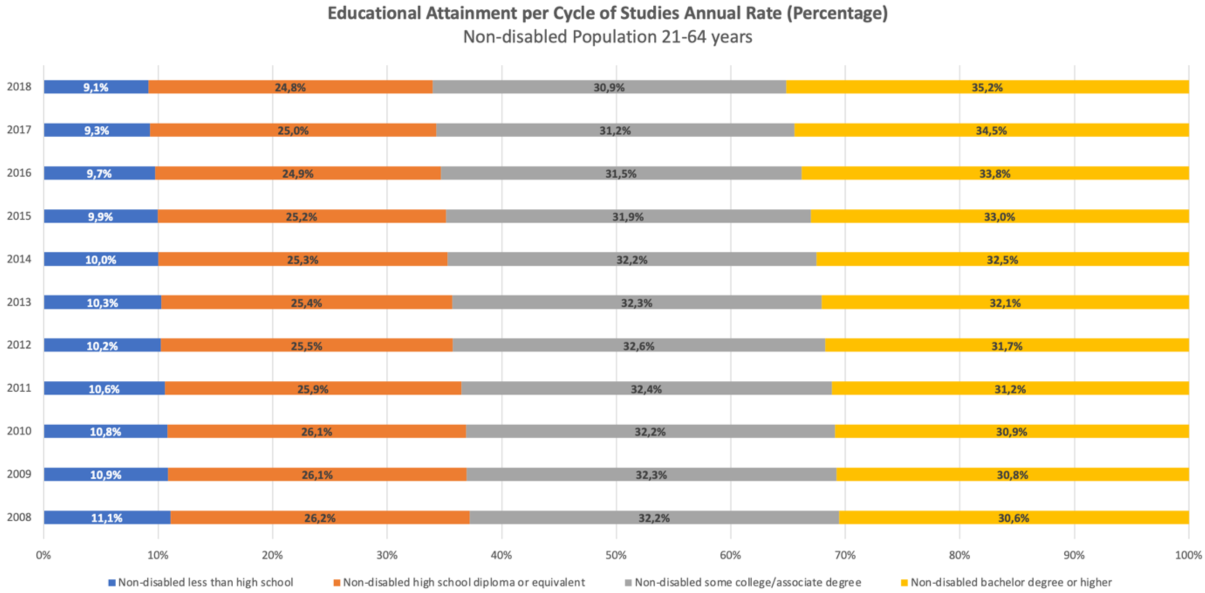

Figure 3.29: Non-disabled population educational attainment per cycle of studies among people aged 21 to 64 years annual rate in percentage 2008-2018.

Relatively to the disabled population's educational attainment per cycle of studies (Figure 3.30), the scenario is somewhat inverted, with most of the population having no higher education. Despite this, it is also verifiable that disabled people have gradually increased the rates of people with higher education, passing from 42% in 2008 (29.7% with some college/associate degree and 12.3% with a bachelor's degree or higher) to 47.2% in 2018 (32% with some college/associate degree and 15.2% with a bachelor’s degree or higher). Despite being below 50% in higher education attainment when contrasted with the non-disabled population (66.1%), the disabled population's educational attainment growth is still positive, growing 5.2% over 2008-2018, a 1.9% relative increase over the non-disabled population's growth over the same period (3.3%), effectively reducing the higher education gap. Regardless of that positive evolution, mainly observable in the reduction of the disabled population with less than a high school diploma and the increase of disabled people with a high school diploma or equivalent and some college/associate degree, the reality remains that most disabled people are under-educated when contrasted with the non-disabled population, with an over-representation in both less than high school and high school diploma or equivalent. Despite disabled people's educational attainment's positive development (Figure 3.30), the educational attainment gap between disabled and non-disabled populations remains (Figure 3.31).

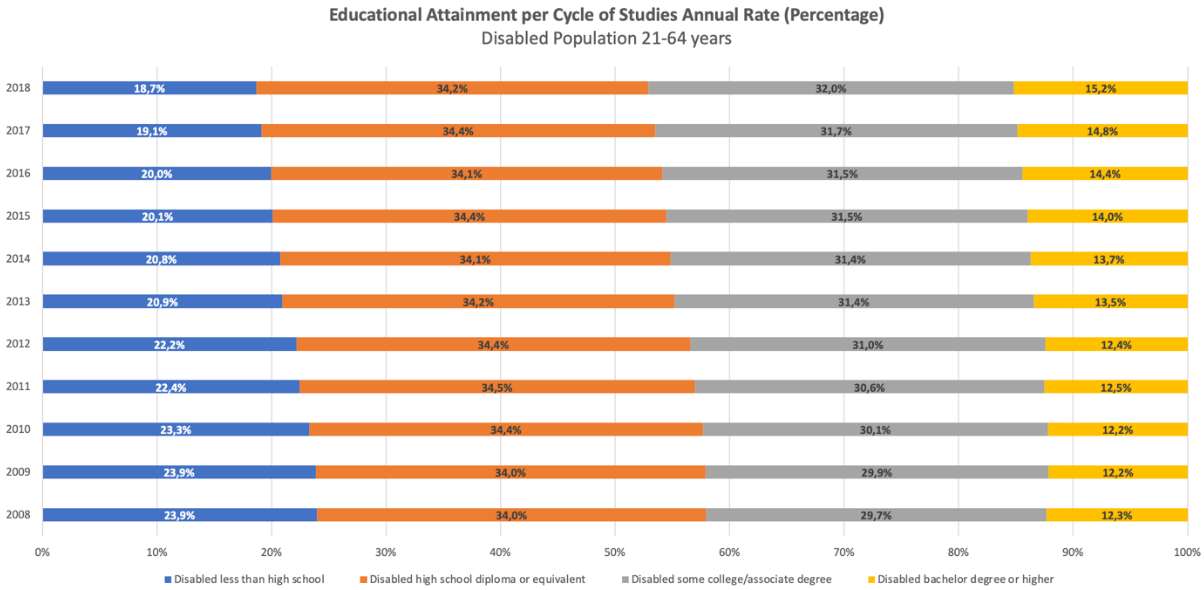

Figure 3.30: Disabled population educational attainment per cycle of studies among people aged 21 to 64 years annual rate in percentage 2008-2018.

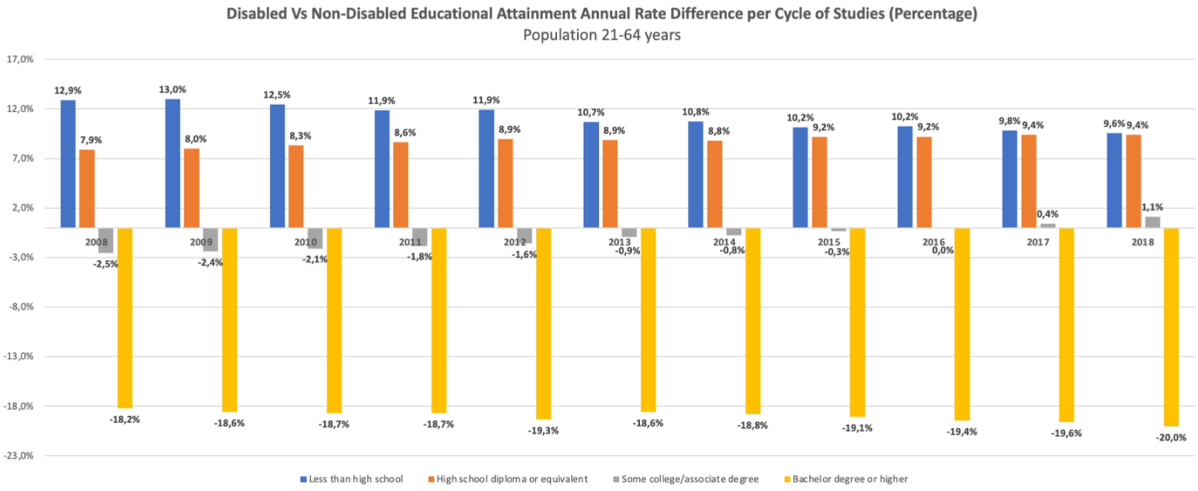

Figure 3.31: Disabled vs non-disabled population educational attainment annual rate difference per cycle of studies among people aged 21 to 64 years in percentage 2008-2018.

When studying educational attainment, especially disabled people’s, it is important to consider the long unequal educational rights history and the lack of access disabled people faced up to the late twentieth century. Still, today, as will be shown below, disabled people face constant prejudice and structural inequalities that negatively impact educational attainment[76].

Racism plays a central role in disabled people's educational attainment in the U.S. As reported by the U.S. Commission on Civil Rights (U.S. Commission on Civil Rights, 2019), disabled students were approximately "twice as likely to be suspended throughout each school level compared to students without disabilities" (p.162). Not only that, but disabled students were also "disproportionately poor, and often students of color", with Black disabled students having a "consistent pattern" of being "suspended or expelled at greater rates than their percentage in the population of students with disabilities", with Black female students being "four times more likely" than their white disabled counterpart to experience school suspensions (p.162). Furthermore, the report concluded that, apart from Hispanics[77] and Asian American disabled students, disabled students of color were more likely to be "expelled without educational services" (p.162), furthering the inequalities that disabled racial minorities are subjected to in their over-penalizing, and under-supported, school experiences. The report concludes thus that the school system's disciplinary methods have proved counterproductive, increasing the likelihood of students' "involvement in the criminal justice system" (p.162).

While students with disabilities served by the Individuals with Disabilities Education Act (IDEA)[78] represent about 12% of the overall student population, they represent, however, 28% of the students who are arrested or referred to law enforcement, with multiracial and minority students with disabilities being "more likely to be referred to law enforcement when compared to white students with disabilities" (p.164). In addition, not only are disabled students more frequently referred to law enforcement, but many SROs [school resource officers] also have poor training, especially in dealing with disabled youth, leading to "law enforcement violating the civil rights of students with disabilities" (p.165). An example of the disparities disabled students face when dealing with law enforcement is the 2015-2016 school year. Despite disabled students making up about 12% of the student population for the year, 71% of the

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[76] Despite the inequalities in educational attainment when comparing disabled with non-disabled populations, it is undeniable the impacts that activism and legislation have had in promoting disabled people's education over the centuries.

[77] Following PEWs' 2019 survey, I have opted to use 'Hispanics' instead of the term Latinx as used in the report since a vast majority of Hispanics (61%) prefer the term Hispanics over Latinx (4%) to denote people of Hispanic heritage (https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/).

[78] The Individuals with Disabilities Education Act of 1990, Pub. L. 101-476, 104 Stat. 1103, suffered important amendments in 2002 with the No Child Left Behind Act, Pub. L. 107-110, 115 Stat. 1425. https://uslaw.link/#q=Pub.%20L.%20107-110%2C%20115%20Stat.%201425.

restrained students by sworn law enforcement officers (SLEOs) were disabled. Poorly trained to deal with disabled students, data clearly shows that SROs increase the likelihood of criminal charges by five times for "disorderly conduct"; in contrast, school counsellors have had the opposite effect in promoting student safety and achievement (p.165).

The report then concludes that schools with greater low-income and/or racial minority students' attendance are more likely to criminalize disruptive behaviors than recognize them as symptoms of an underlying disability, with students of color often being found "ineligible for special education" (p.165). Such disparate treatments result in delayed or lack of specialized assistance to students at risk and in need, contributing to the development of antisocial behaviors, which are known to increase the likelihood of low-income at-risk youth being "funneled into the school-to-prison pipeline" (p.166). When as many as 85% of incarcerated youth have learning and/or emotional disabilities, but only 37% received special education in school, it is hard to ignore a failed institutional school design that is more likely to criminalize disability than to offer "appropriate provision of effective services" (p.166). Regardless of the poor services that most disabled students have access to, the reality is that educational opportunities, while far from acceptable, have considerably expanded in the late twentieth century, offering educational opportunities that were unavailable for older generations. This is in part what explains the lower numbers and rates of disabled people without a high school diploma from 4 384 800 million or 23.9% in 2008 to 3 614 500 million or 18.7% in 2018.

3.7 Health Insurance Coverage

Like previous indicators, it is possible to verify particularities specific to the disabled population[79]. An analysis of non-disabled and disabled populations regarding health insurance coverage shows that disability prevalence leads to different outcomes in health insurance management. While both disabled and non-disabled appear to have similar behaviors regarding

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[79] It is fundamental to note that the universe under review is that of people between the ages of 21 and 64. This segmentation is relevant for the study of health insurance coverage since Medicare is available to everyone over 65 years of age, which significantly impacts health insurance coverage's distribution, which can lead to misrepresentations that a segmented analysis brings forward. For more on the difference between both Medicaid and Medicare programs, see https://www.medicareinteractive.org/get-answers/medicare-basics/medicare-coverage-overview/differences-between-medicare-and-medicaid#:~:text=Medicare%20is%20a%20federal%20program,have%20a%20very%20low%20income.&text=They%20will%20work%20together%20to,coverage%20and%20lower%20your%20costs.

the distribution between the insured and uninsured rates, as observable in Figure 3.33, when analyzed by type of insurance coverage, the picture changes radically.

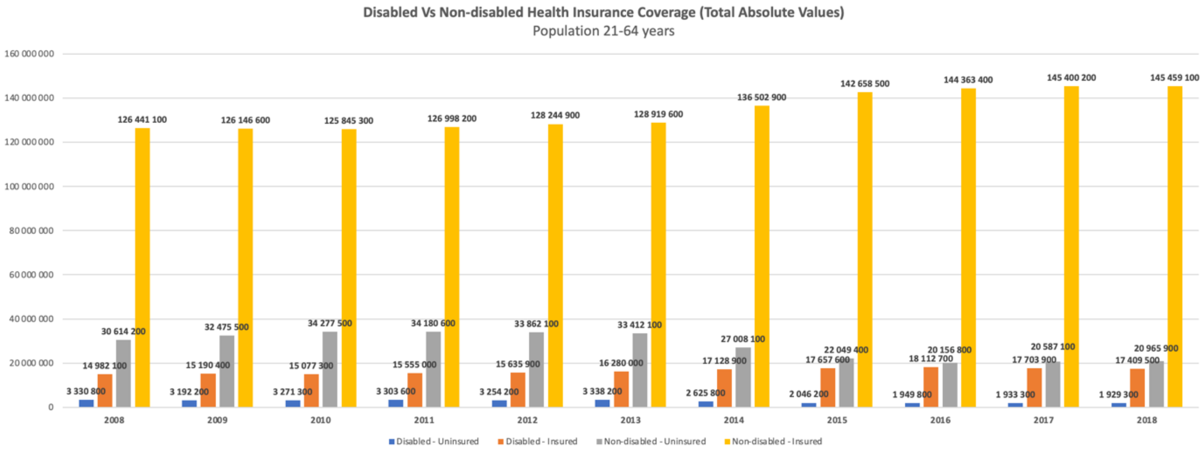

Figure 3.32: Disabled vs non-disabled population health insurance coverage among people aged 21 to 64 years (total absolute values) 2008-2018.

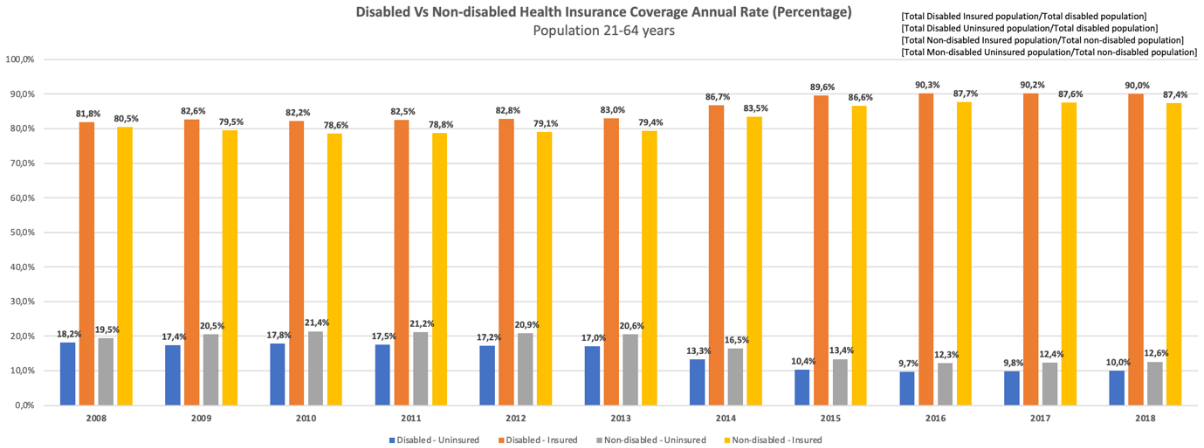

Figure 3.33: Disabled vs non-disabled population health insurance coverage among people aged 21 to 64 years annual rate in percentage 2008-2018.

As verifiable in the figures below, Figures 3.34 to 3.41, the distribution per type of health insurance coverage changes according to the prevalence or absence of disability. As shown in Figures 3.34 and 3.35, regarding the non-disabled population's health insurance coverage type, it is observable that the vast majority, around 70%, relies on employer/union insurance coverage. Despite dropping from 76.2% in 2008 to 70.1% in 2018, the outcomes of that change have little impact since the non-disabled population continues to rely mainly on private insurance obtained via work. The other only notable trend is the increase of Medicare coverage from 5.5% in 2008 to 12.2 in 2018, which more than doubled in 11 years, a substantial increase. Notwithstanding Medicare's coverage growth, it barely affected the overall trends in insurance distribution.

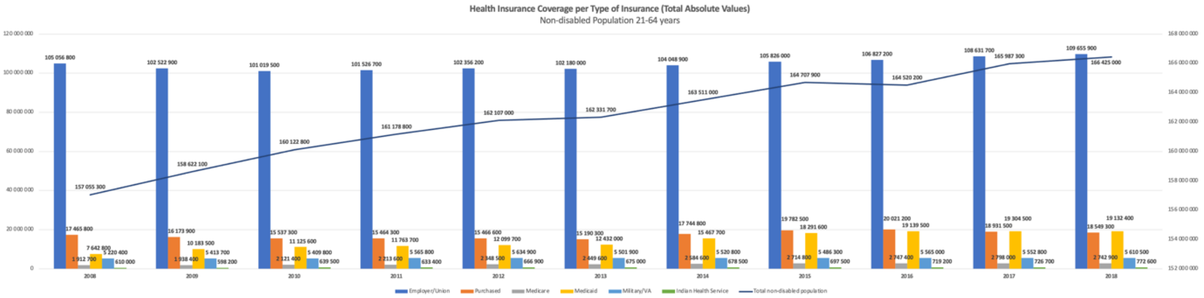

Figure 3.34: Non-disabled population health insurance coverage per type of insurance among people aged 21 to 64 years (total absolute values) 2008-2018.

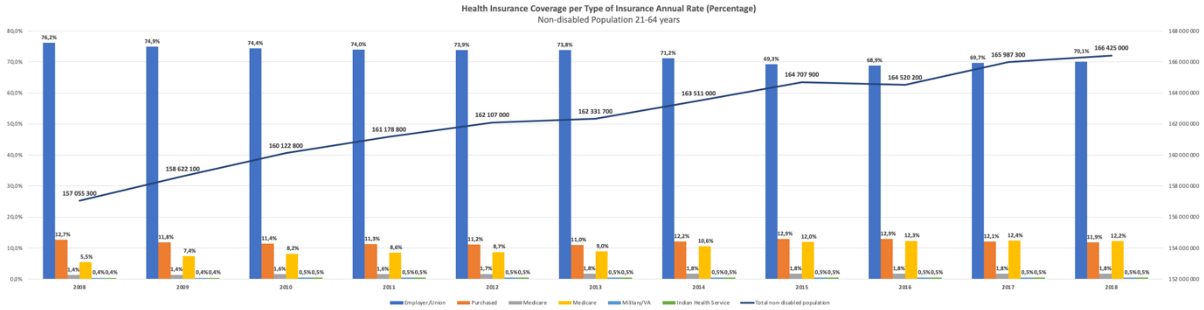

Figure 3.35: Non-disabled population health insurance coverage per type of insurance among people aged 21 to 64 years annual rate in percentage 2008-2018.

On the other hand, the disabled universe presents a more diverse distribution that relies mainly on non-private health insurance providers (see Figures 3.40 and 3.41). As shown in Figures 3.36 and 3.37, Medicaid is the primary source of health insurance coverage for disabled people in America and has been so consistently since 2010. The passage of the Affordable Care Act of 2010, also known as Obamacare, which resulted in a significant expansion of healthcare coverage, explains the Medicaid coverage increase.

As observable in Figure 3.37, as public health care coverage became more accessible, reliance on private insurance, especially employer/union provision, decreased. From 2008 to 2018, disabled people's employer/union health insurance coverage fell by 6.5% from 36% to 29.5%. On the other hand, reliance on public health coverage, especially Medicaid, has increased from 26.8% in 2008 (pre-Affordable Care Act of 2010) to 35.6% in 2018, an 8.8% increase. These are the most significant changes, with other types having minor variations. Purchased insurance decreased from 9.1% in 2008 to 8.6% in 2018, which is consistent with the healthcare insurance provision expansion of the Affordable Care Act of 2010. However, these have also somewhat reverted their declining tendency since 2014, with 2014-2018 having higher averages than 2008-2013, with 2012 and 2013 registering lower values at 7.6%. Relatively to Medicare, the changes were minor since 2008, despite the Affordable Care Act of 2010. Whereas in 2008, the percentage of disabled people between the ages of 21 and 64 covered by Medicare was 20.8%, by 2018, that percentage was slightly lower at 19.9%. Medicare had its highest rate in 2011 and 2012, with 21.9% and 22.2%, a variation of +1.4% from 2008 to 2012, with the maximum difference being +2.3% between the values of 2012 (22.2%) and 2018 (19.9%), the lowest registered rate. The military/VA health insurance coverage also fell, especially from 2013 to 2018, from 6.5% in 2013 to 5.8% in 2018, a variation of -0.7%. From 2008 to 2013, the evolution was consistent, with variations being within the 6.5% to 6.7% range. The largest variation, of 1%, was between 2011 (6.7%) and 2016 (5.7%), an insignificant gap when contrasted with the decline of employer/union health insurance coverage from 2008-2018 (-6.5%) or the rise of Medicaid for the same period (+8.8%). Finally, the last insurance type under review, the Indian Health Services insurance coverage, is consistent across all years, with its variation being of maximum +/- 0.1% between 0.6% to 0.7% and vice versa.

Lastly, it is important to note, as demonstrated by the linear representations of Medicaid and total disabled population evolution over time in Figures 3.36 and 3.37, that despite an increase in Medicaid health coverage, the disabled population is growing at a faster pace than its coverage, which can potentially result in lower coverage percentages, as the public coverage, the one disabled people primarily rely on, is falling behind disabled population's demographic increase despite state agencies' healthcare and service provision expansion.

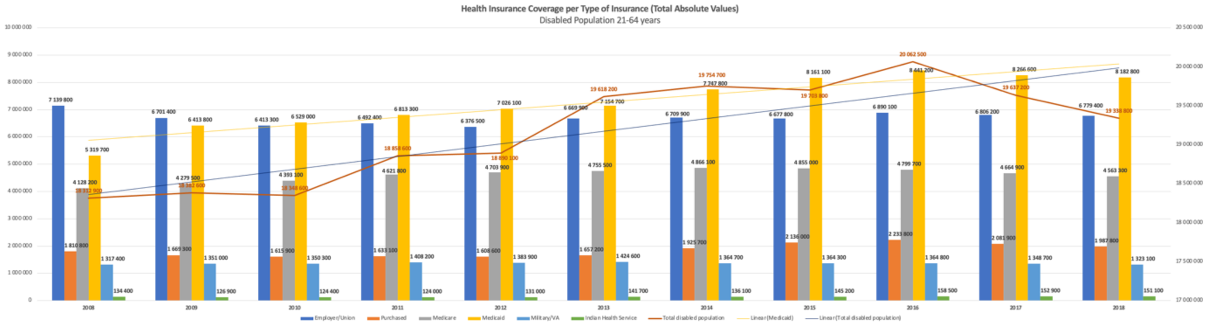

Figure 3.36: Disabled population health insurance coverage per type of insurance among people aged 21 to 64 years (total absolute values) 2008-2018.

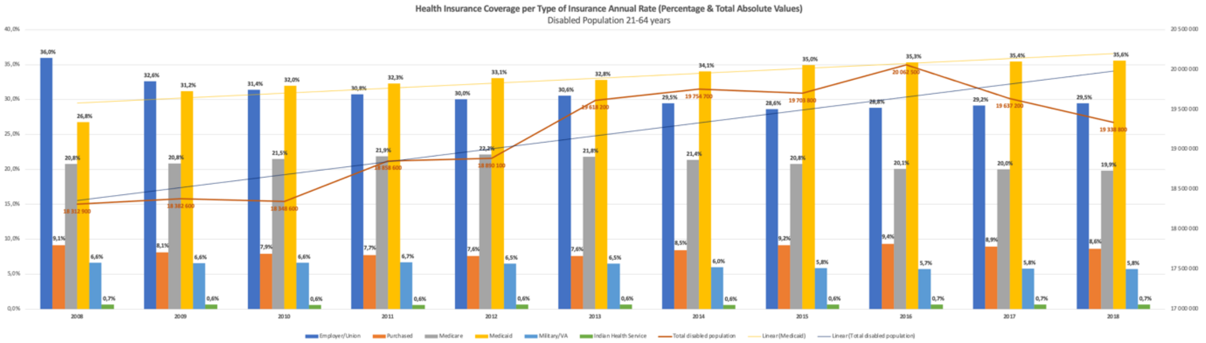

Figure 3.37: Disabled population health insurance coverage per type of insurance among people aged 21 to 64 years annual rate in percentage and total absolute values 2008-2018.

These figures (both Figure groups 3.34 to 3.37 and 3.38 to 3.41) depict a striking difference between disabled and non-disabled health insurance coverage, showing how heavily disability prevalence correlates with public insurance usage and how little non-disabled people rely on public insurance. This is most evident in Figures 3.38 to 3.41, where both absolute numbers and percentages show the high reliance non-disabled have on private health insurance coverage (Figures 3.38 and 3.39), as well as, despite less pronounced, how disabled people are mainly covered by public insurances with its overall and relative numbers increasing (see Figures 3.40 and 3.41). As shown in Figure 3.41, public health insurance coverage rose from 54.9% in 2008 to 61.9% in 2018, a 7% increase. On the other hand, whilst the non-disabled population's reliance on public insurance also grew, especially since the passage of the Affordable Care Act of 2010, the increase was marginal (+3.4%) between 2008 (11.2%) and 2018 (14.6%), a striking difference in values to those of the disabled population for the same period, 54.9% and 61.9% respectively. Despite the gap, both trends depict a growing public intervention from the U.S. government in healthcare provision.

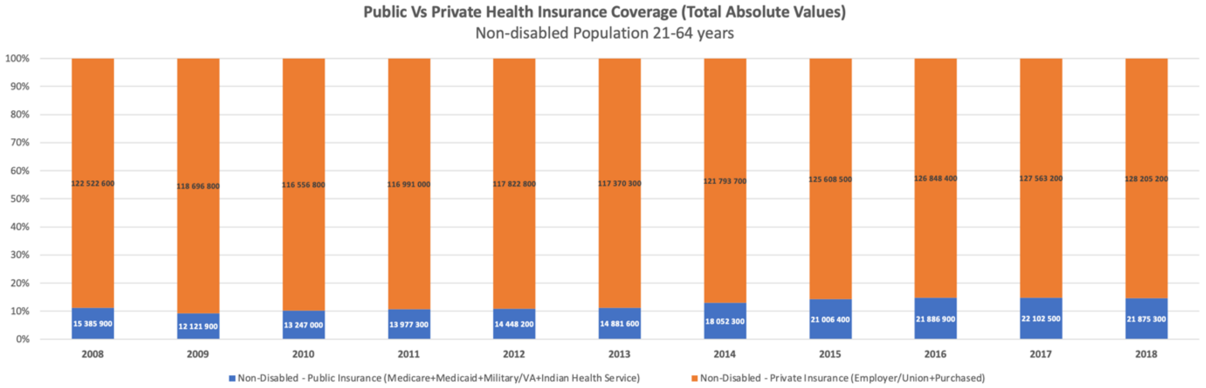

Figure 3.38: Non-disabled population public vs private health insurance coverage among people aged 21 to 64 years (total absolute values) 2008-2018.

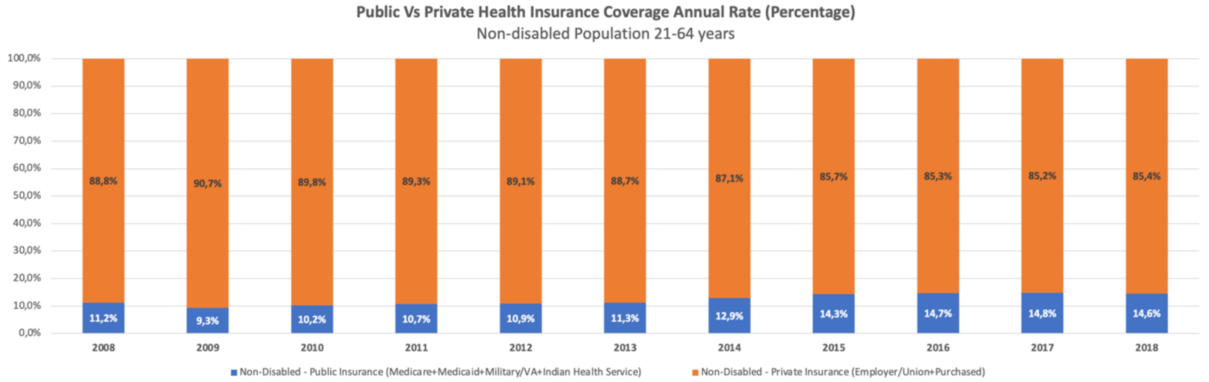

Figure 3.39: Non-disabled population public vs private health insurance coverage among people aged 21 to 64 years annual rate in percentage 2008-2018.

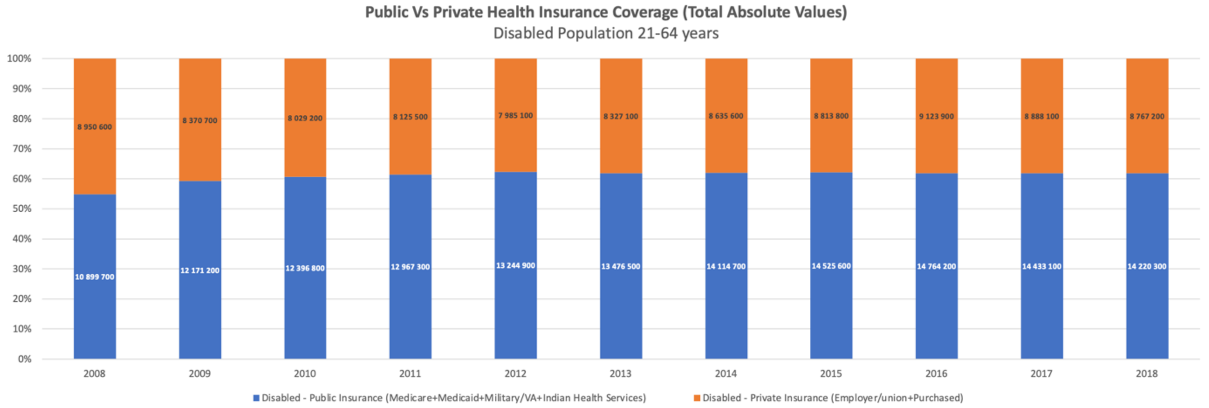

Figure 3.40: Disabled population public vs private health insurance coverage among people aged 21 to 64 years (total absolute values) 2008-2018.

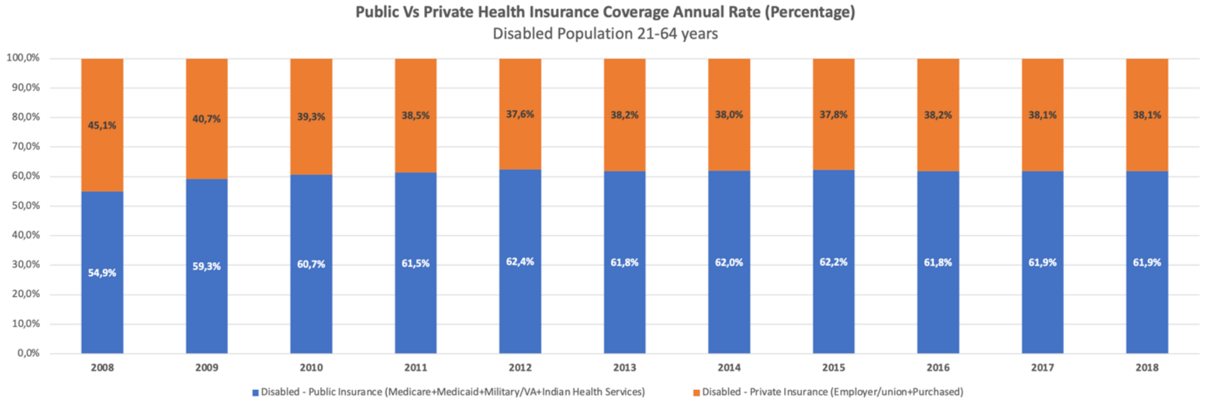

Figure 3.41: Disabled population public vs private health insurance coverage among people aged 21 to 64 years annual rate in percentage 2008-2018.

3.8 Civilian Veterans' Service-connected Disability

Finally, the last indicator under review is civilian veterans' service-connected disability. Perhaps the most particular data being reviewed, civilian veterans' service-connected disability is, however, relevant data in the study of disability due to both the number of people involved with the military, as well as the complexity of injuries and illnesses that result from service.

A clear trend stands out: disability degrees between 2008 and 2018 increased both in absolute numbers (from 2,217,100 to 2,451,100, an increase of 234,000 (Figure 3.42), as well as in the severity of the acquired disability (see Figures 3.43 to 3.45).

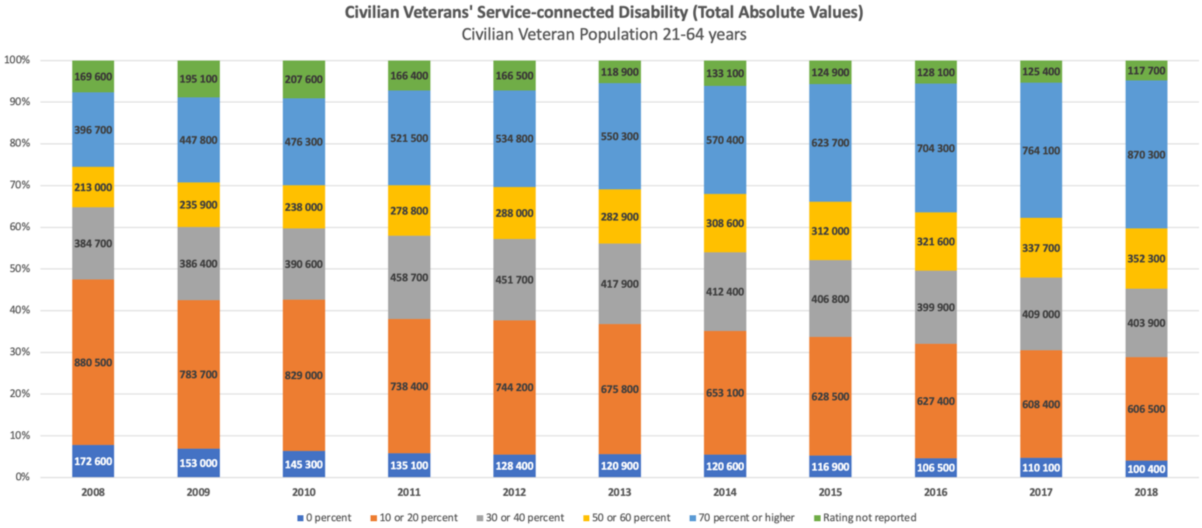

Figure 3.42: Civilian veterans' service-connected disability among civilian veteran people aged 21 to 64 years (total absolute values) 2008-2018.

Whereas in 2008 (see Figure 3.43), the largest civilian veteran's service-connected disability rate group was that of 10 or 20 per cent, with 39.7%, with most disabled civilian veterans having a disability rate lower than 50% (64.9%), in 2018 the proportions had changed. Not only most disabled veterans had a reported disability rate of 50 per cent or higher (52.4%) (see Figure 3.45), but the largest civilian veterans' disability rate group was that of 70 per cent or higher, representing 35.5%of all civilian veteran's service-connected disability when in 2008, the 70 per cent or higher group accounted for only 17.9% of all civilian veteran's service-connected disability as shown in Figure 3.43.

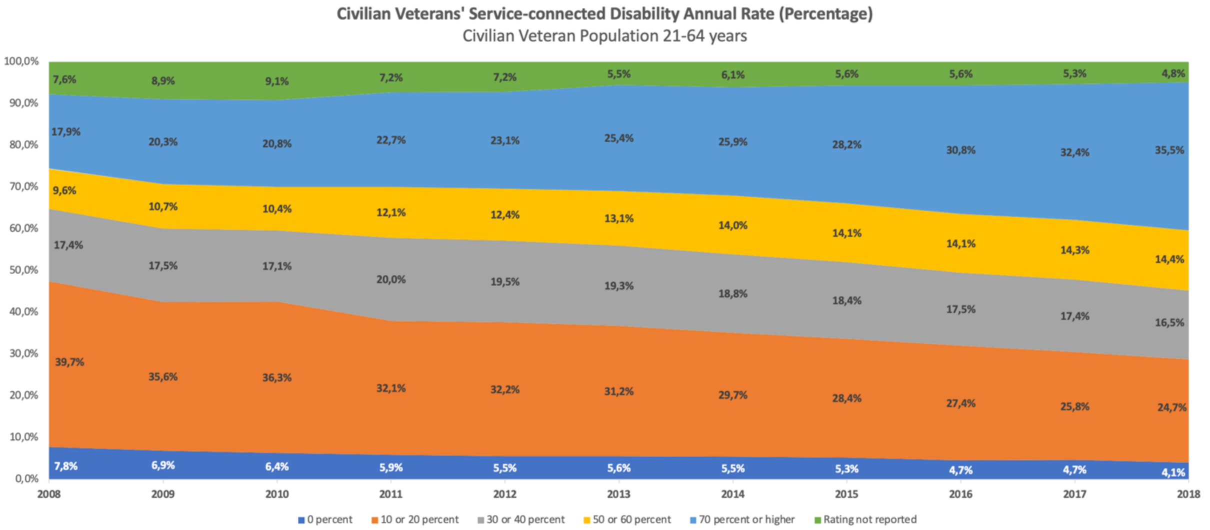

Figure 3.43: Civilian veterans' service-connected disability among civilian veteran people aged 21 to 64 years annual rate in percentage 2008-2018.

Figures 3.44 and 3.45, in the continuation of Figures 3.42 and 3.43, show that civilian veterans' service-connected disabilities, especially severe disabilities, have increased over time, with both absolute values and percentage rates of civilian veterans with service-connected disabilities above 50% disability rate growing at a much faster pace than service-connected disabilities below 50% disability rate (see Figure 3.44). As demonstrated in Figure 3.45, what started as a 40.5% gap between civilian veterans with service-connected disabilities below 50% (70.2%) and civilian veterans with service-connected disabilities above 50% (29.8%) had by 2018 been inverted, with civilian veterans with service-connected disabilities below 50% representing now 47.6%, a 22.6% drop, and civilian veterans with service-connected disabilities above 50% representing now 52.4% of all civilian veterans' service-connected disabilities, a 22.6% increase, inverting thus the gap with the latter being in 2018 above the former by 9.8%.

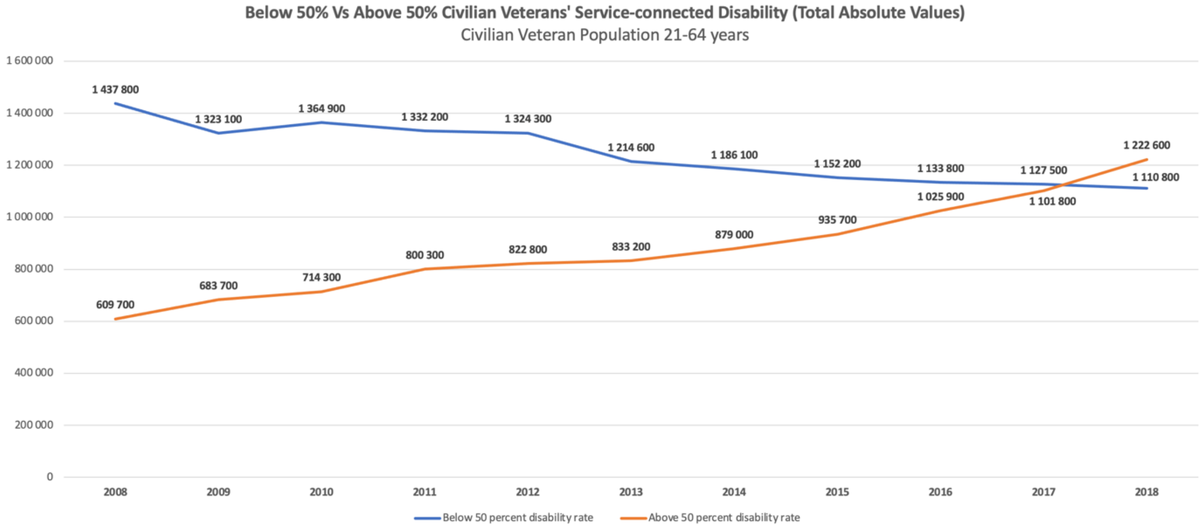

Figure 3.44: Below 50% vs above 50% civilian veterans' service-connected disability among civilian veteran people aged 21-64 years (total absolute values) 2008-2018.

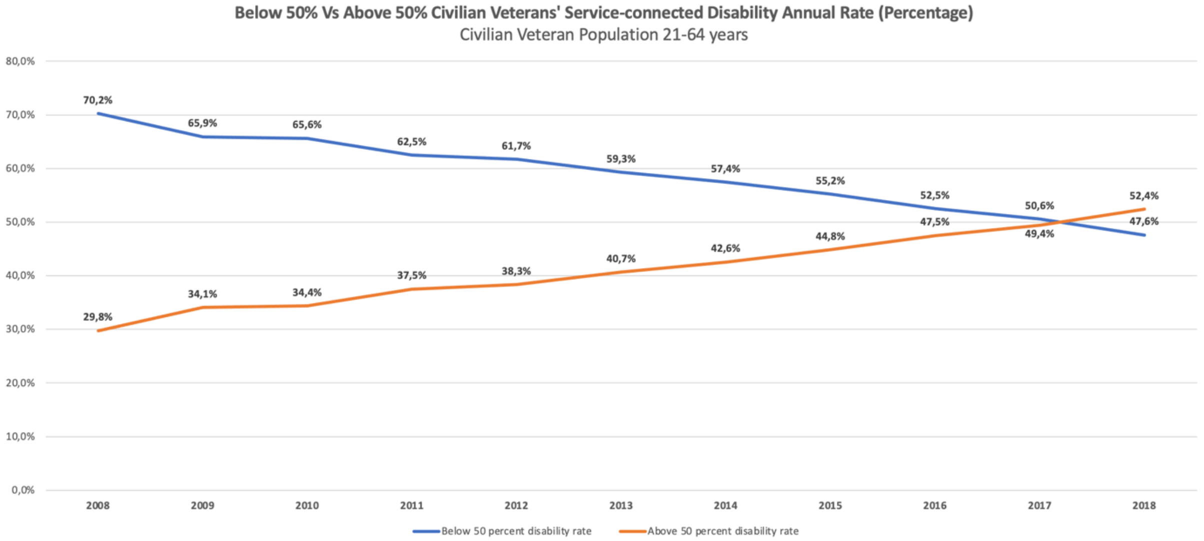

Figure 3.45: Below 50% vs above 50% civilian veterans' service-connected disability among civilian veteran people aged 21-64 years annual rate in percentage 2008-2018.

The U.S. military-industrial complex's expansion and warfare have increasingly resulted in both higher volume and severity of service-connected disabilities, a phenomenon that already in 2018 resulted in more than half (52.4%) of all civilian veterans between the ages of 21 and 64 years of age having a reported disability rate of 50 per cent or higher. A trend that increased over the 11 years under review (2008-2018) shows no signs of regression. The data leaves no margin of error as to the centrality of the U.S. military-industrial complex to the contribution of disability prevalence in the U.S., as an issue that deserves further studying and attention as to the factors within U.S. military organization and interventions that have transformed civilian veterans' service-connected disability severity rate.

Conclusion

Can it be said that the Americans with Disabilities Act of 1990 transformed disabled people's socio-economic position in present-day America?

Despite some significant improvements in disability politics and legislation, with significant advancements in the areas of accessibility and transportation; legal, cultural, and socio-economic data unequivocally show that disabled people continue to be disproportionally overrepresented at the bottom of most statistical indicators, much as they were before the ADA's passage. Not only does disability remain virtually invisible from society at large, contrary to other identity elements like gender, culture, or race, but discriminatory attitudes persist despite the legal efforts to eliminate them.

This study concludes thus that despite advances and attempts to close the disability gap, disabled people's overall condition and integration in the U.S. have failed to meet expectations.

As Marx said, "liberation is a historical and not a mental act" (Marx & Engels 2018, p.38).

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Statistical Appendix

Note on data source

The database in use, Cornell University's Disability Statistics Online Database, uses data from the American Community Survey (ACS), a survey sent each year to a random sample of over 3.5 million households with data collection by Internet, mail, telephone and in-person interviews, focusing mainly on noninstitutionalized disabled people of working age (21 to 64 years old), as working programs are a significant strategy of the U.S. government's approach to disability (Erickson et al., 2020, p.2)[80]. As pointed out by Okoro et al., disability incidence differs from that reported by the U.S. Census since these exclude institutionalized people, who represent a significant portion of the number of people with disabilities in the U.S. (Okoro et al., 2018, p.886). When considering the U.S.'s deinstitutionalization policies in the late twentieth century failed to deinstitutionalize disabled people, replacing asylums and other medical facilities by disabled people's incarceration, the underestimation of disability is an issue that deserves attention. Despite the number of disabled people in public asylums falling by 60% from 475.000 to 138.000 from 1965 to 1980, many of the previously institutionalized, lacking the necessary medical and community support, "joined a new demographic group of young adults with severe or chronic mental illnesses who drifted in and out of emergency medical facilities, psychiatric wards, and correctional institutions" (Mayes & Horwitz 2005, p.255; Grob 1994, p.287). Already by the turn of the century, estimates pointed to the number of incarcerated people in the U.S. suffering from mental illness to double the number of people in psychiatric hospitals (Davis 2003, p.10), with inmates suffering from mental illness representing around 64% of the incarcerated population in the U.S. prison system (James & Glaze, 2006)[81]. Another important factor impacting the misrepresentation of disability is proxy respondents' impact. As Todorov & Kirchner concluded, proxy respondents tend to underreport disabilities for people aged 18-64 while overreporting disability prevalence for those aged 64 or older, a systemic bias that distorts disability prevalence (Todorov & Kirchner, 2000).

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[80] For more information on the ACS census, see http://www.census.gov/acs/www/ and http://disabilitystatistics.org/sources.cfm.

[81] For more on disability incarceration in the neoliberal era, see Rembis, 2014. For another example of an extensive survey of mental illness and prison population, see Fazel & Danesh, 2002.

Disability Definition

The American Community Survey (ACS) definition of disability is based on six questions. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories.

Ambulatory Disability (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?

Cognitive Disability (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

Independent Living Disability (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Hearing Disability (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?

Self-care Disability (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?

Visual Disability (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

Employment

A person is considered employed if he or she is either:

a) "at work": those who did any work at all during the reference week as a paid employee (worked in his or her own business or profession, worked on his or her own farm, or worked 15 or more hours as an unpaid worker on a family farm or business) or

b) were "with a job but not at work": had a job but temporarily did not work at that job during the reference week due to illness, bad weather, industrial dispute, vacation or other personal reasons. The reference week is defined as the week preceding the date the questionnaire was completed.

Full-time/full-year employment

A person is considered employed full-time/full-year if he or she worked 35 hours or more per week (full-time) and 50 or more weeks per year (full-year). The reference period is defined as the 12 months preceding the date the questionnaire was completed.

Earnings

Earnings are defined as wages, salary, commissions, bonuses, or tips from all jobs including self-employment income (NET income after business expenses) from own nonfarm businesses or farm businesses, including proprietorships and partnerships.

Household Income

Household Income is defined as the total income of a household including: wages, salary, commissions, bonuses, or tips from all jobs; self-employment income (NET income after business expenses) from own non-farm or farm businesses, including proprietorships and partnerships; interest, dividends, net rental income, royalty income, or income from real estates and trusts; Social Security or Railroad Retirement; Supplemental Security Income; any public assistance or welfare payments from the state or local welfare office; retirement, survivor or disability pensions; and any other regularly received income (e.g., Veterans' payments, unemployment compensation, child support or alimony). Median household income is calculated with the household as the unit of analysis, using household weights without adjusting for household size.

Poverty

The poverty measure is computed based upon the standards defined in Directive 14 from the Office of Management and Budget. These standards use poverty thresholds created in 1982 and index these thresholds to 2008 dollars using poverty factors based upon the Consumer Price Index. They use the family as the income sharing unit and family income is the sum of total income from each family member living in the household. The poverty threshold depends upon the size of the family; the age of the householder; and the number of related children under the age of 18.

Supplemental Security Income (SSI)

A person is defined as receiving SSI payments if he or she reports receiving SSI income in the 12 months prior to the survey.

Educational Attainment

The highest level of education completed at the time of the survey.

Our definition is based on the responses to the question: "What is the highest degree or level of school this person has completed? If currently enrolled, mark the previous grade or highest degree received". Our category "high school diploma/equivalent" includes those marking the ACS option "Regular high school diploma — GED or alternative credential". Our category "Some college/Associate's degree" includes those marking the ACS options: some college credit, but less than 1 year of college credit; one or more years of college credit but no degree, or "Associate's degree (for example: AA, AS)". Our category "a Bachelor's or more" includes those marking the ACS options: "Bachelor's degree (for example: BA, BS)"; "Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)"; "Professional degree (for example: MD, DDS, DVM, LLB, JD)"; or "Doctorate degree (for example: PhD, EdD)".

Health Insurance Coverage

Is based on the following question: Is this person CURRENTLY covered by any of the following types of health insurance or health coverage plans? Mark "Yes" or "No" for EACH type of coverage in items a – h.

a. Insurance through a current or former employer or union (of this person or another family member).

b. Insurance purchased directly from an insurance company (by this person or another family member).

c. Medicare, for people 65 and older, or people with certain disabilities.

d. Medicaid, Medical Assistance, or any kind of government-assistance plan for those with low incomes or a disability.

e. VA (including those who have ever used or enrolled for VA health care).

f. TRICARE or other military health care.

g. Indian Health Service.

h. Any other type of health insurance or health coverage plan – Specify.

Note: "Other type" were recoded into one of the categories a-g by the Census Bureau.

Civilian Veteran's Service-Connected Disability

A disease or injury determined to have occurred in or to have been aggravated by military service. A disability is evaluated according to the VA Schedule for Rating Disabilities in Title 38, CFR, and Part 4. Extent of disability is expressed as a percentage from 0% (for conditions that exist but are not disabling to a compensable degree) to 100%, in increments of 10%. This information was determined by the following two part question:

a. **Does this person have a VA service-connected disability rating?**

Yes, (such as 0%, 10%, 20%, … , 100%).

No, SKIP to question 28a.

b. **What is this person’s service-connected disability rating?**

Responses included: 0 percent; 10 or 20 percent; 30 or 40 percent; 50 or 60 percent; 70 percent or higher.

Data Source

https://www.dropbox.com/scl/fi/7ymrfregsa91lkehpgoxl/The-state-of-disability-in-the-United-States-of-America-after-the-Americans-with-Disabilities-Act-of-1990.xlsx?rlkey=hc6lzzpqn6nw82bism8i8o27m&dl=0.