

PARENTING WITH A DISABILITY

# Know Your Rights Toolkit



 **CHRISTOPHER & DANA  
REEVE FOUNDATION**  
TODAY'S CARE. TOMORROW'S CURE.®

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Dear Friends,

A parent's nature to do anything to protect his or her children and promote their health and well-being is a strong, irrefutable instinct. But for many of the 4.1 million parents with disabilities in the United States, courts have deemed them unfit to parent simply because they have disabilities. In fact, as of 2012, 35 states still listed disability as grounds for termination of parental rights with no other evidence of abuse or neglect.

Discrimination against parents with disabilities has not received the national attention it deserves. It is not at the forefront of any legislative agenda and there are few officials highlighting the issue or introducing new solutions. It remains one of the deepest injustices across the disability community — to be seen only by your disability rather than as an individual.

That is why the Christopher & Dana Reeve Foundation and the National Council of Disability (NCD) joined forces to equip people living with disabilities with information about their rights as parents.

The *Parents with Disabilities Toolkit* is designed to provide an overview of disability law and the safeguards that exist to protect families nationwide. Inside of the toolkit, you will find information on topics like adoption, custody, visitation, family law and the child welfare system. We have also shared excerpts from NCD's report, *Rocking the Cradle*, with testimonials from parents who have faced discrimination based on their disabilities.

Knowledge is power, and raising awareness of this issue is critical. Through this toolkit, we hope to spark a national conversation about the inequalities that parents with disabilities currently face every day.

There are many ways to get involved to help eradicate these discriminatory practices—chief among them is we will no longer tolerate this clear breach of our community's civil rights. The first step is to know your rights. We hope this toolkit provides a starting point to arm yourself with invaluable information.

Together, we can end discrimination and strengthen the laws to better protect parents with disabilities nationwide.

Peter Wilderotter  
President and CEO  
Christopher & Dana Reeve Foundation

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National Council of Disability



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# Facts on Parenting with a Disability

There are

# 4.1 million

parents with disabilities in the U.S.



# 1 IN 10

children have  
a parent with  
a disability



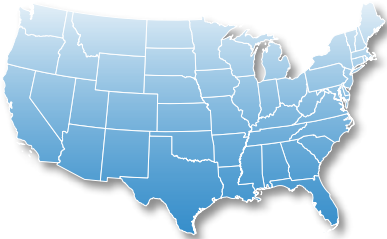
# 35

states include  
disability as grounds  
for termination  
of parental rights





**2/3** of dependency statutes allow the court to determine that a parent is unfit on the basis of disability



***In every state,***

disability of the parent can be included in determining the best interest of the child

**5.6 million**

Americans live with paralysis due to:

- Stroke
- Multiple Sclerosis
- Spinal Cord Injury
- Traumatic Brain Injury
- Neurofibromatosis
- Cerebral Palsy
- Post-Polio Syndrome
- Other



**DC, GA, KS, MD, MS, ND, NM, OH, OK & SC**

allow physical disability as the sole grounds for terminating parental rights, even without evidence of abuse or neglect

*The ADA bans discrimination against people with disabilities. This means you shouldn't receive fewer benefits or services, and agencies may not decline to serve you, solely on the basis of your disability.*

In August 2015, the US Department of Health and Human Services (HHS) and the Department of Justice (DOJ) released important guidance to states on *Protecting the Rights of Parents and Prospective Parents with Disabilities* and **announced** a new collaborative partnership between the agencies, bringing together the federal child welfare and disability rights offices to jointly ensure the safety, permanence, and well-being of children while protecting the rights of parents with disabilities. The new guidelines outline the two principles of national disability rights laws that are crucial to child welfare.

First, child welfare and other entities must provide “individualized treatment” to parents with disabilities, reviewing issues on a case by case basis based on the actual facts of the situation gathered through an individualized assessment (rather than based on stereotypes or broad misconceptions).

Second, parents with disabilities must have access to full and equal opportunities to participate in and benefit from child welfare’s programs, services, and activities, including individualized supports and services. These findings are based on our nation’s disability laws.

The Rehabilitation Act of 1973 and Americans with Disabilities Act of 1990 are the nation’s anti-discrimination laws for people with disabilities. The Rehabilitation Act prohibits discrimination against people with disabilities by federal agencies or any programs or activities that receive federal funding. The Americans with Disabilities Act (ADA) extended this protection to state and local government activities, as well private entities.

Under the Rehabilitation Act and ADA, state child welfare agencies, public and private adoption agencies, and reproductive health facilities are prohibited from discriminating against people with



disabilities and must ensure that they have an equal opportunity to participate in and benefit from their services and programs. These entities must treat parents with disabilities on a case-by-case basis, including providing tailored support and services that are based on the needs of

the person living with a disability. Health care facilities and services, including reproductive health providers, are prohibited from discrimination on the basis of disability by the Affordable Care Act of 2010.

**Under Title 2 of the ADA, *public* entities must:**

- Provide an equal opportunity to participate in programs, services, or activities and make reasonable modifications to policies, practices or procedures
- Provide auxiliary aids and services when necessary to ensure effective communication
- Not deny benefits of program, activities, and services by being inaccessible. Services, programs, and activities must be readily accessible to, and useable by, people with disabilities

**Under Title 3 of the ADA, *private* entities must:**

- Make reasonable accommodations to ensure that people with disabilities have access to their goods, services, facilities, privileges, advantages or accommodations
- Ensure that no person with a disability is excluded, denied services, segregated, or otherwise treated differently because of the absence of auxiliary aids and services

*Tiffany Callo, a wheelchair user with cerebral palsy, gave birth to her first son, David, in 1987. Immediately following delivery, the county child welfare agency determined that Tiffany and her boyfriend, who also had a physical disability, could only take their son home if they had a full-time nondisabled time caregiver with him at all times. Soon, Tiffany's relationship with her boyfriend deteriorated, domestic violence ensued, and the caregiver moved out. David was removed to foster care. When Tiffany gave birth to a second son, Jesse, he was also removed to foster care. In the custody hearing, the county cited Tiffany's slow diapering of David to show her inability to care for her child, despite her active adaptive measures. David and Jesse were eventually adopted by separate families, and Tiffany has an annual supervised visit with the boys.*

This example illustrates the historical and still pervasive discrimination against parents with disabilities in the child welfare system. The following section describes how disability law applies to the child welfare system and which states consider disability grounds for termination of parental rights.

The child welfare system refers broadly to a group of services that promote safety, permanency, and well-being of children and families. This system is responsible for responding to allegations or concerns over the safety of children, usually following an allegation of abuse or neglect.

Child welfare systems are state and locally controlled, but also receive federal funding, meaning that they are subject to anti-discrimination rules under both the Rehabilitation Act and Americans with Disabilities Act (see *Disability Law*).

### **Under Title 2 of the ADA, child welfare agencies must:**

- Provide an equal opportunity to participate in programs, services, or activities and make reasonable modifications to policies, practices or procedures



- Provide auxiliary aids and services when necessary to ensure effective communication
- Not deny benefits of program, activities, and services by being inaccessible. Services, programs, and activities must be readily accessible to, and useable by, people with disabilities

According to the National Council on Disability, “The child welfare system must comply with the ADA, as well as Section 504 of the Rehabilitation Act as long as it receives federal funding. Agencies may not discriminate on the basis of disability and must provide reasonable accommodations to appropriately serve parents with disabilities.”



Even after the passage of the ADA, states continue to include disability as grounds for termination of parental rights. As the result of these prejudices, parents with disabilities continue to face systemic discrimination in the child welfare system, with biases, myths and misconceptions on part of child welfare workers as well as state laws. Parents of color are at even greater risk of discrimination.

As of 2012, ten states list physical disability as grounds for termination of parental rights, even without evidence of abuse or neglect. These are the District of Columbia, Georgia, Kansas, Maryland, Mississippi, New Mexico, North Dakota, Ohio, Oklahoma and South Carolina.

In Georgia, physical disability is only taken into account after evidence of abuse or neglect is submitted to the court. In Oklahoma, physical disability is only considered when the parent is also refusing to comply with “treatment, therapy, or assistance” provided by the state.

## CHILD WELFARE AND THE NATIVE AMERICAN COMMUNITY

The United States of America has a sad history of systematic removal of Native American children from their biological and tribal home. Native Americans with disabilities face intersecting biases and histories of oppression.

In 1978, Congress passed the Indian Child Welfare Act (ICWA), in response to the history of systemic removal of Native American children from their homes and placement into boarding schools and European-American homes. The ICWA provides very strong and specific protections for children enrolled in a federally recognized Indian tribes.

The ICWA requires caseworkers to:

- Provide active efforts to the family
- Identify a placement that fits under the ICWA preference provisions
- Notify the child's tribe and the child's parents of the child custody proceeding
- Actively involve the child's tribe and the child's parents in the proceedings

Unfortunately, despite the dual protections of the ADA and ICWA, parents with disabilities from Native American tribes continue to be overrepresented in child welfare cases. If you, your partner, or your child are a member of a federally-recognized Native American tribe and are involved in the child welfare system, you should be aware of the extra protections of the ICWA. Resources are available from the **Native American Disability Law Center** and **National Indian Child Welfare Association**.

People with disabilities face significant discrimination in reproductive healthcare, either through physical or attitudinal barriers. Assistive reproductive technologies (ART) include intrauterine insemination, in vitro fertilization, surrogacy, and others. ART providers must comply with the ADA and, if they receive federal funding such as Medicare or Medicaid, they must also comply with the Rehabilitation Act. Title 3 of the ADA prohibits discrimination against people with disabilities by denying access to goods and services. This means that reproductive health providers must:

- Not establish eligibility criteria that screen out people with disabilities
- Make reasonable accommodations to ensure that people with disabilities have access to the goods, services, facilities, privileges, advantages or accommodations
- Ensure that no person with a disability is excluded, denied services, segregated, or otherwise treated differently because of the absence of auxiliary aids and services
- Remove architectural barriers
- Make goods or services available through alternate methods if such methods are readily available

Unfortunately, a study cited by NCD found that many fertility specialists regularly practice discrimination based on marital status, sexual orientation, genetic history, HIV status, psychological diagnosis, educational attainment, and physical or cognitive disabilities.

Further, the federal health insurance programs Medicare and Medicaid - through which many people with disabilities receive health insurance - do not cover fertility treatment. However, according to NCD, "Provision of assisted reproductive technology is similar to other ADA-mandated accommodations in the context of reproductive rights." This suggests that ART itself should be seen as a reasonable accommodation for people with disabilities who face infertility.

*Kaney O’Neill is a mother and a veteran with quadriplegia. Ten weeks after she gave birth to her son, her boyfriend sued for custody, claiming Kaney was “not a fit and proper person” to care for their son based on her disability. Kaney had prepared for motherhood by working with an occupational therapy program for expectant parents and had secured adaptive parenting equipment and planned personal assistance services to help as needed.*

*Demonstrating the bias in the system, a family law attorney not affiliated with the case remarked to the press, “Assuming both parties are equal (in other respects), isn’t the child better off with the father” and “What’s the effect on the child – feeling sorry for the mother and becoming a parent.” After a year-and-a-half dispute, Kaney retained custody and came to an agreement that gives the father visitation rights.*

As with all governmental entities, the Rehabilitation Act and Title 2 of the ADA apply to the family court system. Family law courts must:

- Provide an equal opportunity to participate in programs, services, or activities and make reasonable modifications to policies, practices or procedures
- Provide auxiliary aids and services when necessary to ensure effective communication
- Not deny benefits of program, activities, and services by being inaccessible. Services, programs, and activities must be readily accessible to, and useable by, people with disabilities

Unlike child welfare cases, which concern parental unfitness and termination of parental rights, family courts step in when parents are unable to reach a custody or visitation agreement between themselves. Family courts decide child custody based on the “best interest of the child” standard.

Unfortunately, parents with disabilities often face bias and discrimination in family court.

The landmark 1979 court decision *In re Marriage of Carney* dealt specifically with a father with quadriplegia. In this case, after a custody arrangement had been made, the father sustained a spinal cord injury. After his injury, the mother petitioned for the custody arrangement to be changed to reduce his custody. While the trial court approved the change, the California Supreme Court reversed the decision.



According to the National Council on Disability, “The court felt strongly that the parent-child bond was not merely the ability to engage in physical interaction, and thus the father should not have his parental rights severed or reduced simply because of his disability.”

All states use the “best interest of the child” standard in custody determination. However, states differ in their treatment of disability. According to NCD, while all states allow consideration of a parent’s mental or physical health, many remain silent on disability specifically. This also means that most states don’t have any legal protections for parents with disabilities when it comes to custody and visitation. While many family courts continue to discriminate against parents with disabilities, the decades-old ruling in the Carney case should provide some protection in that circuit.

*Rachel (name changed) and her partner spent 15 years, from 1995 to 2010, trying to adopt a baby. They began exploring the process with a local child welfare agency where, as wheelchair users, they were told they were expressly ineligible for foster care or adoption. After significant advocacy, a brother and sister were placed with them, but soon removed after the birth mother learned her children had been placed with wheelchair-using foster parents. In 2004 the couple tried again with a private agency and faced similar discrimination. Finally, in 2009, Rachel and her partner met a child whose foster parents were relinquishing her (which Rachel and her partner assumed might be due to the girl's intellectual and psychiatric disabilities). Rachel and her partner adopted the girl in 2010.*

The ADA and Rehabilitation Act and their protections against discrimination apply to the adoption system, state and local governments, and both public and private adoption agencies. This includes physical and programmatic accessibility and reasonable accommodations for prospective adoptive parents.

According to the National Council on Disability, “Title 3 unquestionably governs access to private adoptions, as it includes ‘adoption agency’ in the definition of public accommodations”.

Not only do the ADA and Rehabilitation Act apply to these agencies, but the ADA specifically calls out adoption agencies and prohibits discrimination against prospective adoptive parents. Adoption agencies may not use “standards or criteria or methods...that have the effect of discriminating on the basis of disability” and may not use eligibility criteria that “screen out an individual with a disability...unless the criteria can be shown to be necessary for the provision” of services. This means that it is illegal for adoption agencies to refuse to serve you solely because of your disability.



Some states have made progress and even passed groundbreaking legislation to protect the rights of parents with disabilities.

### Arkansas

In 1997, Arkansas wrote the ADA into its child welfare statute, stating that the child welfare department “shall make reasonable accommodations in accordance with the Americans with Disabilities Act...to parents with disabilities in order to allow them meaningful access to reunification and family preservation services”.

### Idaho

Due to the efforts of the Idaho State Independent Living Council and the Fathers and Mothers Independently Living with their Youth (FAMILY) Coalition, the Idaho legislature passed four bills in 2002 and 2003 that address the rights of parents with disabilities. Collectively, the laws addressed bias and discrimination in child welfare; divorce, separation, and dependency; and adoption and probate guardianship (guardianship of a minor following the death of a parent).





## **Kansas**

Spurred on by the success in Idaho, the State Independent Living Council of Kansas embarked on a similar effort, focusing on the Kansas Code for Child in Need of Care. In 2005, SB 230 passed the Kansas legislature, prohibiting discrimination against parents with disabilities. SB 230 states that disability alone cannot constitute grounds for removal of parental rights and mandates that child custody determinations will consider the use of accommodations and adaptive equipment.

## **California**

Advocates in California took a different route. Disability Rights California (California's Protection & Advocacy agency) partnered with Through the Looking Glass to sponsor AB 2152 in 2000, which would include adaptive baby care equipment as durable medical equipment to be covered by Medi-Cal (California's Medicaid program). The bill also ensured that adaptive baby care equipment would be considered medically necessary. While the bill passed the legislature, as of the 2012 printing of the National Council on Disability report, the change had not been implemented.

## **Rhode Island**

In 2000, Rhode Island eliminated disability from its statute on termination of parental rights.

## **Vermont**

In 2007, Vermont changed its child welfare law to mandate an "appropriate balance" between protecting children and respecting the rights of a parent or guardian (52 § 49229b). The Vermont statute requires the strengths and needs of parents with disabilities and the possible use of adaptive equipment and supports to be considered in child welfare cases.

## **Maryland**

In 2009, Maryland passed HB 689 and SB 613, prohibiting discrimination on the basis of disability against parents, guardians, or caregivers involved in adoption, custody, or child welfare.

## **Missouri**

In 2011, Missouri passed HB604 and SB555 to strengthen the rights of parents with disabilities in child welfare cases, following a famous case where a couple lost custody because they were both blind.

## SEEKING LEGAL REPRESENTATION

If you are involved in a child custody case, you should speak with a lawyer. In most states, if you are involved in a child welfare case you are entitled to a court-appointed lawyer. However, few attorneys are knowledgeable about disability law and how it interacts with family law and you may want to seek a lawyer with that expertise.



A federally-designated Protection & Advocacy agency exists in each state and territory to provide legal services to people with disabilities. Find the organization in your area from the **National Disability Rights Network**, and learn more at **NDRN.org**. Legal Aid agencies also provide free or low-cost legal help. Find one in your state from **LawHelp.org**. Finally, **Through the Looking Glass**

– a nationally recognized leader in the field of parenting with disability – operates a **legal program** that provides referrals, training, and assistance to parents in need of representation.

Parenting assessments are critical to most child welfare cases and custody/visitation proceedings. Your lawyer should ensure that any evaluation of you as a parent is conducted by a professional with experience in disability and parents with disabilities.

## TAKING ACTION - ADVOCATING FOR CHANGE IN YOUR STATE

Despite years of progress in disability civil rights legislation, parents with disabilities continue to face discriminatory treatment and many states still have outdated statutes regarding parenting with a disability. The National Council on Independent Living (NCIL), through the national network of Centers for Independent Living and Statewide Independent Living Councils, is advocating at the state level for states to update their laws and recognize the civil rights of parents with disabilities. To get involved, contact your **local center** or visit **[www.ncil.org](http://www.ncil.org)**.

## RESOURCES AND ACKNOWLEDGEMENTS

We would like to recognize the following individuals, organizations, and resources that were instrumental in creating this toolkit:

- Robyn Powell and the **Disabled Parenting Project**
- Kelly Buckland and the **National Council on Independent Living**
- **Through the Looking Glass** - a national resource, training, and service center for parents with disabilities
- Elizabeth Lightfoot and Sharyn DeZelar's "**State of the States**" map from the School of Social Work at the University of Minnesota

This toolkit includes extensive excerpts from the National Council on Disability's *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* report.

Please refer to **[ChristopherReeve.org](http://ChristopherReeve.org)** for additional resources and information, including the Christopher & Dana Reeve Foundation fact sheet on parenting with a disability.



## **We're here to help.**

Learn more today!

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