

Research

The Relationship Between Disability Prejudice
and Institutionalization of People with Intellectual
and Developmental Disabilities



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Abstract

There are decades of research indicating ableism is extremely prominent. The aim of this study was to examine the relationships between disability prejudice and institutionalization of people with intellectual and developmental disabilities (IDD). This study had two research questions: how does disability prejudice impact the number of people with IDD who are institutionalized in a state?; and, how does disability prejudice impact spending on institutions? To do so, we utilized secondary data about state utilization of institutions (fiscal year 2015), and disability prejudice data from 325,000 people. Findings revealed, states with higher disability prejudice institutionalize more people, even when controlling for size. Moreover, states with higher disability prejudice also spend more on institutional funding, regardless of size or wealth.

Keywords: institutionalization; disability prejudice; implicit prejudice; people with intellectual and developmental disabilities

The Relationship Between Disability Prejudice and Institutionalization of People with Intellectual and Developmental Disabilities

There are decades of research indicating ableism – social oppression against people with disabilities – is extremely prominent (Abberley, 1987; Barnes, 1997; Baynton, 2001; Harris & Harris, 1977; Keller & Galgay, 2010; Linton, 1998; Phillips, 1990; Schweik, 2009; Shakespeare, 1996; Young, 2014; Zola, 1985). Ableism often manifests itself through structures and social systems (Harpur, 2011; Keller & Galgay, 2010; Linton, 1998; Thompson, Bryson, & de Castell, 2001). The social “devaluation of people with intellectual disabilities can be implicitly evident in the ways that persons with are characterized and discussed” (Carlson, 2010, p. 10). In many ways, these characterizations, and the “many forms of suffering that result from dehumanizing and oppressive practices, attitudes, and institutions” (Carlson, 2010, p. 180), have their origins in institutionalization in the United States.

Institutionalization of People with Intellectual and Developmental Disabilities

In the early 1800s, conceptualizations of intellectual and developmental disabilities (IDD) (previously known as ‘feebleminded’ or ‘idiocy’) shifted to become a more noticeable class. At the time it was believed people with ‘idiocy’ would end up in jail if not educated because it was believed their condition was related to “a failure of the will” (Trent, 1994, p. 16). This was one of the first constructions that individualized and pathologized IDD.

Institutions were utilized as a mechanism to educate out this ‘failure of will’ from people with IDD so they could become ‘productive’ members of society (Trent, 1994). However, as institutions grew in size, these spaces could not manage teaching so many people. Moreover, around the same time, an economic downturn favored hiring nondisabled people in the community rather than educated people with IDD (Carlson, 2010; Trent, 1994). As a result,

institutions' purposes shifted from educational schools to custodial spaces aimed at managing people (Carlson, 2010; Trent, 1994). Rather than focusing on education, institutional settings modeled themselves after 'lunatic' asylums and functioned as locations of care and medical intervention (Carlson, 2010; Trent, 1994). As such, the conceptualization of IDD shifted from an educational model to a medical one.

Conceptualizations of IDD again shifted after the civil war when families that were previously paying institutions privately had less cash because of post war inflation (Trent, 1994). As a result, IDD became linked with state burden and responsibility. Public funding of institutions also led to state appointment boards which created distinct classes of IDD, new policies of custody, and new colony institution arrangements (Trent, 1994). To stretch operations, institutions began putting those people with less severe impairments to work – shifting institutionalization to a vocational enterprise (Carlson, 2010; Trent, 1994).

New trends in heredity led to new etiologies of IDD rather than a 'failure of will' – "studies of the lineage of degeneracy were increasingly used to demonstrate the immutable effects of heredity on certain groups of American citizens" (Trent, 1994, p. 72). Not only was the person's impairment to blame for their poor sense of mortality, it was also the result of a "poor 'genetic environment'" of the parent" (Trent, 1994, p. 70).

In the late early 1900s, science, rather than "sentimental goodwill or public paternalism" (Trent, 1994, p. 137), became the new method for social change because of previous interests in heredity, new developments in intelligence testing, popular social Darwinism, and trends in eugenics. Institution superintendents "believed that the relationships between human beings at all levels of interaction could be reduced to scientific principles... [and] to tamper with the natural order risked jeopardizing the operation of nature itself" (Trent, 1994, p. 135). All of which had

resulted in the construction of IDD as a ‘menace to society.’ Because of this construction, eugenic sterilization of people with IDD became prominent.

In the 1950s, the rise of the confessional parent genre started a new trend of disability as ‘parent tragedy,’ while at the same time portrayed people with IDD as special and angelic. Although institutionalization was still common, having a child with IDD was no longer related to an immoral family heredity (Carlson, 2010; Trent, 1994). According to Trent (1994), “retarded children could be helped; people need not fear retarded children; with proper education and support, many retarded children could develop their potential; and by implication, having a retarded child was nothing to be ashamed of” (p. 241).

John F. Kennedy’s Presidential Panel On Mental Retardation also helped shift the conceptualization of IDD to become a “*health and human development* problem, one that could be tackled scientifically” (Trent, 1994, p. 249). Researchers became the new ‘hero’ and ‘expert’ on IDD; “thus the fight should be a medical fight, a psychological fight, a scientific fight, but neither a psychiatric one, nor a consumer one” (Braddock, 2007, p. 249).

Around the same time, in addition to advocacy by parents, the ‘popularity’ of discrimination and neglect exposés among the media around the same time also helped encourage deinstitutionalization. *Wyatt v. Stickney* (1971) resulted in sweeping reforms of state facilities and standards of care. Deinstitutionalization is also a result of advocacy by people with IDD and their family members who have demanded institutional reform and community alternatives. Since then, *Olmstead v. L.C.* (1999) has also reinforced people with disabilities’ rights to be in the community.

Another monumental contribution was changes to long term services and supports (LTSS), which help people with activities of daily living and instrumental activities of daily

living over an extended period, rather than acute care. For example, the United States authorized the Medicaid Home and Community Based Services (HCBS) waiver program in 1981 as an alternative to intermediate care facilities for individuals with developmental disabilities (ICFDD), a form of institution. HCBS waivers allow states to ‘waive’ key provisions of the Social Security Act (i.e., statewideness, comparability of services, and income and resource rules) to create and expand community LTSS particularly tailored to populations that would typically require institutional care. Surpassing ICFDD funding in 2000, Medicaid HCBS waivers are now the largest funders of LTSS in the United States (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). In 2014, the Centers for Medicare and Medicaid Services (CMS) also reinforced its emphasis on *meaningful* community inclusion of people receiving services by introducing the HCBS Final Settings Rule (2014). The Settings Rule includes a number of stipulations about person-centered planning, as well as creates heightened scrutiny guidelines to identify settings that have the qualities of an institution to ensure HCBS funding only goes to home and community-based settings.

Compared to institutional settings, people with IDD in the community have increased self-determination, larger social networks, increased participation in community life, and increased choice (Beadle-Brown et al., 2016; Larson, Lakin, & Hill, 2013). Community living is also more cost effective than institutions (Braddock et al., 2017). Yet, despite deinstitutionalization being at an all-time high, a sizeable proportion of people with IDD still live in institutions in the United States (Braddock et al., 2017). Moreover, despite the shift toward community living, Medicaid, the largest provider of LTSS of people with IDD (Braddock et al., 2017), continues to have an institutional bias (Blair & Espinoza, 2015; Ligas Consent Decree Monitor, 2016, 2017). While alternative 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” (Crossley, 2017, p. 5). Although the HCBS Final Settings Rule emphasizes community living, it does not end this institutional bias.

Those opposed to deinstitutionalization, frequently small, but very active, parent associations, often argue people need more care than the community can provide, or that institutions result in higher quality (Bagenstos, 2012). Parents opposed to deinstitutionalization have argued, institutions are

the best place for their (often now adult) children. They contended that institutional placement was necessary for many people with developmental disabilities (including their children) to receive the services they needed; that their children needed protection from risk and could not be trusted with the choices they would be required to make to live life in the community. (Bagenstos, 2012, p. 19)

Despite the arguments of people against deinstitutionalization, research has found that even people with more severe impairments benefit from deinstitutionalization and community residential supports (Lakin, Larson, & Kim, 2011; Mirenda, 2014; Young, 2006). In fact, “research denies support for the assertion that people obtain greater or even equal benefit in adaptive behavior from living in institutions... this research suggests that those benefits very consistently accrue more to the people who leave institutions to live in small community homes” (Larson & Lakin, 1989, p. 30).

Purpose

As historically the two have often been intertwined in the United States, the aim of this study was to examine the relationships between disability prejudice and institutionalization of people with IDD in the United States. As such, this study had two research questions:

1. how does disability prejudice impact the number of people with IDD who are institutionalized in a state?
2. how does disability prejudice impact state spending on institutions?

To explore these questions, we used secondary data about state utilization of institutions 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

Data

Institutional Censuses. Data about the number of people residing in institutions was obtained from the *State of the States in Intellectual and Developmental Disabilities* (Braddock et al., 2017). The State of the States is “is a comparative nationwide longitudinal study of the financial and programmatic trends in residential and community services for people with IDD in the United States. The project spans a 39-year period across FY 1977–2015” (Braddock et al., 2017, p. 3). The most recent analysis includes FY 2015.

We utilized state data about the number of people living in residences with 16 or more people with IDD (public and private institutions) in FY 2015. In FY 2015, an average of 1,364 people with IDD ($SD = 1,577$) resided in institutions (public and private) per state (Table 1). Both public and private institution censuses were included to examine the larger culture of institutionalization within the state.

Institutional Spending. States' IDD institutional spending was also obtained from Braddock et al. (2017). In particular, state data about the public spending for IDD services in FY 2015 in public state-operated and private institutions (16 people and larger) was utilized. In FY 2015, an average of \$146.24 million ($SD = \194.89 million) was spent on the institutionalization of people with IDD per state (Table 1).

Disability Prejudice. There are two levels of attitudes: explicit (conscious) attitudes and implicit (unconscious) attitudes (Amodio & Mendoza, 2011; Antonak & Livneh, 2000). As people may feel pressured to conceal their biases, or may be unaware they hold biased attitudes, there are concerns that explicit measures do not capture all attitudes (Amodio & Mendoza, 2011; Antonak & Livneh, 2000). This may be especially true for topics where it is socially undesirable to have negative attitudes, such as against people with disabilities. For this reason, much attitude research has shifted towards examining implicit attitudes. Implicit attitudes can relate to automatic processes triggered by external cues and reflect associations between attitudes and concepts; "'implicit' refers to [lack of] awareness of how a bias influences a response, rather than to the experience of bias or to the response itself" (Amodio & Mendoza, 2011, p. 359).

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 (Karpinski & Hilton, 2001). Scores of .15 to .34 reveal a slight preference for nondisabled people, .35 to .64 a moderate preference, and .65 and greater a strong preference (Aaberg, 2012;

Greenwald, Nosek, & Banaji, 2003). Negative values of the same values above reveal preferences for people with disabilities, and scores from $-.14$ to $.14$ reveal no prejudice (Aaberg, 2012; Greenwald et al., 2003).

Data about implicit disability prejudice was obtained from Project Implicit (Xu, Nosek, & Greenwald, 2014), a database where people can test their implicit prejudices, including against people with disabilities using the DA-IAT. Project Implicit is a non-profit organization which hosts a website where people around the globe can voluntarily participate in online IAT tests and self-report measures in order to determine their implicit attitudes (Xu et al., 2014). While many participants come across the website on the internet, others are asked to take it as part of coursework; however, all participants are volunteers and none are compensated for participation.

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 in United States territories, so their scores were not included. This resulted in a final n of 326,496 or an average of 6,402 participants per state ($SD = 6,185$). Demographic information about the state participants lived in was then used to aggregate DA-IAT scores by state, with the state's average score serving as the state's disability prejudice score. The average state implicit disability prejudice score was $.50$ ($SD = .02$), which is moderate prejudice (Table 1).

Control variables. State wealth was one of the metrics used as a control variable. Personal income data obtained from the Bureau of Economic Analysis (2016) was used as the metric of state wealth. Personal income is:

the income received by, or on behalf of, all persons from all sources: from participation as laborers in production, from owning a home or business, from the ownership of financial assets, and from government and business in the form of transfers. It includes income from domestic sources as well as the rest of world. It does not include realized or unrealized capital gains or losses. (Bureau of Economic Analysis, 2016, n.p.)

In FY 2015, the average state had an aggregate personal income of \$300.5 billion ($SD = \368.3 billion).

State population was the other control variable. State population in FY 2015 was obtained from U. S. Census Bureau (2015). The average population per state was 6.30 million ($SD = 7.20$ million) in FY 2015.

Because personal income and state population caused multicollinearity, we created a new variable (state personal income per capita) to reduce the effect by dividing personal income by state population for the second research question.

Analysis

This study's first research question was: how does disability prejudice impact the number of people with IDD who are institutionalized in a state? To explore this research question, a multiple linear regression model was used with states' disability prejudice scores serving as the independent variable (IV) and states institutional censuses serving as the dependent variable (DV). We also controlled for the state size (state population).

The second research question was: how does disability prejudice impact state spending on institutions? To explore this research question, a multiple linear regression model was used with states' disability prejudice scores serving as the IV and states' spending on institutions as

the DV. We also controlled for state personal income per capita in order to control for state size and wealth.

Results

Institutional Censuses

To explore the relationship between disability prejudice and institutionalization of people with IDD, a multiple linear regression model was run with the IV states' disability prejudice, and the DV, state institutional censuses; we also controlled for state size. The model was significant, $F(2, 48) = 41.21, p < .001$. The model predicted 63.0% of variance.

The regression equation for predicting a state's institutional census from the state's disability prejudice is:

$$\text{Total Institutional Census} = -7244.05 + 15284.68(\text{Disability Prejudice}) + .0002(\text{State Population})$$

Both the disability prejudice score and the total residential population were significant at $t = 2.25, p = .029$ and $t = 8.30, p < .001$ respectively.

According to the model, the lower the state's disability prejudice, the fewer people with IDD will be institutionalized in the state, regardless of the number of people with IDD receiving residential services (see figure 1). For example, a state with an average disability prejudice score of .65 (high prejudice), is expected to institutionalize 2,691 people with IDD when residential services population is controlled. Whereas, a state with an average disability prejudice score of .55 (moderate prejudice) is expected to institutionalize 1,163 people with IDD when residential services population is controlled. When state residential services population is controlled, states with little to no disability prejudice (0 to .34) are not expected to have any people with IDD in institutions.

Institutional Spending

We also explored the relationship between disability prejudice and institutional spending. To do so, a multiple linear regression model was run with the IV implicit disability prejudice and DV state institutional spending; we also controlled for state personal income per capita. The model was significant, $F(3, 48) = 3.44, p = .040$. The model predicted 12.5% of variance.

The regression equation for a state's institutional spending from the state's disability prejudice is:

$$\text{State Institutional Spending (Millions)} = -1583.04 + 3012.60(\text{Disability Prejudice}) + .005(\text{State Personal Income per Capita})$$

The disability prejudice score ($t = 2.34, p = .023$) was significant.

According to the model, the lower the state's disability prejudice, the less the state spends on institutionalization, regardless of personal income per capita (see figure 2). For example, a state with an average disability prejudice score of .65 (high prejudice) is expected to spend \$375.15 million on institutionalization of people with IDD when personal income per capita is controlled. Whereas, a state with an average disability prejudice score of .55 (moderate prejudice) is expected to spend \$73.89 million on institutionalization of people with IDD when personal income per capita is controlled. Controlling for personal income per capita, states with little to no disability prejudice (0 to .34) are not expected to spend money on institutionalization of people with IDD.

Discussion

The *Olmstead v L. C.* (1999) ruling reinforces that institutions often illegally segregate people with disabilities, and that people with disabilities have the right to be in the community. Not only have people with disabilities been advocating for community living, research also

indicates people with IDD have better outcomes in the community, and the community is more cost effective (Beadle-Brown et al., 2016; Braddock et al., 2017; Larson et al., 2013).

One of the few remaining arguments for institutionalization of people with IDD is that people with more severe impairments have better outcomes there; however, research has demonstrated that this claim is not only unsubstantiated but the opposite is true – people with severe impairments have better outcomes in the community (Lakin et al., 2011; Mirenda, 2014; Young, 2006). When outcomes, preferences of people with IDD, expenditures, and state resources are all ruled out as potential rationalizations for continued institutionalization, there are few ‘justifiable’ reasons left for institutionalization other than prejudice.

Prejudice has implications – it is not just how we interact with others. Rather, it seeps into structures and systems. This study was the first of its kind in its ability to expose the influence of disability prejudice on institutionalization of people with IDD. As we have found, people with IDD are more likely to be institutionalized when states have higher implicit disability prejudice. States are also more likely to spend more on institutional funding, regardless of state personal income per capita, when they have higher implicit disability prejudice.

According to Bagenstos (2012), “in the new politics of deinstitutionalization,” parents and unions can be expected to wage epic battles to keep states and courts from downsizing institutions – even if the downsizing efforts focus entirely on people who affirmatively want (and whose families affirmatively want them) to live in the community... [because] it becomes equally imperative to keep the institution from reaching that tipping point or, if it has already reached that point, to apply extraordinary political and legal pressure to delay or forestall what seems fiscally inevitable. (p. 46)

Armed with the findings from this study, states should continue and/or revitalize their deinstitutionalization efforts. Although *Olmstead* was a landmark ruling, progress has been slow, often requiring class-action lawsuits for the actual implementation of the ruling. There needs to be more state momentum to ensure people with IDD receive the opportunities and rights they are entitled to. In addition, states that have higher than average institutionalization rates must also re-examine their practices, particularly because, based on our findings, it is likely they are also more prejudiced against people with disabilities.

Moreover, in addition to continued deinstitutionalization efforts, there must also be an intentional effort to rid *all* services and supports, institutional or community based, of the culture of congregate care. Spagnuolo (2016) argues, “the legacy of institutionalization and congregate care has shaped current residential services, meaning that ‘services today have become standardized, inflexible and unaccountable to those they serve’” (n.p.). This means not only dismantling Medicaid’s institutional bias, but also building up a community infrastructure that is truly person-centered and accountable to those it serves.

Finally, more work must be done to reduce disability prejudice. One of the most harmful parts of the social devaluation of people with disabilities is society’s belief that society plays no role in the social devaluation, thus dictating that society does not need to change (Culham & Nind, 2003). It also places the onus for change on the individuals with disabilities and ignores the ways different types of prejudice can impact people with disabilities. Conceptualizations of disability need to shift so that they recognize the lived experiences of people with disabilities, rather than simply reflect harmful stereotypes and attitudes, including those that result in institutionalization.

Limitations

When interpreting these findings, it should be noted that people volunteered to participate in the DA-IAT and, therefore, there is a chance of selection bias. Moreover, the data on disability prejudice was across disability and not IDD specific; however, given research has found a preponderance of IDD prejudice, its likely similar trends would occur with IDD specific prejudice data. It should also be noted that we did not explore interactions, and that correlation does not necessarily imply causation.

Conclusions

Institutionalization was one of the first instances in the United States people with IDD were pathologized. Even as conceptualizations of IDD have shifted over time and become more nuanced, disability is still synonymous with ideas of “personal pathology, of individual difficulties and of dependency in the face of care” (Goodley, 1997, p. 369). Although deinstitutionalization of people with IDD is at an all time high, institutionalization still continues. Institutionalization has always been and, according to our findings, continues to be intimately intertwined with disability prejudice; recognizing this is one of the first steps toward remedying it.

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Table 1
Descriptive Statistics

State	Institutional Census (16+)	Spending on Institutions in Millions (publicly operated)	Disability Prejudice
Alabama	1,072	\$0.0	0.50
Alaska	5	\$0.0	0.49
Arizona	167	\$28.5	0.49
Arkansas	1,881	\$165.5	0.50
California	3,886	\$554.6	0.49
Colorado	301	\$39.9	0.45
Connecticut	913	\$193.8	0.53
Delaware	183	\$45.8	0.49
District of Columbia	19	\$0.0	0.47
Florida	3,286	\$326.3	0.51
Georgia	1,615	\$63.0	0.52
Hawaii	68	\$0.0	0.51
Idaho	299	\$24.8	0.49
Illinois	5,590	\$415.5	0.48
Indiana	1,700	\$19.9	0.52
Iowa	1,890	\$226.5	0.52
Kansas	317	\$52.3	0.48
Kentucky	1,160	\$146.0	0.51
Louisiana	1,725	\$165.6	0.53
Maine	161	\$13.8	0.49
Maryland	463	\$55.3	0.51
Massachusetts	738	\$132.8	0.48
Michigan	1,188	\$25.0	0.50
Minnesota	885	\$32.8	0.50
Mississippi	2,119	\$206.1	0.53
Missouri	1,603	\$99.1	0.51
Montana	205	\$11.9	0.45
Nebraska	510	\$69.6	0.51
Nevada	179	\$14.3	0.48
New Hampshire	114	\$4.4	0.51
New Jersey	2,729	\$552.4	0.52
New Mexico	93	\$0.0	0.47
New York	4,444	\$569.3	0.51
North Carolina	2,863	\$409.5	0.50
North Dakota	231	\$33.3	0.48

Ohio	5,661	\$488.2	0.51
Oklahoma	1,588	\$66.3	0.48
Oregon	168	\$0.0	0.48
Pennsylvania	4,153	\$523.8	0.51
Rhode Island	66	\$5.9	0.49
South Carolina	927	\$108.8	0.53
South Dakota	277	\$31.0	0.48
Tennessee	789	\$80.3	0.53
Texas	6,118	\$844.9	0.51
Utah	906	\$72.7	0.46
Vermont	28	\$0.0	0.48
Virginia	1,649	\$199.6	0.49
Washington	1,124	\$185.4	0.47
West Virginia	303	\$1.3	0.51
Wisconsin	1,103	\$133.4	0.50
Wyoming	93	\$19.3	0.47

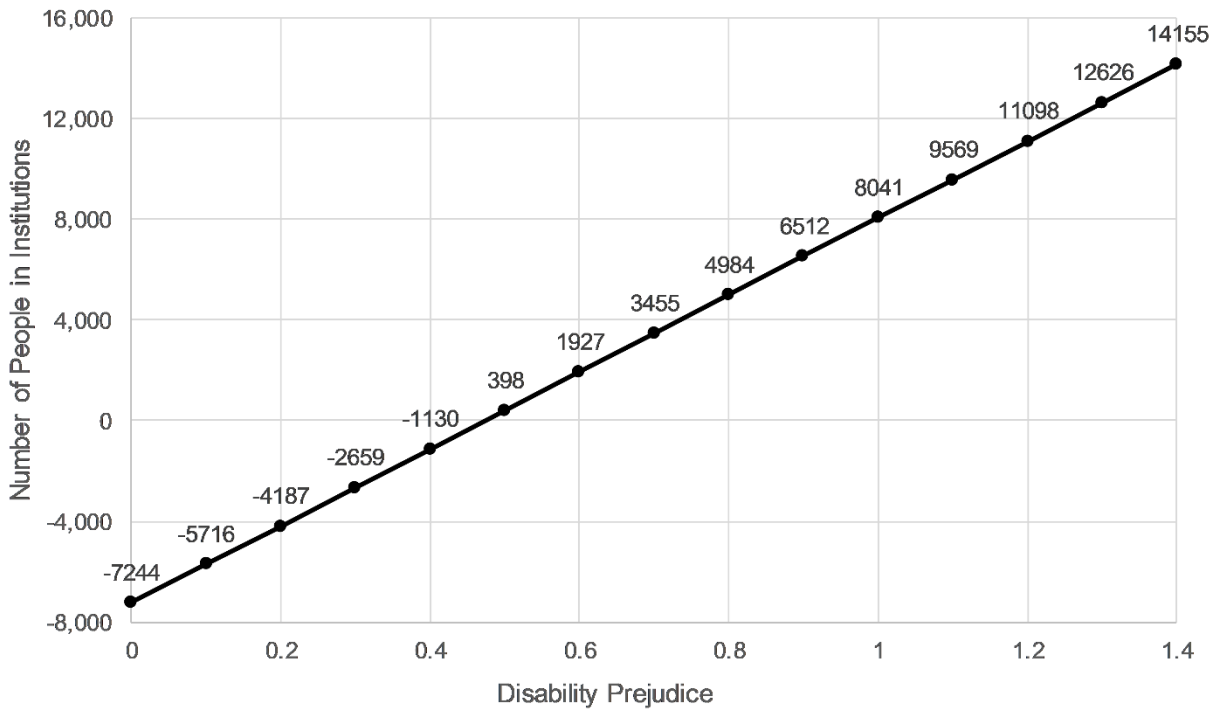


Figure 1. Relationship between state disability prejudice and institutional censuses (controlling for state population).

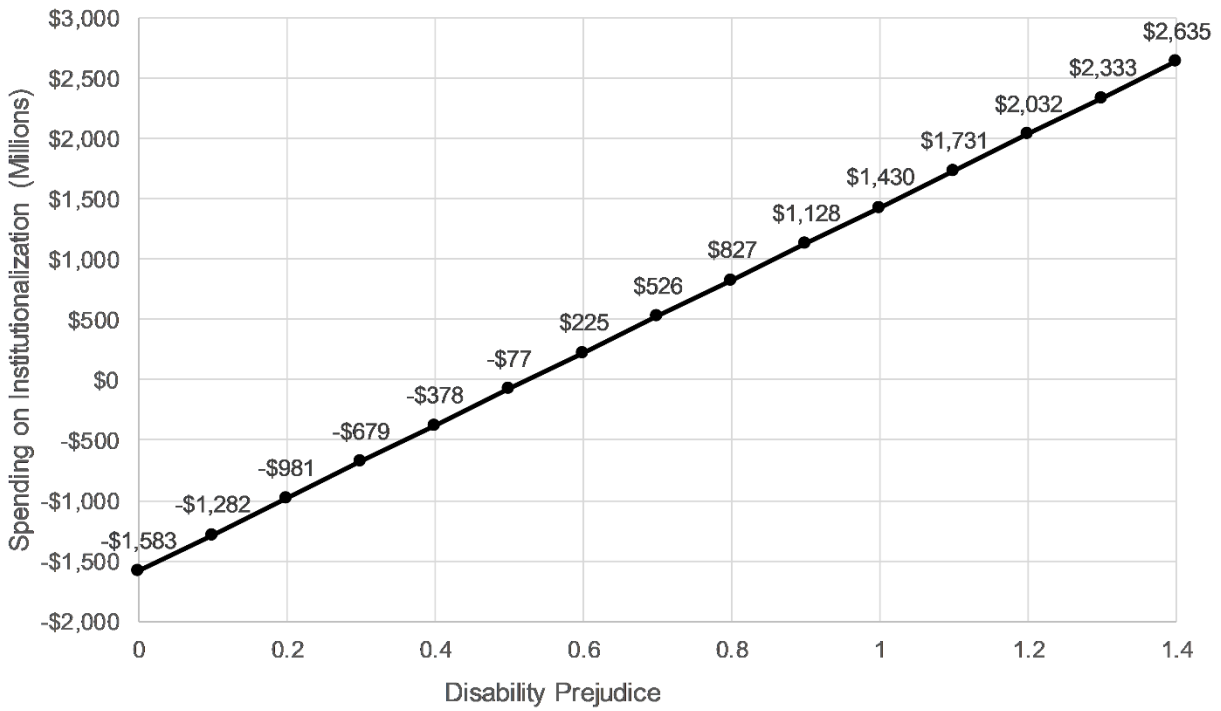


Figure 2. Relationship between state disability prejudice and spending on institutionalization (millions) (controlling for personal income per capita).