PARENTING WITH A DISABILITY

Know Your Rights Toolkit

NATIONAL COUNCIL ON DISABILITY

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

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Dear Friends:

It's normal for parents to want to do everything they can to keep their children safe and make sure they are healthy. But for many of the 4.1 million parents with disabilities in the United States, courts have decided they aren't good parents just because they have disabilities. In fact, as of 2016, 35 states still said that if you had a disability, you could lose your right to be a parent, even if you didn't hurt or ignore your child.

People have not paid enough attention to the way parents with disabilities are treated differently and unfairly. No one makes it their most important issue, and there are not many legislators who are talking about the issue or trying to solve it. And yet, it is still very unfair to have others assume you can't do certain things – like parent – because of your disability.

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

The *Parents with Disabilities Toolkit* provides a summary of disability laws that protect families' rights. 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 parts of NCD's report, ***Rocking the Cradle***, with stories from parents who have been treated unfairly because of their disabilities.

Knowledge is power, and helping people understand this issue is very important. Through this toolkit, we hope to get people talking about the unfair way parents with disabilities are treated every day.

There are many ways to stop the way parents with disabilities are treated unfairly—the most important way is saying it is not okay to treat us unfairly!

The first step is to know your rights. We hope this toolkit gives you lots of helpful information.

Together, we can end the way parents with disabilities are treated unfairly and make the laws better to protect the rights of parents with disabilities all across the country.

Peter Wilderotter
President and CEO
Christopher & Dana Reeve Foundation

Clyde Terry
Chairperson
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

Most state laws say that courts can decide someone isn't a good parent just because they have a 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

DISABILITY LAW

The ADA is a law that says you can't treat people with disabilities unfairly. That means you shouldn't receive fewer benefits or services, and agencies may not say they won't help you, just because you have a disability.

In August 2015, the U.S. Department of Health and Human Services (HHS) and the U.S. Department of Justice (DOJ) gave important advice to the states on how to protect the rights of parents with disabilities and people with disabilities who may become parents. They started working together to make sure that parents with disabilities and their kids are safe and doing well.

The first part of the advice that HHS and DOJ gave to the states was that they needed to treat all parents with disabilities based on what was actually going on in their family's lives and not on what they thought might be going on because a parent has a disability.

The second part of the advice that HHS and DOJ gave to the states was that parents with disabilities must get an equal chance to use child welfare programs and services, including some that are made to help parents with disabilities and their kids.

The Rehabilitation Act of 1973 and Americans with Disabilities Act of 1990 (ADA) protect the rights of people with disabilities. The Rehabilitation Act says that agencies and programs that get money from the U.S. government cannot treat people with disabilities unfairly. The ADA says the same thing for state and local governments as well as private companies.

Because of the Rehabilitation Act and the ADA, state child welfare agencies, public and private adoption agencies, and doctors who help women with pregnancies may not treat people with disabilities unfairly. They must also make sure that people with disabilities can do the same things through their programs as people without disabilities. They must also help people with disabilities based on their individual needs. The Affordable Care Act of 2010 says that all hospitals and doctors' offices, including doctors who help women become pregnant and help them stay healthy while they're pregnant, must treat people with disabilities fairly.

The ADA says that state and local governments must:

- Provide an equal chance for people with disabilities to take part in programs, services, or activities and make some changes if they need to so that the person with a disability can join.
- Provide help when it's needed to make sure that people with disabilities understand what is being said or done. They might have to bring in a sign language interpreter to speak in sign language to a deaf person or have someone take notes to help the person remember what happened.
- Make sure people with disabilities can take part in programs, activities, and services by allowing them to be hard or impossible to use or enjoy because of a person's disability.

The ADA says that private companies must:

- Make reasonable changes so that people with disabilities can use and enjoy their buildings and the goods and services that they are offering.
- Make sure that no person with a disability is kept out, not allowed to use their services, kept apart from people with disabilities, or treated differently because sign language interpreters, notetakers, or other help wasn't provided.

CHILD WELFARE SYSTEM

Tiffany Callo is a wheelchair user with cerebral palsy. Her boyfriend also had a physical disability. In 1987, she gave birth to her first son, David. Right after David was born, the county child welfare agency said that Tiffany and her boyfriend could only take their son home if someone without a disability was there to take care of him all the time. They did have someone who could help, so they took David home. After a while, Tiffany and her boyfriend started fighting and sometimes Tiffany's boyfriend hit her. Because of all the fighting, the person without a disability who helped take care of David moved out. The county child welfare agency took David and put him in a "foster home" where another family took care of David and he didn't live with Tiffany and her boyfriend anymore. When Tiffany had her second baby, a boy named Jesse, the county took him to live in a foster home, as well. The county told a judge that she put David's diaper on too slowly and that meant she couldn't take care of him even though she was trying to take good care of him. The judge sent David and Jesse to live in separate homes away from each other and from Tiffany forever. Now, Tiffany only gets to see her boys once a year and someone has to be there to watch them.

Tiffany's story shows how parents who have disabilities have been treated unfairly because judges, social workers, and others who are trying to protect children think people with disabilities can never be good parents. The next few sections of this toolkit show how laws meant to protect children can sometimes cause parents with disabilities to lose their children.

The "child welfare system" is the name for services that a state or county offer that are meant to help children stay safe and happy, and also to help them either stay in the home they were born in or find a good home where they can stay until they grow up. People who work in the child welfare system sometimes hear that a child is being hurt or is not being taken care of and they are supposed to try and help the child.

The ADA says that child welfare agencies must:

- Give a fair chance to parents with disabilities to take part in programs, services, or activities and make changes to make sure that's possible.
- Provide help when it's needed to make sure that people with disabilities understand what is being said or done.
- Not keep people with disabilities from getting help from programs, activities, and services by making them to be hard or to use because of a person's disability.

Even though the ADA said states had to treat people fairly, some state laws continue to say that a person's disability can be the reason they take away a parent's children. That means parents with disabilities still get treated unfairly by the child welfare system. Parents with disabilities who are Black, Latino, Asian, or other non-White races are even more likely to be treated unfairly.

In the District of Columbia, Georgia, Kansas, Maryland, Mississippi, New Mexico, North Dakota, Ohio, Oklahoma, and South Carolina, if a parent has a physical disability, the state can take away his or her child, even if they didn't hurt or ignore them.

CHILD WELFARE SYSTEM AND THE NATIVE AMERICAN COMMUNITY

Sadly, for a long time, the United States government took Native American children away from their parents and tribes. Native Americans with disabilities were even more likely to have their children taken away because of the parent's disability.

In 1978, a new law called the Indian Child Welfare Act (ICWA) said that it was wrong to take Native American children away from their families.

ICWA says that people who work for child welfare agencies have to:

- Help the family stay together and be healthy and happy.
- Identify where a child can go if they can't stay with the parents, and make sure they stay with a grandparent or aunt or uncle or someone in the family. If there is no family the child can stay with, the child should at least stay with a family in the same tribe.
- Tell a child's tribe and parents anytime a judge considers taking a child away from his or her parents and tribe.
- Make sure that the child's tribe and parents are a part of what the judge is considering.

Even though the ADA and ICWA say that parents with disabilities from Native American tribes cannot be treated unfairly, there are still lots of Native American parents with disabilities who are having a hard time keeping their children.

If you, your partner, or your child are a member of a Native American tribe and the child welfare agency has called or written you, remember that there are laws that say you cannot be treated unfairly. For help with your situation, call the Native American Disability Law Center or the National Indian Child Welfare Association.

REPRODUCTIVE HEALTH CARE

Sometimes a person with a disability really wants to have child, but they need a doctor to help them. When people with disabilities want to become parents but need help from a doctor, doctors and nurses are sometimes very unfair to them because they have wrong ideas about people with disabilities. Sometimes, their offices are hard to visit or the equipment doesn't work for people with disabilities.

When people need help becoming pregnant, doctors help them by using tools that are called "assistive reproductive technologies (ART)." ART includes using tools inside or outside of a woman's body to help her become pregnant or by using another woman who can be pregnant for her instead. Doctors who use these tools must follow what the ADA says and if those doctors accept Medicaid or Medicare, then they have to do what the Rehabilitation Act says, too.

The ADA says that doctors that help women get pregnant have to:

- Not make up reasons to not help people with disabilities use ART
- Give people with disabilities a chance to use ART and change how they do it if they can so that it works for the person with a disability.
- Make sure people with disabilities aren't left out, told they can't use ART, separated from people without disabilities, or treated differently because the doctor didn't give them help they needed like sign language interpreters, notetakers, and other kinds of help.
- Get rid of things about their buildings that make it difficult or impossible for people with disabilities to come inside
- Make it so that the person with a disability who wants to be a parent can get the product and service the doctor would give to people without disabilities in a different way. Doctors only have to do this if it's not too hard though.

Sadly, many doctors who help women get pregnant treat patients unfairly because the patients may not be married, may be gay or lesbian, may have family members with certain medical problems, may have certain disabilities, or may not have finished school. What's more, Medicare and Medicaid—the type of health insurance many people with disabilities have—do not cover the services doctors give to help women get pregnant. But since the ADA says doctors have to make it so people with disabilities can take part in their programs, services, and activities, ART may be something they have to do for a person with a disability who can't get pregnant any other way

CUSTODY, VISITATION & FAMILY LAW SYSTEM

Kaney O'Neill is a mother and used to be in the military. She uses a wheelchair. Ten weeks after she gave birth to her son, her boyfriend told a judge he wanted to keep their son and not let Kaney take care of him. He claimed that she would not be a good mother because of her disability. Kaney had been getting ready to be a mom by working with a program that helps women who will be having babies soon. Kaney also had baby items that were specially made for moms with disabilities and she had someone she could pay to help her if she needed it. Even people who didn't know Kaney said they thought her son would be better off with his father since he didn't have a disability and Kaney did. After a year-and-a-half fight, Kaney was able to keep her son and agreed to let her ex-boyfriend visit their son sometimes.

The Rehabilitation Act and the ADA say that family law courts have to:

- Give a fair chance to parents with disabilities to take part in programs, services, or activities and make reasonable changes to make sure that's possible.
- Provide sign language interpreters, notetakers, or other help when it's needed to make sure that people with disabilities understand what is being said or done
- Not keep people with disabilities from getting help from programs, activities, and services by allowing them to be hard or impossible to use or enjoy because of a person's disability.

If parents don't want to stay together and they are not able to decide which one of them will take care of their children or how they will visit their children, a family court will decide. The judge of a family court decides based on what is best for the child.

It's sad, but many parents with disabilities are treated unfairly in family court because sometimes the judge thinks people with disabilities are not able to do certain things and would be bad parents.

In 1979, there was a very important legal case about parents with disabilities. A father and mother had decided how they would take care of their children, but after they decided, the father got hurt with a spinal cord injury and he couldn't use his hands and arms and feet and legs the same way he used to. The mother wanted to change what they agreed because he had a disability. The first judge agreed with her, but later, another judge said she was wrong and that his disability shouldn't affect how he's allowed to take care of his kids. That judge knew that the way a parent and child love each other is about a lot more than just whether or not they can do certain things together that he might need his hands or feet for.

Judges in every state in the United States decides which parent or parents will be able to take care of children based on what is best for the children. All states say it is okay for a judge to think about the way a parent thinks or how healthy they are, but they don't say whether a judge can think about a parent's disability when deciding who will be able to take care of children. That also means that most states don't have any laws that protect parents with disabilities whenges are deciding these types of cases

ADOPTION AND FOSTER CARE

Rachel (not her real name) and her partner spent 15 years trying to adopt a baby. Because they both used wheelchairs, they were told by a local child welfare agency that they could not adopt a child or be "foster parents" (a "foster parent" is someone who has a child who has problems at home live with them until the child can move back in with their own parents). They told the child agency that that they had been treated unfairly, and finally a brother and sister were sent to live with them with them as foster parents. But the real mother of the brother and sister found out that Rachel and her partner used wheelchairs and she didn't think they could take care of the children, so the child welfare agency took the children away from them. A few years later, Rachel and her partner went to a private agency instead of the state child welfare agency and tried to adopt or be foster parents again. Sadly, that agency didn't think they could be good parents either just because they used wheelchairs and wouldn't help them. Several years later, they met a child whose foster parents did not want to be her temporary parents anymore because she had disabilities, finally, Rachel and her partner adopted the girl and became a family.

The ADA and Rehabilitation Act say that state and local governments and public and private adoption agencies cannot treat people with disabilities unfairly when they try to adopt. This means that they must be given a fair chance to adopt a child or become foster parents, and the agency needs to change how they do things to make sure that can happen.

Not only do agencies have to listen to what the ADA and Rehabilitation Act say, the ADA specifically says that adoption agencies must treat people with disabilities who want to be parents fairly. The ADA says that adoption agencies cannot decide who can adopt a child based on the disability of the person trying to become the child's mom or dad, and they can't make it harder for a person with a disability to adopt than it is for other people unless there is a good reason for the rules that are making it harder.

CUSTODY, VISITATION & FAMILY LAW SYSTEM

Some states have decided to pass important laws that says parents with disabilities should not be treated unfairly.

Arkansas

In 1997, Arkansas said that the ADA applied to their own state laws and said that the child welfare department had to make changes for parents with disabilities so that parents with disabilities would have a fair chance to use state programs that help bring families back together or keep them together in the first place.

Idaho

People who make laws in Idaho passed four new laws in 2002 and 2003 because of the hard work of disability advocates at the Idaho State Independent Living Council and the Fathers and Mothers Independently Living with their Youth (FAMILY) Coalition that said it was not okay to treat parents with disabilities unfairly in different kinds of court cases that involve families and children, including when parents get divorced and when people want to adopt a child.

Kansas

Disability advocates at the State Independent Living Council of Kansas thought what advocates did in Idaho was good and they wanted to do the same thing where they lived. So in 2005, they helped to get a new law that said that parents with disabilities cannot be treated unfairly and that a child cannot be taken away from a parent just because they have a disability. The law also said that when judges figure out what is best for a child, they have to think about how parents with disabilities will use items specially made for parents with disabilities to help them be parents.

California

Disability advocates at Disability Rights California (lawyers in California who help people with disabilities) worked with another group called Through the Looking Glass to try to get a new law passed that would make California Medicaid pay for baby items that were specially made for parents with disabilities. Even though there was a new law, a few years later, still no one was doing what the new law said yet.

Rhode Island

In 2000, Rhode Island said that children couldn't be taken away from a parent just because the parent had a disability.

Vermont

In 2007, Vermont changed its law and said that when judges figure out what is best for a child, they have to think about the things parents with disabilities are good at doing and how parents with disabilities could use helpers and items specially made for parents with disabilities to help them be good parents.

Maryland

In 2009, Maryland passed a law that said parents, guardians, and caregivers with disabilities couldn't be treated unfairly when it comes to adoptions or when a judge has to figure out where a child should live or what is best for a child.

Missouri

In 2011, Missouri passed a law that said that parents with disabilities had to be treated fairly when judges figure out what is best for a child. The law changed after two parents who were blind had their baby taken away from them just because they were blind.

SEEKING LEGAL REPRESENTATION

If parents don't want to stay together and they are not able to decide which one of them will take care of their children or how they will visit their children, a family court will decide. If that is happening to you, you should speak with a lawyer. In most states, the court will have to make sure you have a lawyer that will help you. But even if a court helps you find a lawyer, not many know much about disability laws and what they mean for parents with disabilities, and you may want to find one who does.

The U.S. government gives money to each state to have a group of lawyers in every state and territory to provide legal services to people with disabilities. To find that group in your area, visit the website of the National Disability Rights Network at www.NDRN.org.

Legal Aid agencies also provide free or low-cost legal help. Find one in your state by visiting their website at www.LawHelp.org.

A group called "Through the Looking Glass" is also very good at helping parents with disabilities. They have a program that helps parents find information, get help with how to parent, and other types of help, too. Their website is www.lookingglass.org.

Figuring out how someone takes care of and treats his or her child is a very important part of how judges decide what is best for a child for where they should live and who should be able to visit them. Your lawyer should make sure that whoever is trying to figure out how you take care of and treat your child knows about disabilities and how to work with parents with disabilities.

TAKING ACTION – ADVOCATING FOR CHANGE IN YOUR STATE

Even though there are lots of very good disability laws, parents with disabilities continue to be treated unfairly and many states still have laws that allow that unfair treatment to happen. A disability rights group called the National Council on Independent Living (NCIL), which has lots of centers in every state, is fighting hard to make states change their laws so that parents with disabilities are treated fairly. If you want to help them, go to the center closest to you or go online to learn more at www.ncil.org.

RESOURCES AND ACKNOWLEDGMENTS

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- Through the Looking Glass – a national resource, training, and service center for parents with disabilities

This toolkit includes lots of information that is from a report written by the National Council on Disability called *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*. You can look at a copy of that report online by going to http://www.ncd.gov/publications/2012/Sep272012.

Please visit the Christopher and Dana Reeve Foundation online for more information about parenting with a disability. Go to their website at www.ChristopherReeve.org

We're here to help.

Learn more today!

Christopher & Dana Reeve Foundation

636 Morris Turnpike, Suite 3A
Short Hills, NJ 07078
(800) 539-7309 toll free
(973) 467-8270 phone
ChristopherReeve.org

National Council on Disability

1331 F Street, NW, Suite 850
Washington, DC 20004
(202) 272-2004 (voice)
(202) 272-2074 (TTY)
www.ncd.gov