

# Research

The Relationship Between Disability Prejudice  
and Medicaid Home and Community-Based  
Services Spending



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**The Relationship between Disability Prejudice and  
Medicaid Home and Community-Based Services Spending**

Carli Friedman & Laura VanPuymbrouck

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*Corresponding author:*

Carli Friedman, PhD  
CQL | The Council on Quality and Leadership  
100 West Road, Suite 300  
Towson, MD 21204  
United States  
[cfriedman@thecouncil.org](mailto:cfriedman@thecouncil.org)

Laura VanPuymbrouck, PhD, OTR/L  
Department of Occupational Therapy  
Rush University  
600 S. Paulina St.  
Chicago, IL 60612  
United States  
[laura\\_vanpuymbrouck@rush.edu](mailto:laura_vanpuymbrouck@rush.edu)

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### Abstract

**Background.** Medicaid is one of the most important health care safety nets for people with disabilities in the United States. Yet, from the beginning Medicaid only covered long-term services and supports (LTSS) through institutional care. In 1981 changes to Medicaid allowed states to provide home and community-based services (HCBS) instead so people with disabilities could receive LTSS in their own homes or in the community. As a result of these changes, there has been a significant decline in institutionalization of people with disabilities in favor of HCBS in the United States. However, the priority of HCBS can be impacted by ideas about community living and disability attitudes, among others. How these attitudes may trickle down to impact Medicaid funding decisions is unknown.

**Objective.** The aim of this study was to examine the relationship between HCBS and disability prejudice in the United States.

**Methods.** We used secondary data about state LTSS expenditures from across the nation in fiscal year (FY) 2015, as well as disability prejudice data (Disability Attitudes Implicit Association Test) from 325,000 people residing in all 50 states and the District of Columbia.

**Results.** Findings revealed regardless of the state size or wealth, states with more disability prejudice direct less of their LTSS funding towards HCBS.

**Conclusions.** Biases and prejudice in disability policy decision-making are obstacles to equality of opportunity and full participation in society, as promised by civil rights.

*Keywords:* institutionalization; community living; long term services and supports; people with disabilities; ableism

## Introduction

Systematic institutionalization of people with disabilities (PWD), especially those with psychiatric disabilities and intellectual and developmental disabilities (IDD), began in the 18<sup>th</sup> century, first in Europe and then in the United States (US), as a moral approach to care<sup>1-3</sup>. The moral treatment model heralded treating the ‘feeble-minded’ holistically and humanely to facilitate making them a productive member of society<sup>1</sup>. Institutions or ‘schools’ were established across the US to train sociability and usefulness to the ‘idiots’ of society<sup>4</sup>. However, in addition to horrible conditions wherein patients were “herded like cattle” and “stripped of every vestige of human decency” (p. 262)<sup>5</sup>, it was not uncommon for these facilities to employ harmful techniques such as shock therapy, frontal lobotomies, and forced sterilization<sup>3</sup>. These approaches were justified through scientific theories regarding diminishing negative behaviors. Drastic social cultural changes in the demographic landscape of the US throughout the 19<sup>th</sup> and early 20<sup>th</sup> century also lead to a flourishing eugenics movement where people with disabilities were perceived as threats to the country’s social order<sup>6</sup>. These perceptions, plus a rash of other socio-cultural perceptions and economic circumstances, helped create an embrace for a strong state-run institutional bias for ‘caring’ for PWD.

In the 1950s and 1960s there were a number of different factors that resulted in a shift away from large state run institutionalization in the US, which peaked at approximately 800,000 people<sup>7</sup>. Overcrowding and increasing reports of poor care, in addition to other factors, created a public opinion open to consider alternatives to institutionalization. One major influence was the passing of the Community Mental Health Centers Act of 1963 by President Kennedy, which called for a reduction by 50% or more of institutionalized people within twenty years<sup>8</sup>. This Act was the direct result of persistent and ardent advocacy by PWD and their families<sup>1</sup>. Around the

same time, the ‘popularity’ of discrimination and neglect exposés among the media also helped encourage deinstitutionalization<sup>1</sup>. For people with psychiatric disabilities in particular, new developments in psychiatry reframed symptoms as something that could be managed rather than requiring constant care, and offered new health insurance mechanisms for outpatient treatment, allowing more people to receive services in the community<sup>3</sup>. Government funding shortages also resulted in the emphasis on outpatient treatment over more costly institutional care<sup>5,9</sup>.

Legal rulings and legislation also resulted in reforms to state facilities creating new standards of care. For example, *Wyatt v. Stickney* (1972) resulted in closing most of Alabama’s institutions as a result of its ruling that people should receive treatment, not custodial care or punishment. The Americans with Disabilities Act (1990) mandated societal integration of PWD. One of the more important legal rulings for deinstitutionalization was *Olmstead v L. C.* (1999), a Supreme court determination invoking civil rights claims of Title II of the ADA, which ruled institutions illegally segregate PWD. Moreover, *Olmstead* declares states have an affirmative obligation to offer long-term services and supports (LTSS) in the least restrictive setting possible<sup>10</sup>. Despite *Olmstead*’s landmark ruling on community integration, progress and support for deinstitutionalization has been slow, often requiring class-action lawsuits for actual implementation of the ruling.

As a result of policies, legislation and shifting perspectives of how best to provide LTSS, deinstitutionalization is at an all-time high in the US<sup>7</sup>. However, despite research indicating community living has more benefits than institutions, even for those with more severe impairments<sup>11</sup>, a sizable proportion of PWD still live in institutions in the US<sup>3,9</sup>. Moreover, many people with psychiatric disabilities have simply moved from state institutions to other institutional settings, such as nursing homes or jails/prisons<sup>3,5,7</sup>. In fact, because of federal

policy prohibiting inpatient psychiatric care in institutions for people with psychiatric disabilities, Medicaid funded nursing homes serve as a substitute for care<sup>12</sup>. Indeed, research shows mental or cognitive disability is one of the most common admitting diagnoses to nursing facilities, and for those non-elderly admitted, psychiatric disability has overtaken dementia as the leading cognitively based diagnosis<sup>13</sup>. Research also finds most people with a diagnosis of serious mental illness admitted to nursing homes are younger than 65 and these combined characteristics result in increased likelihood of becoming permanent nursing home residents<sup>2</sup>. These findings are troublesome because nursing homes not only isolate PWD, but also are ill-equipped to provide support to people with psychiatric disabilities<sup>13</sup>. In addition, many people with psychiatric disabilities are capable of living in home and community-based settings with appropriate supports<sup>2</sup>. Scholars are referring to this shift toward nursing home placement as transinstitutionalization, rather than deinstitutionalization<sup>14</sup>. In fact, as a result of Medicaid's institutional bias, skilled nursing facilities are the preferred institution for discharge from state psychiatric hospitals<sup>9</sup>. Research suggests transinstitutionalization of PWD is not a result of population increases, poverty rates or changes in employment rates, rather they are likely due to a lack of community-based infrastructure to create and sustain such services, and the large gap between legislation, policy and practice<sup>2, 14</sup>.

### **Medicaid Long-Term Services and Supports**

Today Medicaid is “one of the most important components of the health care safety net” for PWD in the US (p. 101)<sup>15</sup>. Modern Medicaid funding began in the 1960s providing national matching funds to states in order to provide mechanisms for states to offer medical and non-medical services to people in poverty, including those LTSS needed by individuals with chronic care needs; Medicaid is the nation's principal source for long-term care<sup>16</sup>. As well as being the

primary funding source for LTSS, it is also the primary insurer of PWD<sup>16, 17</sup>. LTSS are medical and nonmedical services and supports provided over an extended period due to disability or chronic illness; approximately forty-three percent of those receiving LTSS are younger than 65<sup>18</sup>.

From the beginning comprehensive Medicaid LTSS were available only through institutional care, such as residential or skilled nursing facilities<sup>17</sup>. Some states made efforts to “piece together federal funding” (p. 6) to develop services and supports for PWD living in home and community settings but these services were available to only a small percentage of the disability community<sup>19</sup>. Medicaid funding for non-medical services, such as assistant care to bathe or prepare meals, often required the person to be institutionalized. This process resulted in a loss of self-determined control of the person as well as a loss of basic civil rights. This process not only systematically segregated PWD from participating fully in society, but established a system where providers determined what services and supports were provided and how, rather than the PWD themselves<sup>20</sup>.

However, in 1981 the Omnibus Budget Reconciliation Act (OBRA) Section 2176 created Section 1915(c) of the Social Security Act authorizing Medicaid to provide home and community-based services (HCBS). This HCBS waiver program authorized states to provide an alternative to institutional care; the HCBS waiver program was fashioned after state programs that had been small but notably successful in New York and California<sup>19</sup>. HCBS waivers allow states to ‘waive’ key provisions of the Social Security Act (i.e., state-wideness, comparability of services, and income and resource rules) to create and expand community LTSS particularly tailored to populations that would typically require institutional care to allow them to live in their own home or community instead. As a result of OBRA, the *Olmstead* ruling, the preferences of PWD, and the cost effectiveness of community services, over the last few decades states have

shown a significant decline in institutional Medicaid spending in favor of HCBS<sup>9</sup>. In addition, the Patient Protection and Affordable Care Act of 2010 (PPACA) (2010) also created opportunities for states to rebalance their allocation of Medicaid LTSS toward HCBS.

### **Attitudes and Community Living**

As the HCBS program aims to maximize *successful* community living, states are able to tailor their systems as they see fit; although doing so has many benefits, it also results in wide variance across states and programs. States have the flexibility to determine not only what benefits they cover under the programs, but who is eligible and how many people served, resulting in some states covering a larger percentage of its entitled citizens<sup>16</sup>. States primarily fund their share of Medicaid through taxes and, as a result, state climates favoring tax cuts find reduced revenues dedicated to Medicaid services<sup>21</sup>. These decisions about dedicating revenues, as well as the priority of HCBS programs and other related policies, are impacted by not only states' stances on taxation but also ideas of 'entitlements,' community living, and disability attitudes, among others. These beliefs inform claims to Federal matching dollars, determination of State plans on eligibility, and, ultimately, the dissemination of dollars between plans<sup>22</sup>. This creates an environment where attitudes toward PWD can impact decisions regarding state policies, including distribution of LTSS funding. For most individuals in society, including policy makers and those in positions to determine funding distribution, attitudes toward disability are acquired over time, socially constructed, and influence the action of its members<sup>23, 24</sup>.

Unfortunately, not only is disability prejudice – ableism – embedded within systems and structures, in many ways, the “many forms of suffering that result from dehumanizing and oppressive practices, attitudes, and institutions” have their origins in formalized processes of institutionalization of PWD<sup>25</sup>. For example, stereotypes tend to overestimate the incapacity and



dependency of PWD<sup>24</sup>, both of which could impact nondisabled people's opinions about the need for institutionalization of PWD. Moreover, people often erroneously believe PWD are a drain on the financial integrity of a community<sup>26</sup>. Not only has ableism resulted in institutionalization of PWD, the ways we understand disability in this country have been shaped by institutional knowledge/understandings about PWD's abilities, needs, and the etiologies of their impairments<sup>1, 25</sup>. Ableism often manifests itself through structures and social systems; institutionalization and community living are no exception.

If, and how, Medicaid systems continue to preserve early institutional attitudes about disability, such as of deservedness and pity, is unknown. How these attitudes may trickle down to impact Medicaid funding decisions, including HCBS expenditures, is also unknown. Exploring the attitudes and beliefs of community members toward a marginalized group can expose how societal level structural barriers are not only created but also reinforced; a better understanding of these barriers can pave a path toward their elimination. For these reasons, the aim of this study was to examine the relationship between HCBS and disability prejudice in the US. Our research question was: how does disability prejudice impact state spending on HCBS? To explore this question, we used secondary data about state LTSS expenditures from across the nation in fiscal year (FY) 2015, as well as disability prejudice data from 325,000 people residing in all 50 states and the District of Columbia.

## Methods

### Medicaid Expenditures

Data about state Medicaid expenditures was obtained from Eiken, Sredl, Burwell, Saucier<sup>29</sup>. Eiken et al.<sup>29</sup> produces longitudinal reports about Medicaid LTSS expenditures, including HCBS expenditures, utilizing Center for Medicare and Medicaid Services (CMS) “CMS-64 Quarterly Expense Report that states submit to CMS to claim federal matching funds” (p. 23). In particular, we obtained data about states’ total HCBS expenditures (across population) from FY 2015. We also obtained data about states’ total LTSS expenditures, so it could be used to control for state wealth and size. Total LTSS expenditures includes total HCBS expenditures and total institution (i.e., nursing facilities, intermediate care facilities for individuals with intellectual disabilities, institutions for mental disease, and other institutional LTSS) expenditures. We created a new variable, percent of total LTSS spending directed towards HCBS, by dividing states’ HCBS spending by total LTSS expenditures, to minimize multicollinearity.

### Disability Prejudice

There are two level of attitudes: explicit (conscious) attitudes and implicit (unconscious) attitudes<sup>27</sup>. As people may feel pressured to conceal biases, or may be unaware they hold biased attitudes, there are concerns explicit measures do not capture all attitudes<sup>27</sup>. For this reason, much attitude research has shifted towards examining implicit attitudes. The Disability Attitudes Implicit Association Test (DA-IAT) is one of the most common methods to measure implicit disability prejudice. The DA-IAT presents participants with ‘disabled persons’ and ‘abled persons’ categories, and ‘good’ and ‘bad’ attitudes, and asks them to sort word and symbol stimuli accordingly. The DA-IAT examines people’s associations and attitudes by measuring

reaction time when items are sorted in stereotype congruent and incongruent ways; the quicker the reaction time, the stronger the association between groups and traits. Scores of 0.15 to 0.34 reveal a slight preference for nondisabled people, 0.35 to 0.64 a moderate preference, and 0.65 and greater a strong preference<sup>28</sup>. Negative values of the same values above reveal preferences for PWD, and scores from -0.14 to 0.14 reveal no prejudice<sup>28</sup>.

Data about implicit disability prejudice was obtained from Project Implicit<sup>30</sup>, a database where people can test their implicit prejudices, including against PWD using the DA-IAT. A total of 728,134 participants from all 50 states and the District of Columbia participated in the DA-IAT between 2004 and 2017. Approximately half of those participants (44.8%) also completed demographic information about their residency (state). 401,638 participants did not complete information about residence, or lived outside the US or in US territories, so their scores were dropped. This resulted in a final *n* of 326,496 – an average of 6,402 participants per state (*SD*=6,185). Demographic information about the state participants lived was then used to aggregate DA-IAT scores by state, with the state's mean score serving as the state's disability prejudice score.

### **Analysis**

SPSS 23 was utilized to conduct all analyses. This study's research question was: how does disability prejudice impact state spending HCBS? To explore this research question, a linear regression model was conducted using SPSS 23 with states' disability prejudice scores serving as the independent variable (IV) and states' spending on HCBS (out of total LTSS spending) as the dependent variable (DV).

## Results

The mean state implicit disability prejudice score was 0.50 ( $SD=0.02$ ), which is moderate prejudice. Disability prejudice ranged from 0.45 (Colorado) to 0.53 (Mississippi) (see Figure 1).

In FY 2015, an average of \$1.70 million ( $SD=\$2.33$  million) was spent on HCBS per state. In FY 2015, an average of \$3.10 million ( $SD=\$3.88$  million) was spent on LTSS per state. In FY 2015, the average state projected spending 53.1% ( $SD=11.4\%$ ) of their LTSS on HCBS, ranging from 31.0% (Mississippi) to 82.0% (Oregon) (see Figure 2).

To explore the relationship between disability prejudice and HCBS expenditures, a linear regression model was run with the IV states' disability prejudice, and the DV FY 2015 percent of LTSS expenditures for HCBS. The model was significant,  $F(1, 49)=11.30, p=0.002$ . The model predicted 18.7% of variance.

The regression equation for predicting a state's HCBS spending from the state's disability prejudice is:  $\% \text{ LTSS spending on HCBS} = 1.72 - 2.39(\text{Disability Prejudice})$ . The disability prejudice term was significant,  $t=-3.36, p=0.002$ .

According to the model, the higher the state's disability prejudice, the less LTSS spending directed towards HCBS (see Figure 3). For example, a state with an average disability prejudice score of 0.50 (moderate prejudice) is expected to spend 52.3% of their LTSS on HCBS services. Whereas, a state with an average disability prejudice score of 0.65 (strong prejudice) is expected to only spend 16.4% of their LTSS on HCBS services.

## Discussion

Many modern stereotypes about PWD, such as those surrounding their in/abilities have their origins in institutionalization<sup>1</sup>. Medical diagnoses such as ‘feeble-minded’, ‘lunatics’, or ‘idiots’ were used in the late 19<sup>th</sup> and early 20<sup>th</sup> century to identify flawed and undesirable characteristics of a person, deemed inheritable and incurable<sup>4</sup>. Institutionalization of PWD was considered one means of preserving the normed standards of society, ultimately reinforcing stereotypes and attitudes toward PWD<sup>1</sup>.

Although institutionalization is less prominent today than it was half a century ago, ableism still persists in everyday interactions, cultural biases, and systems<sup>31</sup>. Indeed, the findings of this study expose distinct patterns of disability prejudice in the prioritization of HCBS for PWD. Findings from this study revealed, regardless of the state size or wealth, states with more disability prejudice direct less of their LTSS funding towards HCBS. For example, Mississippi not only had the highest disability prejudice scores across the states (0.53) but also directed the lowest percent of LTSS funding towards HCBS (31.0%). This correlation suggests at least part of the motivation behind these policy decisions is a bias against disability. Understanding where PWD fall within the social mindset may help us understand states’ approaches to care. Moreover, improved advocacy efforts by disability communities and their allies on the cost saving benefits of well-run HCBS programs may benefit the community integration of PWD.

Disability prejudice is harmful because it can influence decisions not only about HCBS but about health care and policy more broadly, which can directly impact the quality of life of PWD. Basing fiscal priorities on biased information or stereotypes about PWD not only serves to reinforce this prejudice and normalize it, but also contributes to the legacy of oppression of PWD.

The normalization of institutional discrimination can “manifest itself as rules, policies, and procedures of private or public entities in positions of power that can consciously and purposefully restrict rights and opportunities” (p. 1)<sup>32</sup>. Extending this concept to PWD, Oliver<sup>33</sup> notes institutional ableism includes “established structures of disadvantage toward people with disabilities, supported by those in power that require anti-discrimination legislation in order to change behaviors” of discrimination (p. 83). As a result of established structures within individual States, LTSS policy makers and funders may not only be influenced by stereotypes and attitudes about PWD, and by continuing institutionalization, they may also be indirectly perpetuating social stigmas and negative disability bias.

It is important to note we only explored the relationship between HCBS funding and disability prejudice; it is likely these findings only scrape the surface – disability prejudice likely also impacts and/or trickle downs to many other policies and practices, including within HCBS and Medicaid more broadly. For example, how might the program and policy procedures for acquiring and receiving HCBS services be unnecessarily complicated or ambiguous due to negative attitudes toward PWD and/or stereotypes about Medicaid recipients? How might political decisions regarding reducing or ending Medicaid be based in ableist and racist attitudes? Do PWD who successfully navigate service provision then encounter attitudinal barriers from staff and providers because negative bias is so normalized?

### **Increasing HCBS and Reducing Institutionalization**

Remedying the impact of disability prejudice on policy and funding decisions regarding HCBS and institutionalization requires changes from the top to the bottom of the system. First, Medicaid’s institutional bias must be ended. In fact, advocates, such as ADAPT, have been pushing for the Disability Integration Act (H.R.2472 and S.910), which aims to end Medicaid’s

institutional bias, in favor of community based LTSS<sup>34</sup>. The current Medicaid system is designed in such a way that states must provide institutional care but HCBS is optional<sup>35</sup>. Although alternative community-based Medicaid funding mechanisms exist, they “do not eliminate states’ obligations to pay for services provided in the isolation of institutions... In Medicaid, integration is optional, but segregation is mandatory” (p. 5)<sup>35</sup>. As Medicaid’s institutional bias is both historical and structural, Medicaid should eliminate states’ obligations to pay for institutions.

States also need to direct more funding, or at least a larger percentage of their funding, toward HCBS. By recognizing ableism is interwoven into their state system, and impacting their allocation decision-making as a result, states can work to counter these prejudices by directing attention to HCBS and building a better community infrastructure to support PWD. Currently, although HCBS results in better outcomes than institutional living, even many people in the community remain isolated<sup>36</sup>. Greater emphasis on HCBS, and the resulting strengthened community infrastructure, will not only lead to increased quality of life of PWD, it may reduce the general public’s disability prejudice as more PWD become their community members, their neighbors, and their friends, rather than abstract stereotypes. It is also important states and policies recognize cuts to Medicaid HCBS funding may not only result in the re-institutionalization of PWD, which is less cost-effective than community living<sup>9</sup>, but could also violate the rights PWD are entitled to according to *Olmstead* and the ADA<sup>35</sup>.

In addition to increasing HCBS funding, states should also continue and/or revitalize their deinstitutionalization efforts. Although *Olmstead* was a landmark ruling for community integration and deinstitutionalization, progress has been slow, often requiring class-action lawsuits for actual implementation. Rather than be reactive and only make changes in response to legal rulings, states need to proactively take steps to expand deinstitutionalization. This is

particularly true of states such as Mississippi that not only have some of the lowest HCBS rates and highest institutionalization rates in the country<sup>9, 29</sup>, but also have a preponderance of disability prejudice. Likely the relationship between disability prejudice and institutionalization is bidirectional – with more disability prejudice comes more institutionalization, and with more institutionalization comes more prejudice. As such, taking steps to increase deinstitutionalization and community living may facilitate the reduction of disability prejudice.

In recognition of the influence of disability prejudice in not only policies but also practices, there should be more intentional efforts to hire more PWD to leadership roles overseeing and contributing to decisions about these policies and systems. Not only will this account for structural factors that reduce their opportunities to enter these roles, they typically have less disability prejudice than nondisabled people<sup>37</sup>, and their involvement may be one mechanism to help ensure disability prejudice is minimized in policy or funding allocation decisions. Research also suggests groups that include a variety of different identities and minority groups typically can be more creative, better problem solvers, and less susceptible to groupthink<sup>38</sup>.

Moreover, influenced by their professional commitment to “advocate for the social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being” (p. 2)<sup>39</sup>, healthcare providers can use their power to influence state healthcare policies through lobbying efforts. The American Medical Association (AMA) is a well-organized and influential body with a history of advocating for social and healthcare policy changes for those communities of society in most need<sup>40</sup>. State and national provider groups informed with the findings of this study could survey how their efforts to push healthcare policy decisions are also biased by the rhetoric of prejudiced agendas.



Finally, there need to be concerted efforts to reduce disability prejudice, not just in relation to state Medicaid decisionmakers and politicians, but in the general population. Although the general population of a state may not have direct decision-making capacity, they do have the power to influence decisions that impact the lived experiences of PWD by voting for ballot measures, electing politicians, and direct action. As such, and because ableism is extremely prominent<sup>31</sup>, stereotypes about PWD need to be dismantled.

### **Limitations**

It should be noted people volunteered to participate in the DA-IAT and, there is a chance of selection bias. The sample's demographics may not mirror the demographics of the state. This study explored the relationship between two variables, causality should not be assumed. This was an analysis of secondary data; we could not add additional variables or ask participants additional questions. We also did not explore interactions. Based on this data there was no way to differentiate attitudes towards different disabilities. As different disability groups are associated with different stereotypes and stigmas, it may be fruitful to explore the relationships between HCBS, and attitudes towards individual disability groups.

### Conclusions

How states allocate the limited funds available to them highlights their priorities. States that decide not to allocate significant funding to HCBS demarcate the community living of PWD as less important. Not only is this not the most fiscally sound decision since HCBS is significantly more cost effective than institutionalization<sup>5,9</sup>, according to our findings, it can also be steeped in disability prejudice. Biases and prejudice in disability policy decision-making are obstacles to equality of opportunity and full participation in society, as promised by civil rights.

Understanding how established beliefs and attitudes toward disability can translate to critical policy decisions impacting PWD's quality of life is vital. The often-subtle structural biases and prejudices against PWD have a long history that demand closer examination to recognize how this history may influence today's policies and practices. Despite current trends toward deinstitutionalization, some states have yet to fully embrace HCBS as the ultimate goal of LTSS in their legislation and practices. Deinstitutionalization requires states make concerted efforts to provide options for LTSS beyond nursing facilities. There is much research indicating the benefits of community living, however, long-standing prejudices appear to continue to overshadow this evidence. The findings from this study may help to address institutional, normalized, and often unspoken prejudices against PWD.

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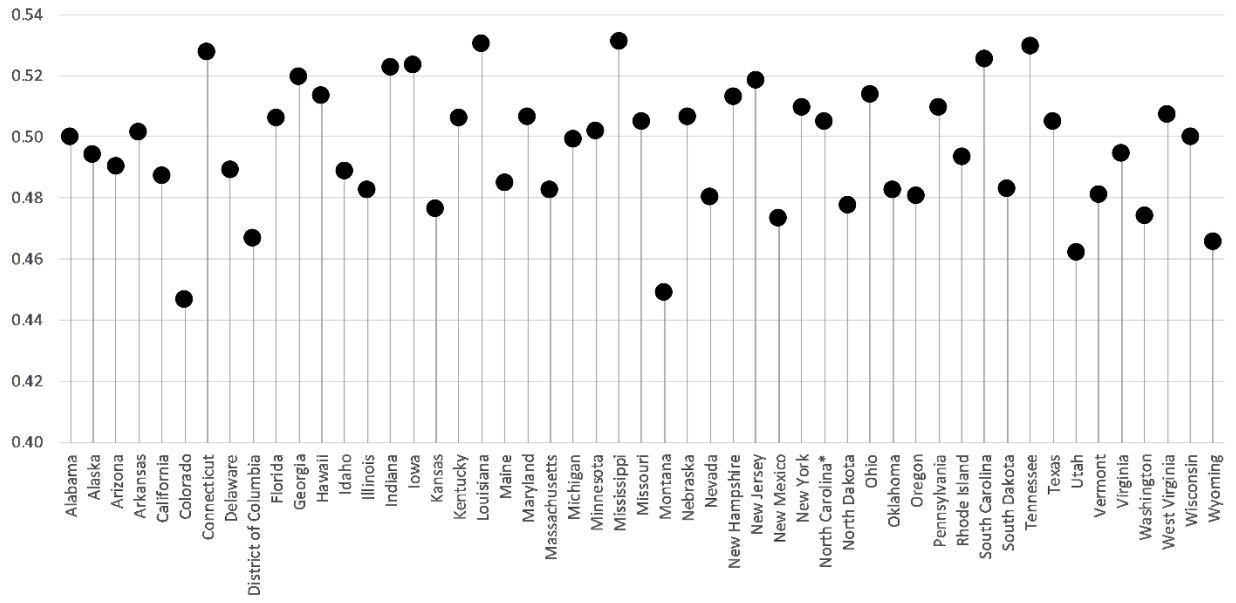


Figure 1. Disability prejudice by state.

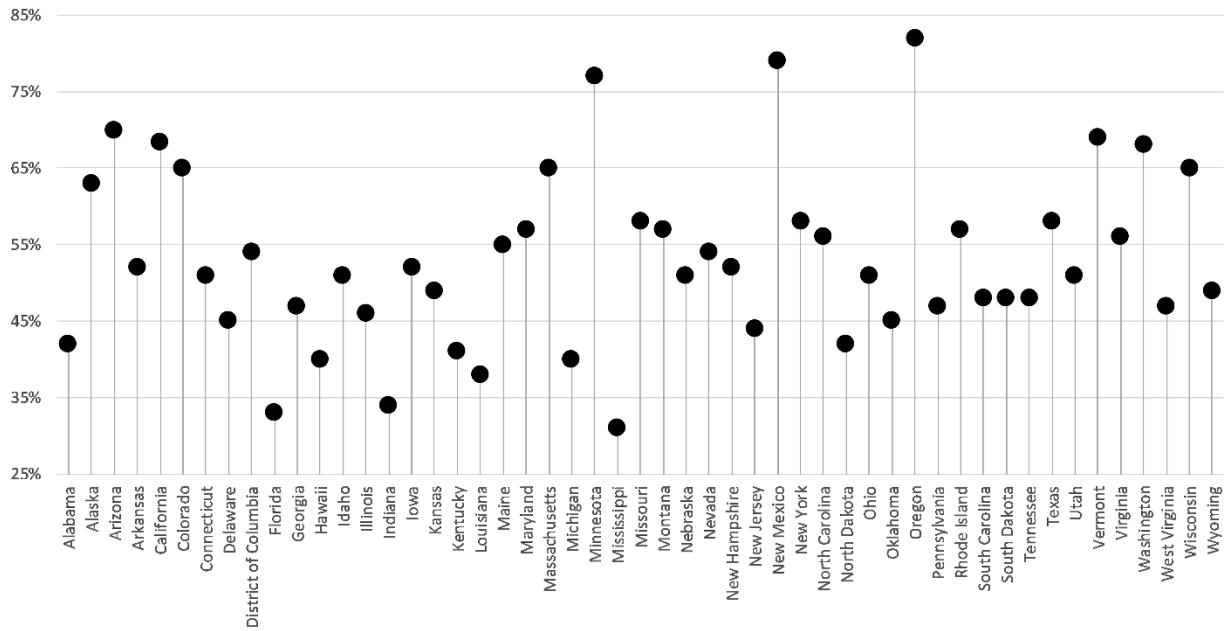


Figure 2. Percent of LTSS spending on HCBS by state. It should be noted that California and North Carolina data do not include managed care programs data as it was unavailable.



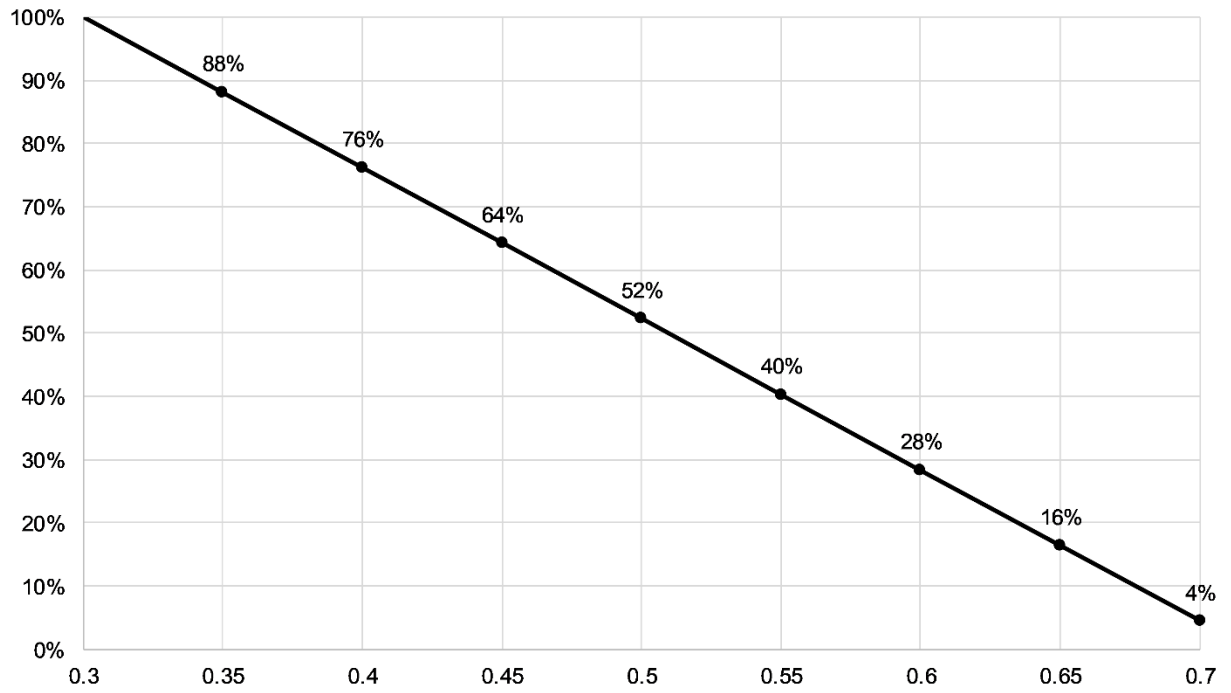


Figure 3. Relationship between disability prejudice and HCBS allocation.