

UC Berkeley

Recent Work

Title

State of Change: State-Level Actions to Protect the Rights of Parents with Disabilities and Their Children

Permalink

<https://escholarship.org/uc/item/08m32081>

Authors

Callow, Ella
Sirianni, Lucy
Schweik, Susan

Publication Date

2018-09-21

State of Change:

State-Level Actions to Protect the Rights of Parents with Disabilities and their Children

Written by Ella Callow, Susan Schweik, and Lucy Sirianni with scholarship and recommendations from scholars of the Haas Institute Disability Studies Research Cluster at UC Berkeley



Published by the Haas Institute for a Fair and Inclusive Society at UC Berkeley

This policy brief is published by the Haas Institute for a Fair and Inclusive Society. This brief represents research from scholars of the [Haas Institute Disability Studies](#) research cluster which includes the following faculty from UC Berkeley:

Karen Nakamura, Haas Distinguished Chair
Anthropology

Charis Thompson
Gender & Women's Studies

Arlene Mayerson
Berkeley Law

Alastair T Iles

Stephen Rosenbaum
Berkeley Law

Jane Mauldon Goldman
School of Public Policy

Zeus Leonardo
Graduate School of Education

Nancy Scheper-Hughes
Anthropology

Marsha Saxton
Disability Studies

Raymond Lifchez
Architecture, City and Regional Planning

Georgina Kleege
English

Mel Y. Chen
Gender & Women's Studies

Katherine Sherwood
Art Practice

Susan Schweik
English

About the Authors

Ella Callow is the Director of Legal Program The National Center for Parents with Disabilities and their Families in Berkeley, California.

Lucy Sirianni is a doctoral candidate and Graduate Student Instructor in UC Berkeley's English department, where she is completing a dissertation on nineteenth-century women's anti-racism poetry and has taught a variety of courses on social justice and minority literature. She also serves as the Lydia Maria Child Society's Vice President of Inclusive Excellence and Social Action and is deeply passionate about disability history, rights, and justice.

Susan Schweik is a Professor of English at UC Berkeley. She has been involved with Berkeley's disability studies program for over twenty years. She is the author of *The Ugly Laws: Disability in Public* (NYU Press, 2009) and is completing a new book titled *Unfixed: How the Women of Glenwood Asylum Overturned Ideas About IQ—and Why You Don't Know About Their Work*.

Editor

Stephen Menendian

Layout & Design

Al Nelson

Charts & Graphs

Al Nelson

Citation

Ella Callow, Susan Schweik, Lucy Sirianni. "State of Change: State-Level Actions to Protect the Rights of Parents with Disabilities and their Children" Haas Institute for a Fair and Inclusive Society, University of California, Berkeley, CA. September 2018. <http://haasinstitute.berkeley.edu/stateof-changepolicybrief>.

Published: September 2018

Thank you to the Evelyn and Walter Haas, Jr. Fund for supporting this research.

Cover image: In an outdoor setting, an African American woman in a wheelchair with braids is shown hugging a young boy whose eyes are closed and who is smiling. The woman's face cannot be seen, her back is to the camera. Part of a wheelchair she is sitting in is visible. The image wraps around to the back cover which continues to image and shows a large tree.



@haasinstitute

Contents

Introduction	4
Key Findings and Recommendations	8
Overview of Existing Legislation	10
Legislative Changes: Proposals and Models	13
Additional Recommended Practices	16
Conclusion	17
Works Cited	18

Introduction

In 1927, Carrie Buck, at the time just 21 years old, was sterilized against her will. Her right to parent her daughter Vivian was terminated, and the little girl was taken from her mother and died just five years later.

Why? Because Carrie Buck had been determined to be "feeble-minded." She was the first person to be sterilized under legislation modeled by US eugenicist Dr. Harry Laughlin, who contended unequivocally that the "basis of designation for sterilization is inferior potential parenthood." She would not be the last to endure the life-altering effects of Laughlin's legislation. The Supreme Court upheld the constitutionality of the state of Virginia's sterilization of Carrie Buck in the case *Buck v. Bell*. Over the course of the twentieth century, over 60,000 American citizens would undergo forced sterilization, many poor and of color,¹ some as young as 10 years old.²

In 2018, not quite 100 years after Carrie Buck's sterilization, another disabled woman gave birth to another baby girl. The woman was Illinois senator and double-amputee Tammy Duckworth, and the baby, Maile Pearl Bowsbey, was the first to be born to a sitting US senator. Senator Duckworth had access to fertility specialists and a supportive family.³ Her fellow senators publicly congratulated her and organized a baby shower; the media and public hailed her as a trailblazer. On the surface, her experience as a disabled mother could not have been more different from Carrie Buck's.

Yet while reading Buck's and Duckworth's stories side by side might seem to suggest a narrative of progress, even triumph, many twenty-first-century individuals with disabilities may feel their experiences of parenthood have been less akin to Duckworth's than to Buck's. In 2018, the notion of "inferior potential parenthood" still undergirds US family and child welfare law, serving as the justification for 33 state laws that allow for the severing of the constitutionally-protected parent-child relationship because of a parent's status as disabled.⁴

Parents with disabilities are suffering under these laws, as are their children. According to the National Council on Disability's landmark 2012 report "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children," parents with psychiatric disabilities are believed to have their parental rights terminated 70-80 percent of the time, while it is estimated that 40-60 percent of those with intellectual disabilities lose their children.⁵ The deaf, blind, and physically disabled communities report elevated child welfare involvement and fearfulness thereof as well.⁶ A study in Minnesota found that residents who receive special

1 Painter, 2011; Gallagher, 1999

2 Reilly, 1991

3 Chicago Sun-Times, 2018

4 **Schweik** and Callow, 2014

5 National Council on Disability, 2012

6 National Council on Disability, 2012

education services as children are three times more likely than their non-disabled counterparts to become involved in child welfare cases as adults.⁷

In 2017 the results were published of the only study since 1991 to determine what portion of the child welfare parent population is comprised of parents with disabilities. In all three of the child welfare and dependency court systems chosen—Los Angeles, CA, Hennepin County, MN, and El Paso, TX—the findings were astounding. In LA and El Paso where no formal screening is conducted for parental disability, the case filings and materials still revealed a parental disability rate of 37 percent and 30 percent, respectively. And in Hennepin County, where a pilot program had allowed parental assessment for disability to be conducted on each parent entering the system, that rate jumped to 67.6 percent. Sadly, these numbers are close to those found decades earlier by Taylor, et al, in the US and Llewellyn, et al, and Booth & Booth in Australia and the UK.⁸

Little if any chance of remedy exists when parents with disabilities lose their children in the dependency court system, especially, where a termination of parental rights is like a civil death penalty. For instance, whereas at least one study has shown a meager appellate success rate of 12 percent in dependency cases, another has shown that the success rate for parents with intellectual disabilities was only 2.3 percent.⁹ The pseudo-scientific reliance on IQ as a predictor of parenting capacity may play a role in these disparate rates.

7 Singh et al, 2013

8 Callow & Jacob, 2017

9 Callow et al, 2016

Further, while the mere fact of having a disability is listed in many state laws alongside such acts as abuse, neglect, and abandonment, the termination of a disabled parent's rights need not coincide with any of these factors. In 2010, Erika Johnson, a blind mother living in Missouri with her blind partner, had her newborn daughter removed from her custody and placed in foster care for 57 days after requesting breastfeeding support from hospital staff.¹⁰ In 2018, Amy Fabbri and Eric Ziegler, a couple with intellectual disabilities living in Oregon, regained custody of their two young sons after legal proceedings that lasted over four years. As in the case of Johnson, no abuse or neglect had been alleged, and the evidence in favor of terminating Fabbri and Ziegler's parental rights included such negligible offenses as forgetting to apply sunscreen and providing unhealthy snacks.¹¹

In short, disabled parents and their children are routinely threatened with separation on no grounds more compelling than disability-related bias and speculation. And while termination of parental rights may be the most extreme consequence of such bias and speculation, other aspects of parenting are affected, too. Disabled individuals who seek to retain full or partial custody of their children in divorce proceedings, who attempt to become foster or adoptive parents, or who wish to access assisted reproductive technologies also face significant legal barriers.¹²

For years, in a variety of ways, several UC Berkeley faculty members directly affiliated or otherwise associated with the **Haas Institute Disability Studies research cluster** have done research on

10 ABC News, 2010

11 Oregon Live, 2018

12 National Council on Disability, 2012

subjects related to this issue. **Susan Schweik's** work with Ella Callow on legislative discrimination has emerged out of a broader cluster of work that pertains to disability and parenting and/or more broadly to the legacies and ongoing dynamics of eugenics. Disability Studies chair **Karen Nakamura** has written about eugenic sterilization and other forms of controlling the reproductive sexuality of disabled people in Japan¹³ and traces the creation of the 1948 Japanese Eugenic Protection Law to its Nazi German precursors, which themselves were inspired by American eugenics laws, one of the earliest being a state law passed in Indiana in 1907.

Although the Eugenic Protection Law in Japan changed its name in 1996 to the Mother's Body Protection Law and disabled sterilization was nominally removed, there continue to be deeply felt effects of decades of eugenic practices on disabled and other communities in Japan. **Nakamura's** most recent research has been exploring the effect of the Eugenic Protection Law and its successors on transsexual and transgender communities, especially in terms of the continued mandatory eugenic sterilization of trans people.

Other cluster faculty have been equally active. Charis Thomson works, as she puts it, "on the policy implications of including disability in a comprehensive switch from reproductive rights to reproductive justice, the policy implications of the rise of selecting technologies such as genome editing and the need to empanel those with disabilities in decision-making and assessment roles on social trends in deselection, and on moving the emphasis away from the prenatal scene, where people with disabilities keep having to account for the value of

their very existence, to a more life-long, situated perspective that includes structural inequality among the causes of many preventable forms of excess morbidity and mortality and care and access shortages."¹⁴ **Marsha Saxton's** ongoing work on reproductive justice also now primarily involves genetic screening, selective abortion, wrongful life lawsuits, and other issues of reproductive technology. Her overview on these issues has been a staple of a standard disability studies textbook through multiple printings,¹⁵ and in earlier years her scholarly and activist work included direct focus on the discouragement of reproduction by disabled people and the devaluation of disabled parents.¹⁶ **Jane Mauldon** co-authored a policy brief in 2010 on "CALWORKS Children with Disabled Parents on SSI," exploring strategies for strengthening these families by "providing a broader system of support for all families."¹⁷ She is currently working on a demographic and policy-focused analysis of families in which children, caregiver(s), or both are disabled.

14 Thomson, 2017, 2016, 2015

15 Saxton, 2016

16 Saxton, 1984

17 Mauldon. Spiegelman and Sadar, 2010

13 Nakamura, 2014, 2013, 2006

This policy brief will provide an overview of current legislation that discriminates against parents with disabilities. It will also consider non-discriminatory legislation that has been enacted or is currently being enacted at the state level, with the hope of encouraging more states—eventually all states—to adopt similar legislation. It is our strong belief that such legislative changes are both needed and deserved by the at least 4.1 million disabled parents currently raising children under the age of 18 in the US as well as by the roughly 6.1 million children who rely on them for care.¹⁸

As Susan Schweik and Ella Callow note in their not-yet-published paper "Dismantling Harry Laughlin," "Parenting is to the disability movement what marriage was for the LGBTQ movement—the centerpiece... and the most public symbol of equality."¹⁹ What is at stake, they remind us, is "the veracity of our national commitment to disability human rights—the real integration of people with disabilities into the human family."²⁰

18 Kaye, 2011

19 Schweik and Callow, 2014, quoting Hsu, 2006

20 Schweik and Callow, 2014

Key Findings and Recommendations

+ The United States Supreme Court "has avowed continuously and with conviction that parents' rights to the care and custody of their children are protected under the Due Process Clause of the 14th Amendment."²¹ This claim has been reiterated and upheld in a long history of Supreme Court rulings, including *Meyer v. Nebraska* (1923), *Pierce v. Society of Sisters* (1925), *Stanley v. Illinois* (1972), and *Troxel v. Granville* (2000). Further, it is widely recognized that it is in the best interest of children to remain with their biological parents unless doing so would cause clear and present danger.

Our findings indicate that neither the legal rights of disabled parents nor the best interests of their children are being adequately served by existing legislation. The California legislature should reassert public authority over broadband network deployment by repealing SB1161, which places some limits on such public oversight, and should adopt legislation that establishes enforceable fiber deployment benchmarks that apply to all providers.

+ In the US, 6.2 percent of parents raising children under the age of 18 identify as having a disability, and almost 10 percent of children under 18 are being raised by a disabled parent.²² These percentages are higher in populations most often over-represented in child welfare systems: 13.9 percent of American Indian/Alaska Native parents and 8.8 percent of African American parents have a disability, while 6 percent of white, 5.5 percent Latino/Hispanic, and 3.3 percent of Asian/Pacific Islander parents identify as disabled.²³ Thus, the effects of discriminatory legislation are more widespread than many realize.

+ Studies have shown that parental disability does not negatively affect children's development or outcomes²⁴—and may in fact have a positive impact. Children of parents with physical, sensory, psychiatric, and intellectual or developmental disabilities may exhibit increased levels of empathy and emotional awareness, and adult children of parents with disabilities overwhelmingly report feeling that their parents' disabilities led to positive outcomes, including greater compassion and tolerance, awareness of disability oppression and empowerment, understanding of civil rights, enhanced resourcefulness and problem-solving skills, and achieving stronger family bonds.²⁵ As such, we can see that laws discriminating against the right of disabled

21 National Council on Disability, 2012

22 Kaye, 2011

23 Kaye, 2011

24 Shade, 1998; Preston, 2011

25 Marsh, 1998; Collentine, 2005; Lightfoot et al, 2010; Eden et al, 2017; etc

individuals to raise children are rooted in prejudice about their capabilities, without taking into account the reality of life as a disabled parent or as the child of a disabled parent.

- + Our findings reveal that the best remedy for the current legal situation of parents with disabilities will take place at the state level.²⁶ We offer this document in the hope that it will lead all states that have not yet done so, and most particularly the 33 that list disability as grounds for termination of parental rights, to enact legislation based on the model legislation provided in *Rocking the Cradle*, as states including Colorado, Idaho, and South Carolina have already successfully done.²⁷ It is our belief that the legislation adopted must be comprehensive in nature, encompassing all disabilities and applying to both dependency and family law as well as adoption law.
- + In addition to sweeping legal reform, we advocate additional supports for both those parents with disabilities who may require them and the professionals who work with them. After a detailed examination of current and proposed legislation, we will consider the possibility of offering legal and practical support for parents with disabilities through regional centers modeled on Berkeley's *Through the Looking Glass* as well as the need for increased training for social workers and legal professionals who may come in contact with disabled parents.

Children of parents with physical, sensory, psychiatric, and intellectual or developmental disabilities may exhibit increased levels of empathy and emotional awareness, and adult children of parents with disabilities overwhelmingly report feeling that their parents' disabilities led to positive outcomes, including greater compassion and tolerance, awareness of disability oppression and empowerment, understanding of civil rights, enhanced resourcefulness and problem-solving skills, and achieving stronger family bonds.

²⁶ Schweik and Callow, 2014

²⁷ CO HB 18-1104, 2018; ID Code Ann. 16-1601, 16-2001(2), 32-717(5), 32-1005(3), 2004; SC HB 3538/SB 291, 2017

Overview of Existing Legislation

AS PREVIOUSLY STATED, no less than 33 states currently list disability as grounds for termination of parental rights. As of this writing, those states are Alabama, Alaska, Arizona, Arkansas, California, Delaware, Georgia, Hawaii, Illinois, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Tennessee, Texas, Virginia, Washington, Washington DC, and Wisconsin. Of the states listed, only Kansas, Missouri, and Oklahoma stipulate that disability cannot be the sole grounds for termination of a disabled parent's rights.²⁸ One additional state, Utah, does not refer to disability specifically but does use language vague enough that it could be construed as doing so, stating that a parent's rights may be terminated in the event "that the parent is unfit or incompetent" and "that there is a substantial likelihood that the parent will not be capable of exercising proper and effective care in the near future."²⁹ These statutes run counter to the Americans with Disabilities Act as well as to Section 504 of the Rehabilitation Act, both of which prohibit state and local agencies such as those in the child welfare system from categorically discriminating on the basis of disability, yet they continue to inform state policy.

Of the states that include disability as grounds for termination of parental rights, 32 make specific mention of psychiatric disability or mental illness, 30 reference intellectual or developmental disabilities, and 9 list physical disabilities. Crucially, however, proceedings to terminate parental rights due

to disability are often undertaken even in states where disability is not included as grounds for doing so. Erika Johnson and Blake Sinnett, the blind couple referenced in this brief's introduction, had their baby placed in foster care in Missouri in 2010 despite the fact that nowhere in Missouri law is physical disability listed as grounds for termination of parental rights.³⁰ In Oregon, where Amy Fabbrini and Eric Ziegler fought for four years to regain custody of their sons, no disability of any kind is listed as grounds for termination. We find, therefore, that in order to best support the rights of parents with disabilities, even those states that do not include disability in their grounds for termination of parental rights must join those that do in enacting legislation that actively prohibits discrimination in dependency court proceedings on the basis of disability.

States that have eliminated disability as grounds for termination of parental rights include Colorado, Idaho, South Carolina, and West Virginia.³¹ New York, Oregon, and Rhode Island are working toward enacting similar legislation.³² Washington has enacted a bill specifically to counteract discrimination against parents with intellectual or developmental disabilities.³³ In spite of these praiseworthy steps toward equity, however, discrimination persists and must be dealt with via further action at the state level.

Parents with disabilities who find themselves navigating the family court system may fare marginally better than those in the dependency court system. In 2017, the American Bar Association's House of

28 Revised Kansas Code for Care of Children, Kan. Stat. Ann. 38-2201, 2006; MO HB 604/SB 555, 2011; 10A Okl. St. Ann. 1-4-90413, 2014

29 U.C.A. 1953 78A-6-507

30 V. A. M. S. 211.477, 2003

31 CO HB 18-1104, 2018; ID Code Ann. 16-1601, 16-2001(2), 32-717(5), 32-1005(3), 2004; SC HB 3538/SB 291, 2017; WV HB 2200, 2015

32 NY AB 02444; OR SB 1526; RI HB 5395

33 HB 2616, 2014

Delegates adopted Resolution 114, which urges equal protection for parents with disabilities regarding child custody, visitation, and other family matters and which is modeled in part on a similar resolution passed on behalf of LGBTQ parents. The ABA's resolutions are, in part, a way in which issues are brought to the attention of state-level lawmakers and the judiciary around the country. The ABA's action is timely, and the attention from state actors, greatly needed. Yet still, only California, Idaho, Maryland, Minnesota, Nebraska, Oregon, Tennessee, and Utah have enacted legislation that explicitly prohibits family courts from considering parental disability in judgment awarding custody or visitation unless clear and convincing evidence shows that it affects the child's best interest.³⁴ Similar legislation is under review in Massachusetts, New York, Rhode Island, and Virginia.³⁵ Illinois and South Carolina have enacted legislation specifically to protect the rights of blind parents in family court proceedings,³⁶ while Georgia, Hawaii, New York, Ohio, Oregon, and Virginia are in the process of doing the same.³⁷

While we are happy to see states moving toward more equitable legal treatment of parents with disabilities, our findings indicate not only that more states need to take action to adopt such legislation but also that the legal changes made should strive for broader comprehensiveness. The exclusion of dependency court proceedings from the legislation outlined in the above paragraph, as well as the exclusion of people with certain types of disability from much of that legislation, still leaves room for the rights of many disabled parents, particularly those rendered most vulnerable by race and socioeconomic status as well as by misconceptions about their specific disabilities, subject to legalized discrimination.

We find that despite the California Supreme Court's ruling in the landmark *In re Marriage of Carney* case (1979), which overturned the lower court's decision that a previous custody order should be altered because the father involved had

sustained a spinal court injury and become quadriplegic, discrimination remains pervasive. A judge maintained that a mother with a mobility disability should not be awarded custody of her children despite multiple assessments documenting her capability because he assumed that her children would function as her attendants, despite the fact that the mother was independent and the children had no more than the usual amount of household chores³⁸ and despite the preponderance of evidence revealing that the notion of children taking on extra care-giving duties as the result of having a disabled parent is rooted only in stereotypes, not reality.³⁹ In North Dakota case *Holtz v. Holtz*, a mother lost primary custody of her seven-year-old son due to concerns about her developmental and learning disabilities despite the father's admission that he had had almost no contact with his son prior to the lawsuit.⁴⁰ Stories like these are far from uncommon, and some disabled individuals have even stated that fear of losing custody of their children has prevented them from leaving abusive relationships.⁴¹ Clearly, further clarification of existing law as well as expansion of legal protections for parents with disabilities in family court proceedings are urgently needed.

The same is the case for protections for individuals with disabilities who wish to become foster or adoptive parents. Currently, only Colorado, Idaho, Maryland, Michigan, Missouri, Nebraska, South Carolina, and Wisconsin explicitly prohibit discrimination against prospective foster and adoptive parents on the basis of disability, though the Wisconsin legislation addresses physical disability only.⁴² The above-mentioned legislation currently under review in Rhode Island and Virginia would follow suit.⁴³ All of the blindness-specific legislation, both currently enacted and pending enactment, also prohibits discrimination on the basis of blindness in state foster care and adoption systems.

38 Kirshbaum et al, 2003

39 Cohen, 1998; Olkin et al, 2006; etc

40 Holtz v. Holtz, 1999

41 Nosek et al, 2001

42 CO HB 18-1104, 2018; ID Code Ann. 16-1501, 2002; MD HB 976/SB 765, 2016; MI Comp. Laws Ann. 722.957, 1994; MO HB 604/SB 555, 2011; NE HB 845, 2018; SC HB 3538/SB 291, 2017; WI Stat. 48.82(5), 1991

43 RI HB 5395; VA SB 70

34 CA SB 1188, 2010; ID 32-717, 2004; MD HB 976/SB 765, 2016; MN Stat. 518.17, 2005; NE HB 845, 2018; OR HB 2433, 2013; TN HB 693/SB 749, 2013; UT HB 157, 2017

35 MA HB 845/SB 896; NY AB 02444; RI HB 5395; VA SB 70

36 IL HB 2626, 2017; SC HB 4469/SB 687, 2014

37 GA HB 891; HI SB 2208; NY AB 0171/SB 02366; OH HB 309; OR HB 3392; VA HB 2273/SB 1199

Yet despite this progress, and despite the fact that Titles II and III of the Americans with Disabilities Act prohibit public and private adoption agencies from discriminating against prospective parents on the basis of disability, foster care and adoption proceedings remain riddled with de facto and de jure disability discrimination.⁴⁴ A blind mother was denied the opportunity to adopt a four-year-old boy because the child, she was told, was "too active" for her to care for.⁴⁵ A couple, both wheelchair users, waited 15 years to be matched with their child due solely to disability-based discrimination from birth parents and public and private adoption agencies.⁴⁶ A couple successfully fostering two children while working to adopt them had to fight to regain custody after their agency learned that the mother was HIV+.⁴⁷ They ultimately won their case, but tragically, the mother died the day after the adoption was finalized.

Stories like the above are legion and are devastating not only for the many parents with disabilities eager to provide safe and loving foster and adoptive homes but also for the countless children in need of permanent families in the US and around the world. Action must be taken at the state level to clarify and implement existing federal law.

Disabled parents seeking to have children with the aid of assisted reproductive technologies face similar legal barriers. In 2000, Kijuana Chambers, a blind woman from Colorado, filed a lawsuit after a fertility clinic refused to work with her, stating that her blindness posed a safety risk to her not-yet-conceived child.⁴⁸ After a lengthy battle, the 10th Circuit Court of Appeals sided with the clinic. "It was the right thing to do," an attorney on the case claimed.⁴⁹

As we know from the opening paragraphs of this document, the United States has a long history of efforts to prevent individuals with disabilities from having children, so it should come as no surprise that stories like Chambers's are common. In surveys, 79 percent of physicians working in the assisted reproductive technologies field have

indicated that they would refuse to work with a prospective mother with a severe genetic disorder, while 32 percent would refuse treatment to a prospective mother with a below-average IQ, 66 percent to a prospective bipolar mother, and 95 percent to an HIV+ mother.⁵⁰ Such discrimination violates the Americans with Disabilities Act, under Titles II and III of which providers of assisted reproductive technology services who receive any federal funding, such as Medicaid or Medicare, are legally barred from discriminating on the basis of disability. We reiterate that state laws must codify this as well as clarify the ADA's direct threat provision, which allows medical professionals to refuse care to a patient if that patient poses a direct threat to others. As per ADA regulations, the determination that an individual poses a direct threat must be based on individualized assessments, medical expertise, and/or objective evidence, but in practice, it is often applied indiscriminately as in the case of Kijuana Chambers. State-level guidance to counteract this tendency should be implemented.

Beyond the shadow of a doubt, legally sanctioned discrimination against parents with disabilities is rampant, and its life-altering consequences are devastating for parents and children alike. The situation must be remedied. In the next section, we will turn to the question of how this can best be accomplished.

44 Shade, 1998; National Council on Disability, 2012

45 Adams v. Monroe, 1998

46 National Council on Disability, 2012

47 Doe v. Nebraska, 2003

48 National Council on Disability, 2012

49 USA Today, 2003

50 Shade, 1998; Mutcherson, 2009

Legislative Changes: Proposals and Models

WHILE A FIX AT THE federal level such as an amendment to the Americans with Disabilities Act would seem the most elegant solution to the widespread discrimination faced by parents with disabilities, such a fix is unlikely to be forthcoming given the current political climate. Far from increasing protections for individuals with disabilities, the current administration has consistently sought to take away existing safeguards.⁵¹ Timely action is needed to stop the ongoing separation of families, and we cannot allow such separations to continue unchecked while we wait for a more opportune moment for federal reform.

Moreover, previous federal intervention has failed to achieve the desired results. In 2015, after intervening on behalf of Sara Gordon, a Massachusetts mother with an intellectual disability whose 2-day-old daughter had been removed from her care and placed in foster care for over two years, the Department of Justice and the Department of Health and Human Services jointly issued a document outlining the obligations of state and local child welfare agencies and courts under the ADA. Noting that discrimination complaints from disabled parents to both the Health and Human Services Office for Civil Rights and the Department of Justice Civil Rights Division were numerous and on the rise, the document clarifies the non-discrimination requirements in Title II of the ADA and Section 504 of the Rehabilitation Act, reiterates the need for objective and convincing evidence to support a claim of direct threat, and emphasizes the impor-

tance of individualized treatment and full and equal opportunity for parents and prospective parents with disabilities.

The guidelines set forth are clear and thorough, yet as evidenced by cases like the protracted legal battle of Amy Fabbrini and Eric Ziegler, which continued for over two years after the federal guidelines were issued, its effects have failed to stem the tide of discrimination. Quite simply, such guidelines are not widely disseminated, and child welfare workers and legal professionals remain unaware of them—in significant part because there is no mandatory training on parental disability for social workers and officers of the court. Federal guidelines are only as powerful as their application, and these guidelines, regrettably, are not being cited or circulated.

However, state-level action to remove discriminatory laws and replace them with actively supportive ones has gained momentum in recent years and has been effective. As **Susan Schweik** and Ella Callow conclude in their white paper, we should therefore pursue legislative change using a state-by-state strategy. We need to replicate the synergy and uniformity of the LGBTQ fight to legalize gay marriage, augmenting and synthesizing current efforts.⁵² What, then, should these legislative changes look like, and how might they come about? A summary review of what has and has not worked at the state level is instructive as we turn to these questions.

Idaho has long been considered the gold standard for anti-discrimination reform on behalf of parents with disabilities. The series of legislative changes enacted there between 2002 and 2004 are sweeping and unequivocal, modifying every custody-relat-

51 See the attempted passage of HR 620, which would have made it significantly easier for businesses to avoid ADA compliance, and the Department of Education's rescinding of 72 guidance documents outlining the rights of disabled students.

52 **Schweik** and Callow, 2014

ed section of the Idaho statutes and even serving as the basis for the proposed model legislation set forth in the National Council on Disability's *Rocking the Cradle*. Not only do Idaho's state laws avoid all mention of disability in their discussion of grounds for termination of parental rights except to stipulate that nothing in the section may be construed as allowing disability-based discrimination,⁵³ they also make clear that disabled parents have the right to provide evidence regarding how adaptive equipment and/or supportive services will enable them to carry out parenting responsibilities, that evaluations of parental fitness must take into account adaptations and supportive services and must be conducted by or with assistance from a person who has expertise in such adaptations and services, and that adoptions must not be denied solely on the basis of the disability of a prospective adoptive parent.⁵⁴ In any cases where a parent's disability is found to have an effect in court proceedings, specific documentation of the nature of that effect must be provided.⁵⁵

Other states have followed in Idaho's footsteps with varying levels of success. Colorado and South Carolina have passed similarly comprehensive legislation to prohibit disability-based discrimination against parents and prospective parents in the dependency court, family court, and adoption and foster care systems, with Colorado's legislation signed into law mere days before the publication of this policy brief.⁵⁶ West Virginia has removed disability as grounds for termination of parental rights and stipulates that courts must ensure that child welfare agencies make reasonable accommodations for parents with disabilities in accordance with the ADA.⁵⁷ Other states including Arkansas, Kansas, Missouri, and Oklahoma also make clear that reasonable accommodations must be provided,⁵⁸ but at the same time, they continue to list disability as an acceptable consideration in dependency court decisions, though Kansas, Missouri, and Oklahoma stipulate that it cannot be the sole consideration. We have seen above that a handful of states have

passed laws pertinent only to family court proceedings and/or to adoption law or to parents with specific disabilities (namely, blindness and intellectual disability). Additionally, California has taken a valuable step toward supporting parents with disabilities by including adaptive baby-care equipment among the items covered by the state's Medicaid program, MediCal.⁵⁹

The legislation in Idaho and the states that have joined it in enacting comparable legislation, in particular Colorado and South Carolina, should leave us with no doubt that other states can follow suit, passing legislation addressing discrimination in the dependency court, family court, and adoption and foster care systems and applying to individuals with all types of disabilities. Moreover, these states' landmark efforts have shown us that this kind of comprehensive legislative reform is effective. In the 2006 *Lieurance-Ross v. Ross* case, for instance, an Idaho father appealed the decision of a family court magistrate that he could not be awarded custody of his children due to stroke-induced cognitive disabilities. Demonstrating what they had learned from Idaho's then-quite-new legislation, the court of appeals engaged in a discussion of adaptive parenting equipment and services and ruled in the father's favor.⁶⁰ In South Carolina, a mother with an intellectual disability was reunited with her baby, who had been removed from her custody through a private action due to the mother's disability even though she had appropriate supports in place to care for her child. The judge in the case used South Carolina's new Persons with Disabilities Right to Parent Act⁶¹ to effect the reunification.⁶² While the initial removals in both of these cases should not have happened, the legislation in place allowed them to be resolved more quickly and with less evident disability-related bias than has been present in similar cases in states without comparable laws.

Recent legislative changes have also proven the power of sustained involvement by disability activists and disability rights organizations. The success of the Idaho legislation, for instance, is likely due

53 Code Ann. 16-1601, 16-2001(2), 2004

54 Code Ann. 32-717, 32-1005, 16-1501, 2004

55 Code Ann. 32-717(5), 2004

56 CO HB 18-1104, 2018; SC HB 3538/SB 291, 2017

57 WV HB 2200, 2015

58 AR SB 489, 1997; Revised Kansas Code for Care of Children, Kan. Stat. Ann. 38-2201, 2006; MO HB 604/SB 555, 2011; 10A Okl. St. Ann. 1-4-90413, 2014

59 CA SB 2152, 2000

60 *Lieurance-Ross v. Ross*, 2006

61 HB 3538/SB 291

62 *Able South Carolina*, 2018

in large part to the integral participation of multiple disability rights organizations from the beginning, namely the Idaho State Independent Living Council and the then Berkeley-based disability movement and clinical family services agency Through the Looking Glass National Center for Parents with Disabilities and their Families.⁶³ Compare this broadly comprehensive legislation with the anti-discrimination legislation in Washington, where only parents with intellectual disabilities are protected. There, disability rights organizations were not consulted until comparatively late in the process, and the resulting legislation, though commendable, is more limited in scope than it might otherwise have been.⁶⁴ We strongly encourage states enacting legislation to follow Idaho's lead in working closely throughout the process with disability rights organizations where there is expertise in and ideally firsthand knowledge of both the rights and the capabilities of parents with disabilities.

Praiseworthy though the steps forward above detailed unquestionably are, even the most comprehensive current legislation could be improved upon. For instance, no existing state law makes specific mention of discrimination against prospective disabled parents by professionals providing access to assisted reproductive technologies. This could be remedied by modeling proposed legislation on the template found in Appendix C of *Rocking the Cradle*.⁶⁵ Further, no law addresses the fact that parental mental illness is one of the few bases on which the hard-won protections of the Indian Child Welfare Act of 1978 are often circumvented by state court systems.⁶⁶ Particularly given that roughly 26.5 percent of Native American parents and caregivers from whom agencies have removed children identify as disabled as well as the vast over-representation of Native American children in the child welfare system, this disturbing dynamic should be named, and a restatement that the ICWA applies with equal vigor where parents have disabilities of any type should be included in remedial legislation at the state level.⁶⁷

While a number of positive changes have been made in recent years, the inconsistencies across state lines and disability populations are troubling, and we urge states to take the model legislation in *Rocking the Cradle* and the legislation passed in Colorado, Idaho, and South Carolina as a template and work to pass broadly comprehensive legislation of their own, keeping in mind the following:

- + Such legislation must address discrimination in the dependency court, family court, and adoption and foster care systems and should be applicable as well to the question of assisted reproductive technologies.**
- + It should encompass all disabilities, including physical and sensory, emotional and psychiatric, and intellectual and developmental ones, while also taking into account the specific needs of American Indian and Alaskan Native families where ICWA is implicated in their child welfare case.**
- + Legislation should be drafted in consultation with experts in disability law and the practical techniques and lived experience of parenting while disabled.**
- + Legislation must incorporate protections against the continuing use of pseudo-scientific measures for parents with intellectual and psychiatric disabilities. Reliance on IQ to determine parenting capacity for people with intellectual disability, and personality testing for those with psychiatric disability, must be prevented.**

We believe that only with such legislation in place will parents with disabilities and their children begin to receive the just and equitable treatment they so clearly deserve.

63 **Schweik** and Callow, 2014

64 **Schweik** and Callow, 2014

65 National Council on Disability, 2012

66 **Schweik** and Callow, 2014

67 National Council on Disability, 2012

Additional Recommended Practices

WHILE THIS DOCUMENT has focused on the particular and pressing need for holistic and progressive state legislative changes to combat legalized discrimination against parents with disabilities, other innovations are equally needed and can also be accomplished at the state level. For instance, social workers and other professionals key to the child welfare and custody systems must receive more education on the rights of this population and the reality versus the stereotypes of their parenting capabilities. The child welfare system, which has been particularly resistant to legislative reform in this field, must surrender the false premise of "rival interests" in child welfare cases.⁶⁸ Requiring that this issue be integrated into law and social welfare undergraduate and graduate programs certified by the State, along with state mandates for regular, required training for working social workers and attorneys in the child welfare, and dependency and family courts from a source that can provide legal, clinical, and cultural expertise could substantially lessen the system's tendency to fall back on this trope. In turn, the likelihood of support without fear of prejudice could encourage parents with disabilities to ask for help from the State more often—a great boon to parents and their children alike. In the current climate, parents with disabilities often hesitate to reach out for needed supports due to fear of losing their children.

Each state should prioritize funding free trainings for tribes, tribal ICWA workers, attorneys, the governing body, and other key child welfare/ICWA personnel. The State has the power to do this. Such training should concern the rights of parents with disabilities in the state child welfare system, best practices for child welfare agencies working

with families where a parent has a disability, and the special tools tribes have at their disposal to challenge the state when it falls short of complying with the law.⁶⁹ It is quite possible that the State can foster this through prioritizing grants of Court Improvement Project (CIP) monies to local and tribal courts, who will work in conjunction with disability law programs.

States should seek to increase their capacity to provide best practice services to families where a parent is disabled. This could be accomplished by creation of regional organizations modeled on Through the Looking Glass, a Berkeley-based agency that at one point offered free, nationwide legal expertise, non-pathological in-home early intervention services, and adapted baby-care equipment and assessments for parents with disabilities. The legal and practical supports such centers could offer create the ability for the state to comply with the law and with best practice.

There is precedent for federal and state funding for such endeavors. See, for instance, Vermont's Green Mountain 360 project, which provided practical and legal supports to parents with intellectual disabilities and was funded first by Project 360 of the Administration on Intellectual and Developmental Disabilities, a program of the Administration for Community Living of the Department of Health and Human Services, then by the state of Vermont.⁷⁰ Australia provides an example of how a large and diverse nation can formalize and systematize such capacity. Its Healthy Start program supports parents with intellectual disabilities, is available in every state and territory.⁷¹

68 Schweik and Callow, 2014

69 Callow, 2013

70 National Council on Disability, 2012

71 National Council on Disability, 2012

Conclusion

ACROSS THE UNITED STATES, 4.1 million parents with disabilities are capably and lovingly raising 6.1 million children. Too many of them are also living in fear—fear rooted not in doubts about their own parenting abilities but in the fact that legally sanctioned prejudice may rob them of the chance to prove those abilities. They are all too aware that minuscule mishaps non-disabled parents would seldom think twice about—fumbling during a first diaper change or sending a child to school with a too-tight ponytail—could result in a call to Social Services,⁷² and they know that once such a call is made, they are too often subject to the legally sanctioned biases of social workers and legal professionals, with too few legal safeguards in place to shield them from devastating consequences. Meanwhile, countless other individuals with disabilities dream of becoming mothers and fathers but know that their access to adoption, foster care, and assisted reproductive technologies will likely be severely curtailed.

While those who resist such changes will claim that a child is never removed due to parental disability unless there is a nexus between the disability and some predicted or manifested harm to the child, the fact is that we know this is a policy fairytale. Social workers and lawyers, judges and the press, are all too quick to tacitly agree that the disability of a parent must necessarily cause some harm to the child, now or in the future. The requirement of nexus, even where explicitly included in the law, is rarely enforced.

Of the use of disability as an admissible factor in assessing current or potential parental fitness, Robert L. Hayman concludes, "The formal classification should be abolished as a basis for state interference

with the parent-child relationship. The classification has no empirical foundation, and its political roots are not ones to be proud of. The classification results, meanwhile, in a schematic processing of the labeled parent's claim to family, reducing individualized adjudications to formalities and foregone conclusions. In the end, the scheme makes us all a little less human."⁷³

Let us waste no time in answering this call to action. Let us do the work that is necessary to make parents and prospective parents with disabilities less vulnerable to legalized discrimination, to make children safer from being removed from or denied loving homes, and to make us all a little more human.

72 National Council on Disability, 2012

73 Hayman, 1990

Works Cited

- ABC News. "Missouri Takes Baby Away from Blind Parents." July 28, 2010. <http://abcnews.go.com/Health/missouri-takes-baby-blind-parents/story?id=11263491>.
- Callow, Ella. "Indian Child Welfare Act and Americans with Disabilities Act." *Clearinghouse Review*, Vol. 46, 2013.
- Callow, Ella, and Jean Jacob. "Parental Disability in Child Welfare Systems and Dependency Courts: Preliminary Research on the Prevalence of the Population." *Child Welfare Journal*, Vol. 93, No. 6, 2017.
- Callow, Ella, Munazza Tahir, and Maurice Feldman. "Judicial Reliance on Parental IQ in Appellate-Level Child Welfare Cases Involving Parents with Intellectual and Developmental Disabilities." *Journal of Applied Research in Intellectual Disability*, Vol. 30, No. 3, 2016.
- Chicago Sun-Times. "Tammy Duckworth is Pregnant; Will be 1st Senator to give Birth." January 23, 2018. <https://chicago.suntimes.com/columnists/tammy-duckworth-pregnant-first-sitting-senator-give-birth/>.
- Cohen, Lisa Jo. *Mothers' Perceptions of the Influence of their Physical Disabilities on the Developmental Tasks of Children*. Ph.D. Dissertation, California School of Professional Psychology, 1998.
- Collentine, Alexis C. "Respecting Intellectually Disabled Parents: A Call for Change in State Termination of Parental Rights Statutes." *Hofstra Law Review*, Vol. 34, 2005.
- Eden, Sigal, Shlomo Romi, and Einat Braun Aviyashar. "Being a Parent's Eyes and Ears: Emotional Literacy and Empathy of Children whose Parents have a Sensory Disability." *Journal of Research in Special Educational Needs*, Vol. 17, No. 4, 2017.
- Gallagher, Nancy L. *Breeding Better Vermonters: The Eugenics Project in the Green Mountain State*. Lebanon, NH: University Press of New England, 1999.
- Hayman, Robert L. "Presumptions of Justice: Law, Politics, and the Mentally Retarded Parent." *Harvard Law Review*, Vol. 103, 1990.
- Kaye, Stephen H. *Population Estimates and Demographics of Parents with Disabilities in the United States*. Berkeley CA: Through the Looking Glass, 2011.
- Kirshbaum, Megan, Daniel Taube, and Rosalind Lasian. "Parents with Disabilities: Problems in Family Court Practice." *Journal of the Center for Family, Children, and the Courts*, Vol. 4, 2003.
- Lightfoot, Elizabeth, Katharine Hill, and Traci LaLiberte. "The Inclusion of Disability as a Condition for Termination of Parental Rights." *Child Abuse and Neglect*, Vol. 34, 2010.
- Marsh, Diane T. and Rex M. Dickens. *How to Cope with Mental Illness in your Family: A Guide for Siblings, Offspring, and Parents*. New York: Tarcher/ Putnam, 1998.
- Mauldon, Jane, Richard Speigman, and Christina Sogar. "CalWORK's Children of Disabled Parents on SSI." http://www.cfpic.org/sites/default/files/CFPIC_SSI_Parent_Brief_eVersion.pdf
- Mutcherson, Kimberly L. "Disabling Dreams of Parenthood: The Fertility Industry, Anti-Discrimination, and Parents with Disabilities." *Law and Inequality*, Vol. 27, 2009.
- Nakamura, Karen. *Barrier-Free Brothels: Sex Volunteers, Prostitutes and People with Disabilities*. In *Capturing Contemporary Japan: Differentiation and Uncertainty*. Ed. Glenda Roberts, Satsuki Kawano, and Susan Long. Honolulu: University of Hawaii Press, 2014.
- Nakamura, Karen. *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan*. Ithaca, NY: Cornell University Press, 2013.
- Nakamura, Karen. *Deaf in Japan: Signing and the Politics of Identity*. Ithaca, NY: Cornell University Press, 2006.
- National Council on Disability. *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children*. September 27, 2012.
- Olkin, Rhoda, et al. "Comparison of Parents With and With Disabilities Raising Teens: Information from the NHIS and Two National Surveys." *Rehabilitation Psychology*, Vol. 51, No. 1, 2006.
- Oregon Live. "Judge Determines Couple with Low IQs can Parent Both their Boys." January 11, 2018. http://www.oregonlive.com/pacific-northwest-news/index.ssf/2018/01/judge_determines_couple_with_l.html
- Painter, Nell Irvin. *The History of White People*. New York City: W. W. Norton and Company, 2011.

- Preston, Paul. "Parents with Disabilities." *International Encyclopedia of Rehabilitation*, ed. J.H. Stone and N. Blouin, 2011.
- Reilly, P.R. *The surgical Solution: A History of Involuntary Sterilization in the United States*. Baltimore: Johns Hopkins University Press, 1991.
- Saxton, Marsha. "Born and Unborn." In *Test Tube Women: What Future for Motherhood?* Ed. Rita Arditti, Renate Duelli Klein, and Shelley Minden. London: Thorsons, 1984.
- Saxton, Marsha. "Disability Rights and Selective Abortion." In *The Disability Studies Reader*. Ed. Lennard Davis. New York: Routledge, 2016.
- Schweik, Susan and Ella Callow. "Dismantling Harry Laughlin: Protecting the right to Family for Parents with Disabilities and their Children." Unpublished, written 2014.
- Shade, Dave. "Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act." *Law and Inequality*, Vol. 16, 1998.
- Singh, S., Piescher, K.N., LaLiberte, T., Lightfoot, E., and Hong, S. *Parental Disability and Termination of Parental Rights in Child Welfare*. Minn-Link Brief No. 12, accessed November 12, 2014, Center for Advanced Studies in Child Welfare: <http://www.cehd.umn.edu/ssw/cascw/research/minnlink/minnlinkpublications.asp>
- Thomson, Charis. "Collect Reliable Data on Embryo Selection." *Nature*, 2017.
- Thomson, Charis. "IVF Global Histories USA: Between Rock and a Market Place." *Reproductive Biomedicine and Society*, Vol. 2, 2016.
- Thomson, Charis, Marcy Darnovsky, Ruha Benjamin, and Jessica Cussins. "Innovation and Equity in an Age of Gene Editing." *The Guardian*, May 19, 2015.
- USA Today. "Blind Woman Loses Federal Discrimination Lawsuit Against Fertility Clinic." November 21, 2003. http://www.usatoday.com/news/nation/2003-11-21-fertility-lawsuit_x.htm.

The Haas Institute for a Fair and Inclusive Society brings together researchers, community stakeholders, and policymakers to identify and challenge the barriers to an inclusive, just, and sustainable society in order to create transformative change.

Contact

460 Stephens Hall
Berkeley, CA 94720-2330
Tel 510-642-3326
haasinstitute.berkeley.edu



[@haasinstitute](https://www.instagram.com/haasinstitute)