

Passing Legislation to Protect the Rights of Parents with Disabilities and Their Children Toolkit for Legislators

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THE HELLER SCHOOL
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National Research Center for Parents with Disabilities
Parents Empowering Parents
Padres Empoderando a Padres

Introduction and Background

In the United States, parents with disabilities and their children experience policies and practices that threaten their right to remain together. Parents with disabilities face bias and speculation that leads to over-representation within the child welfare system as well as disproportionately high rates of termination of parental rights. Disabled parents are also often denied custody or visitation during divorce disputes. Further, some people with disabilities are prevented from becoming foster or adoptive parents because of discrimination.

This toolkit is a product of the National Research Center for Parents with Disabilities, located at the Lurie Institute for Disability Policy at Brandeis University. We are a collaborative research and advocacy project that aims to support parents with disabilities and their families. For this toolkit, we conducted interviews with 19 advocates, attorneys, legislators, and legislative staff from across the country to learn about the barriers and facilitators to passing state legislation to support the rights of parents with disabilities. The recommendations included below come from those interviews.

Facts about Parents with Disabilities and Their Children

- An estimated **5% to 10% of parents in the United States have a disability**.¹
- Nearly **10% of children in the United States have a disabled parent**.²
- At least **19% of children in foster care have a parent with a disability**.³
- Parents with disabilities have **22% higher odds having their parental rights terminated**.⁴
- Parents with psychiatric disabilities are **eight times more likely to have child welfare system involvement** than nondisabled parents and 26 times more likely to have their children removed from their homes.⁵
- Nearly **two-thirds of state laws list disability as grounds for termination of parental rights**.⁶
- Generally, **a parent's disability does**

not affect their ability to care for their children, and most challenges are related to factors not related to their disability (e.g., poverty, social isolation, inadequate supports).⁷

State Legislative Efforts

In the 2012 report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, the National Council on Disability proposed model legislation aimed at preventing discrimination against parents and prospective parents with disabilities by the child welfare system, family courts, adoption and foster care agencies, and reproductive health care providers. Since then, nearly 30 states have passed or introduced legislation related to parents with disabilities.



South Carolina's Success Story

After strong advocacy by the disability community over two legislative sessions, South Carolina passed the "[Persons with Disabilities Rights Parent Act](#)" in 2017. The first version of the bill was unsuccessful because legislators found it too long and unfocused. The bill was reintroduced with stronger and more targeted language. The bill included clear definitions of relevant provisions, such as adaptive parenting equipment and support services. Its definition of disability matched the ADA's. The bill also repealed a prior law that included a parent's disability as grounds for termination of parental rights. The legislation protects the rights of disabled parents in child welfare and family proceedings as well as adoption and foster care.

Advocates point to many strategies that helped them in getting this legislation passed. First, a local center for independent living had a lobbyist who helped them find sponsors and garnish support by legislators. Support by local and national disability and legal organizations was crucial. They also were able to acquire bipartisan support. Further, this legislation built on a prior bill that protected the rights of blind parents. Finally, advocates found that telling their stories was crucial to getting legislators to understand the issues.

While the legislation varies from state to state, generally, the bills prohibit discrimination against disabled parents, eliminate disability as grounds for termination of parental rights, and require child welfare agencies and courts to consider how adaptive parenting equipment or supports can alleviate alleged parenting issues. Most states' legislation covers all disabilities; however, a few states' bills address specific disabilities (e.g., blindness or intellectual disabilities).

Key Principles of Effective Legislation

In order to pass legislation that will effectively support the rights of parents with disabilities and their children, we identified eight principle provisions that must be included in state legislation. Language for most of these provisions can be found in the *Rocking the Cradle* report.

1. **Remove discriminatory language from existing laws.** Many state child welfare and family law statutes include discriminatory language, such as the inclusion of disability as grounds for termination of parental rights or loss of custody or visitation. As such, it is important that these laws be repealed or amended.
2. **Comprehensive definition of disability.** Legislators and others sometimes want to exclude certain disability types from these bills. However, comprehensive and inclusive language is far more effective. Remember, many people with disabilities have more than one type of disability! We recommend using the ADA's definition of disability: "(a) a physical or mental impairment that substantially limits one or more major life activities of such individual; (b) a record of such an impairment; or (c) being regarded as having such an impairment."
3. **Key definitions, such as adaptive parenting equipment, adaptive parenting strategies, and supportive services.** Parents with disabilities often rely on a variety of equipment, strategies, and supports to care for their children. Unfortunately, courts and child welfare agencies do not always understand these concepts.
4. **Reaffirm the ADA's application to child welfare, family law, adoption, and foster care systems.** While the ADA should apply to parents with disabilities, it is often misapplied or ignored. Legislation should include a provision explicitly stating that the ADA applies to child welfare, family law, adoption, and foster care systems. For example, case plans for child welfare cases must include reasonable modifications.
5. **Nexus between disability and the alleged harm.** Whoever raises concerns that parent's disability affects their parenting abilities should be responsible for demonstrating to the court a nexus between the disability and actual harm to the child(ren) in question. For example, if the child welfare agency makes the claim that a child could be harmed by their parent's disability, that agency should prove a nexus between the disability and alleged harm. Similarly, if the other parent is making similar allegations, the burden should be on them to prove.
6. **Written court findings.** Court decisions concerning child welfare or family law cases should include written findings describing a nexus between a parent's disability and alleged harm that cannot be alleviated by adapting parenting equipment or support services.
7. **Adaptive parenting assessments.** Parents and prospective parents with disabilities should have access to adaptive parenting assessments for child welfare, family law, adoption, and foster care cases. These assessments should be conducted by an evaluator trained in working with parents with disabilities. The assessments should be fully accessible and consider the use of adaptive parenting equipment and strategies and support services.
8. **Training.** Child welfare and court professionals often lack training on working

with disabled parents. These professionals should receive ongoing training on their legal obligations, adaptive parenting equipment and strategies, and support services. Training should include parents with disabilities who can share their lived experiences.

Action Strategies for Passing Legislation

Passing legislation that supports the rights of parents with disabilities is challenging. Below are strategies that can assist in getting these bills passed.

1. **Bipartisanship.** Disability is an issue that has historically garnered bipartisan support. Likewise, parenting is not a partisan issue. As such, a bipartisan bill can gain the support of a diverse group of legislators that may or may not agree with your political affiliations.

“ I think personal stories help a lot, a whole lot. And having people that have not had their kids removed makes a difference too, to be able to come and say, ‘Hey, I am a successful blind mom.’ ‘I am a successful quadriplegic dad.’ —legislator

2. **Cross-disability support.** A central tenet of effective legislation for parents with disabilities is ensuring that it has cross-disability support. Bills that only cover some types of disabilities will likely not gain attention by the broad cross-disability community. Remember, there is strength in numbers!
3. **Stakeholder coalitions.** Passing legislation without stakeholder input and support will be nearly impossible. Building coalitions with state and national organizations can be a powerful tool for fine-tuning your bill. For example, invite child welfare professionals, attorneys, and judges to collaborate in

developing the bill. While you may not agree on everything, consensus-building can be crucial to successfully pass legislation.

4. **Framing.** Not everyone will have the same view of this issue. Some may see the issue as a human rights one, others may approach it from a family values point of view. Knowing your audience will help gain support from a variety of other legislators.
5. **Develop relationships.** You are not alone in this fight, nor should you try to be. Partnering with both local and national groups that support this issue will help you nuance your arguments and help gain the support of other legislators.

“ You really have to get through to the Speaker or the committee chairperson, mainly the speaker. I think a public awareness... would probably be a good thing because that’s what they respond to. I’ve actually taken a gentle approach, gone to the speaker, had the conversations, said, ‘This is important’ and try to make a plea for it. He basically just ignores it. That’s one aspect. —former legislator/advocate

6. **Testimony from parents with disabilities.** Having disabled parents share testimony has a value that cannot be stressed enough. Parents who have faced difficulties, such as termination of parental rights, as well as those who have not, should testify at hearings and meet with other legislators to tell their stories. Stories and pictures can be very helpful.
7. **Research.** In addition to personal stories, incorporate facts and peer-reviewed research into testimony and fact sheets. Make sure to use recent research that does not pathologize a parent’s disability but rather studies the circumstances in which families live.

8. **Understand the issues.** Knowing what you're fighting for and being able to back it up is important. Educating yourself on the issue will allow you to help persuade others to support it based on fact. Be prepared to counter "talking points" from those who oppose the bill. Shutting down misinformation as it comes up will work to strengthen your argument in supporting the bill.
9. **Persistence and adaptation.** Bills of this type do not always pass on their first attempt. Reaching out to advocates to see what they think can be incredibly beneficial. Be open to reworking your bill and your strategies for gaining support to get it through. If at first you don't succeed, try, try again!



Just this week, the member of the House of Delegates who was incredibly helpful reached out and said, 'Hey, do you guys want to do this again?'...He really seemed to have embraced this. He wants all of his advice from us....Very rarely do I get a delegate who calls me and says, 'Do you want to introduce this legislation again?' —advocate

10. **Celebrate all successes.** Getting legislation through takes time and perseverance. Don't bend on the important issues but remember that incremental success is still a success.

Additional Resources

For additional information, please check out the following resources.

- [National Research Center for Parents with Disabilities](#)
- [National Federation of the Blind's model blind parent legislation](#)
- [Rocking the Cradle report by the National Council on Disability](#)
- [Guide for Creative Legislative Change: Disability Status in Termination of Parental Rights and Other Child Custody Statutes by the University of Minnesota](#)
- [American Bar Association's resolution urging states to adopt legislation](#)

Endnotes

1. Li, H., Parish, S.L., Mitra, M., & Nicholson, J. (2017). Health of US parents with and without disabilities. *Disability and Health Journal*, 10(2), 303-307. doi: <http://dx.doi.org/10.1016/j.dhjo.2016.12.007>; Sonik, R. A., Parish, S. L., Mitra, M., & Nicholson, J. (2018). Parents with and without disabilities: demographics, material hardship, and program participation. *Review of Disability Studies: An International Journal*, 14(4).
2. Kaye, H. S. (2012). Current demographics of parents with disabilities in the U.S. Berkeley, CA: Through the Looking Glass. Retrieved from <https://www.lookingglass.org/national-services/research-a-development/126-current-demographics-of-parents-with-disabilities-in-the-us>.
3. Lightfoot, E., & DeZelar, S. (2016). The experiences and outcomes of children in foster care who were removed because of a parental disability. *Children and Youth Services Review*, 62, 22-28. doi:10.1016/j.childyouth.2015.11.029.

How to Cite

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