



# Child Law Practice

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Helping Lawyers Help Kids

## IN PRACTICE

### Maintaining Families When Parents Have Disabilities

by Ella Callow

**A** child whose parent has a disability faces a serious threat of removal by child welfare authorities. Parents' attorneys and children's representatives must have information and knowledge about the special challenges these families face in child welfare cases. Disability-aware advocacy can help prevent unnecessary traumatic removals of children from parents with disabilities.

There are times when children must be removed from parents with disabilities, just as they sometimes must be removed from able-bodied parents. Not all parents will succeed in regaining custody, though their odds greatly improve when they are provided proper accommodations and strong advocacy. Attorneys in such cases must aim to protect a child and parent, uphold the legitimacy of the proceedings, and satisfy due process.

The exact services, accommodations, expertise, and equipment a parent will need is based largely on the parent's individual disability. A full discussion of specific disabilities is beyond the scope of this article. What follows is a general discussion of families with disabilities and key steps advocates can take to improve the odds that they remain intact.

#### Families with Parental Disability

A person with a disability is "a person who... has a physical or mental impairment that substantially

limits one or more major life activities...has a record of such an impairment...or, is regarded as having such an impairment."<sup>1</sup>

Fifteen percent of all American families contain a parent with a disability. Among some communities the number of parents with disabilities is higher still:

- 16.3% among Hispanics
- 18.7% among African Americans
- 24% among single-parent families
- 25% among Native Americans<sup>2</sup>

It is a community with significant numbers of foreign-born members (33% of the deaf community is foreign born).<sup>3</sup>

Despite gains over the last 20 years, the disability community still experiences disparate treatment and greater social problems than the general American population. People with disabilities are three times more likely to be in poverty and twice as likely to be unemployed as able-bodied people, and twice as likely to drop out of school. They are three times as likely as

able-bodied people to be unable to access needed health care. They are also twice as likely to be unable to access transportation, though they are far more likely to need those services than the general population.<sup>4</sup>

Children in such families face staggering removal rates: 70-80% when the parent has a psychiatric disability, and 40-60% when the parent has an intellectual disability. In families where the parental disability is physical, 13% have reported pathologically discriminatory treatment in custody cases, and the deaf and blind communities report extremely high rates of child removal and loss of parental rights.<sup>5</sup>

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## U.N. Convention on the Rights of People with Disabilities, Article 23

The U.N. Convention on the Rights of People with Disabilities has been signed by President Obama and sent for ratification by the United States Senate. Featured prominently in the Convention is Article 23: Respect for Home and the Family. Its provisions include:

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that . . . [examples omitted].
2. States Parties shall ensure the rights and responsibilities of persons with disabilities with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States parties shall render appropriate assistance to persons with disabilities in the performance of their child rearing responsibilities.
3. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures that such separation is necessary for the best interests of the child. *In no case shall a child be separated from parents on the basis of disability of either the child or one or both of the parents.\**

This last sentence shows where good minds are on the issue. It stresses the need to show a nexus between the behavior of the parent and the need for removal and termination of parental rights versus basing the removal/termination on status, speculation, and guesswork.

\* U.N. Convention on the Rights of Persons with Disabilities, 8th Session, at 14, A/61/611 (2006). Available at [www.un.org/disabilities/convention/conventionfull.shtml](http://www.un.org/disabilities/convention/conventionfull.shtml).

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This is the only class of children facing loss of family integrity due not to the behavior of their parents, but to their parent's disability status and how this is perceived and understood by child welfare professionals.

### Attitudinal Bias and Remedial Legislation

In the mid-20<sup>th</sup> century, the Eugenics movement spawned policy that led to institutionalizing millions and sterilizing tens of thousands of people with disabilities for the "good of society."<sup>6</sup> In the latter part of the century, the Rehabilitation

Act and the Americans with Disabilities Act (ADA) were passed, making it illegal to discriminate against someone based on their actual or perceived disability.<sup>7</sup> Nonetheless, discrimination is still pervasive due to attitudinal bias: the pathologizing of people with disabilities based on their status.

The ADA specifically includes child welfare agencies and courts in the continuum of state affiliates that, based on the taking of federal funds, may not discriminate against people with disabilities. However, the language is broad and vague on what that means. Parents with disabilities have a right to participate in pro-

grams and activities and to accommodations that will aid their participation. The state affiliates can raise defenses where their participation or accommodation requires major alteration of the program or is financially too burdensome.

What does this mean practically for families in child welfare cases? That question is being decided differently all over the country. If you are going to represent a parent with a disability or that parent's child, you must know how this question is being answered in your jurisdiction.

### Disability-Specific Interviewing and Investigation

In addition to whatever you typically include in your initial interviews, for this population you also need to be familiar with the disability, the parent's circumstances, and what the parent needs vis-à-vis the disability. You must know the following disability-specific information:

- Which specific disability or disabilities does the parent have? This could include 'invisible' or medical disabilities like HIV or cancer. Does the child have any disabilities?
- If a parent is deaf, do they sign? If so, what form of sign is used in the home? Does the child sign? If not, what other means of communication are they using?
- Has the parent been prescribed medication and are they taking it? Parents will often forgo medications and live with pain or other symptoms of their disability because the side effects interfere with parenting.
- Is the parent now in pain, suffering from other symptoms of their disability or impaired by medication? Does the parent need medical attention?
- Does the parent have needed equipment (e.g., is the parent's wheelchair working)?

- Is the parent literate? If blind, can the parent read braille? If deaf, does the parent sign and, if so, what type of sign?
- Does the parent have accessible housing? Accessible transportation?
- Has the parent experienced attitudinal bias/discrimination in the case so far?
- Has the parent received accommodations from the court or child welfare agency so far?

Similarly, you will need to add some features to your usual background investigation:

- **Talk to the social worker and review the case file** to determine how much is known about the parent's disability, how concerning the worker finds it, and any misdiagnosis or attitudinal bias.
- **Verbally establish an agreement that the parent is disabled within the meaning of the ADA**, and then document it in a correspondence immediately. Note any immediate equipment or medication needs of the parent.
- **If an 'incident report' (i.e., domestic violence) initiated the case, determine if the domestic violence perpetrator or even the child was used by police to interpret or explain what happened.** This is common and obviously undermines the credibility of the report.
- **If a report from hospital staff after the child's birth or a neonatal intensive care unit (NICU) stay initiated the case, review notes by nurses, hospital social workers and doctors.** It can be powerful to show there was no behavior, just the parent's status, that motivated a staff member to call child welfare.

## Accommodations Hearings and Meetings

The success of the case will turn in

part on whether the parent can meaningfully participate in formal decision making. To ensure the parent has that opportunity, begin immediately using the existing ADA legal structure to ensure accommodation occurs. To this end:

- **Establish with the parent what accommodations the parent will need** to be aware of and participate in the meetings and hearings.
- **Contact the courthouse and child welfare agency ADA coordinators and request the accommodations** before any further child welfare agency meetings or any court hearings occur.
- **If the parent is denied a reasonable accommodation, be prepared to appeal** where such process exists or to file a complaint with the departmental, state, or federal agency empowered to investigate discrimination by the court or child welfare agency. At the federal level a complaint can be filed with the Department of Justice, Civil Rights Division, 950 Pennsylvania Ave., NW, Disability Rights Section-NYAV, Washington, DC 20530 ([www.usdoj.gov](http://www.usdoj.gov)).
- **While accommodations can be straightforward, like an interpreter, they can also be less obvious.** An example is a client

with multiple sclerosis (MS). In some people with MS, their condition is exacerbated by stress and heat. If this is true for your client, you may wish to ask the court to break up hearings into parts to allow the parent to rest and cool down periodically.

## Visitation and Services

Each disability requires different, specialized assessments and experts to allay the fears of child welfare agencies and courts and show parental fitness. However, there are also general guidelines for accommodating visitation and services that apply across disabilities:

- **Visitation should occur frequently and last longer.** This is especially true with young children to give the child and parent time to adapt to one another. It also gives the child a visual and auditory history of the parent, who may look, move, or sound different from people without disabilities, or use unfamiliar equipment. Also, visitation should occur in the family's home since this population relies more on physical environment and, sometimes, adaptations to enable or enhance parenting. For example, blind parents rely heavily on their knowledge of the placement of objects and

## Accommodations for Hearings and Meetings

Accommodations for parents at hearings and meetings may include:

- phone contact, e-mail, or brailled notices of hearings and meetings to blind parents
- meeting or hearing rooms that a parent with a physical disability can use with their equipment
- real-time transcription or other technology so deaf parents can follow proceedings
- meetings held at a time of day when a parent with psychiatric disabilities is least impaired by psychotropic medications
- allowing an advocate to accompany a parent with intellectual disabilities to help them meaningfully participate in the proceedings

## Parenting Adaptations

Adaptations that can help meet the needs of parents with disabilities include:

- **talking thermometer**—so parents who are blind can monitor the health of their child
- **vibrating bed fire alarm system**—so parents who are deaf can react early to a fire alert system and help their child safely exit the home
- **walker with an attached baby carrier**—so a parent with a physical disability involving mobility can safely transport their child
- **chart to manage feedings and other child care tasks**—for parents with developmental disabilities
- **medication protocol for parents with psychiatric disabilities**—to reduce impact of medication regimens on capacity to parent

furniture in their home to facilitate parenting. You can view adaptive baby care equipment on the Through the Looking Glass Web site ([www.lookingglass.org](http://www.lookingglass.org)).

- **Help the parent access disability community resources.** Independent Living Centers can usually help with a personal assistant, employment, medical and/or housing benefits and support. Specialized help with these needs is usually required if a parent is to comply with visitation and other case plan requirements. Specialized institutions like schools for the deaf or blind or dedicated agencies, like The National Association of the Deaf, The National Federation of the Blind, and The ARC can provide additional resources.
- **Help the parent access general community resources that will address special disability-related concerns in their cases.** For instance, work with the parent to get the child involved in an Early Head Start or other child development program as a preemptive strike against the common child welfare allegation that the child's development will be undermined by the parent's disability.
- **“Parent education” is a common case plan service that**

**should begin immediately with this population** because locating properly trained practitioners and completing the process can take longer. A properly trained practitioner is informed by both infant mental health or child development *and* disability perspectives. Universities, rehabilitation hospitals, and Zero to Three (a dedicated think tank focused on the health and development of young children) are all good resources for locating such individuals.

- **Find out what tests, assessments, and evaluations you want and don't want for a parent with a disability.** Some of these measures are necessary in light of the parent's disability. An example is the Adapted Baby Care Assessment for parents with physical disabilities. While not commonly provided, this assessment is crucial for the finder of fact because it is the only assessment that actually addresses the current functioning of the parent and identifies whether, after introducing proper techniques and adaptations (including baby care equipment) the parent can safely parent the child.

Other measures are completely inappropriate in light of the disability, but are commonly required. An example is the

traditional I.Q. test for a parent with a developmental disability. This is commonly provided, however, it is the supported opinion of many experts in parenting with developmental disabilities that it is an inappropriate measure for this population in general. It is also a poor predictor of parenting capacity, and tends to be used as a poor substitute for more reliable evaluation methods, such as long-term observation of parent-child interaction.

- **All services and visitation should be located in places that are physically accessible** to parents. Transportation should be accessible and able to accommodate the parent's disability.

### Courtroom Advocacy

Zealous advocacy for families where a parent has a disability differs from what a practitioner typically does in a child welfare case. Practitioners need to take special steps once in the trial or courtroom phase. This is in addition to ensuring the child welfare agency and court provide needed accommodations so the parent can meaningfully access the legal process and participate in services and visits.

- **Identify witnesses.** Subpoena people who can attest to the child being adequately cared for by the parent. Begin thinking about this early in the case so steps can be taken to generate witnesses by involving the parent and child in appropriate activities and programs (church/Sunday school, Mommy and Me classes, Early Head Start, etc.).
- **Use video.** This is the 21<sup>st</sup> century. Make a short film of the parent with the child. Good ones include simple text explaining how the parent is performing a certain child care task with a special technique or piece of equipment. Include simple clips

of the parent and child doing average things together, both at home and in the community. For balance, also film the parent and child during play or other interaction where the disability is less salient.

- **Contact experts.** Practitioners cannot learn enough about this subject once they come into a case to make the arguments without an expert. There is nothing more dangerous in these cases than the practitioner who doesn't know what they don't know. Depending on the disability, you may need an occupational therapist, a psychiatrist, an infant mental health specialist, psychologist, or cultural expert. These professionals can evaluate whether removal was warranted early on, help shape case plans, analyze whether services provided were reasonable, and provide insight into outcomes for children in these types of families.
- **Raise the ADA.** Raise it early and often. Consider appealing and/or filing an ADA complaint in the federal court if:
  - the removal was based solely on the parent's disability;
  - the court will not order accommodations of hearings, meetings, or services; or
  - a decision of the court to continue jurisdiction over the child is not reasonable based on witness and expert testimony and other evidence.
- **Say No.** Do not allow the state to humiliate the parent in proceedings. In one case, a parent was made to get out of her wheelchair and crawl across the floor to show she could escape in a fire. In another case, a parent was told to hold a vase over his head and run around a table to show he could carry a heavy child. Evaluations can answer these safety

## Case Example

Jaime was a developmentally disabled Onondaga tribal member and the mother of a five-year-old girl, Kayla. Jaime's need to access services for her disability led the child welfare agency to open a case on Kayla. Jaime contacted the legal program of the National Center for Parents with Disabilities and their Families/Through the Looking Glass for help. The child welfare agency had told her the social worker's report would recommend that Kayla be removed based on Jaime's:

- disability;
- reliance on personal assistants in managing her household;
- inability to help Kayla with her school work by the time she was 8 or 9; and
- difficulty remaining the authority figure in the household.

When Jaime found and requested a copy of this report at Through the Looking Glass's urging, she was told it was illegal for her to give it to anyone and she would go to jail if she did. Jaime persevered and located outside counsel through her local Native American Legal Services. With Through the Looking Glass's free technical assistance, the new attorney began documenting the disability bias, poor practice, and speculation that was occurring. Ultimately, the case was closed and Kayla and Jaime remained together as a family.

Now they only have to make it through 13 more years and they can stop worrying that this might happen again.

Practitioners are encouraged to contact the Legal Program of the National Resource Center for Parents with Disabilities and their Families/Through the Looking Glass for free technical assistance and litigation strategies for their specific cases.

### **The National Center for Parents with Disabilities and their Families/Through the Looking Glass**

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questions far more adequately without denigrating the parent.

## Conclusion

Understanding the history of people with disabilities and their special challenges in society and in child welfare cases is important to help prevent the unnecessary traumatic removal of children who have parents with disabilities. Learning to adapt how you interview, investigate, and litigate in these cases is even more important. Not every removal can or should be prevented. However, every removal should be about the behavior of parents and the well-being of children, not the

status of the parent as disabled or baseless speculation about the parent's caregiving potential.

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#### Endnotes

<sup>1</sup> Americans with Disabilities Act, 42 U.S.C. §12101 et seq.

<sup>2</sup> McNeil, J. American with Disabilities: 1991-1992. Current Population Reports P70-33. Washington, DC: U.S. Bureau of the Census, 1993. The number of Native Americans is actually the percentage with disabilities in general; the number of Native American parents with disabilities is unknown.

<sup>3</sup> National Organization for Disabilities/Harris Survey, 2004.

<sup>4</sup> Ibid.

<sup>5</sup> Kennedy, R., L. Garbus and S. Davis. *Different Moms*. Arlington, TX: ARC Publications, 1999; Larson, S., et al. "Characteristics of and Service Use by Persons with MR/DD living in their Homes or with Family Members: NHIS-D Analysis." *MR/DD Data Brief* 3(1), 2001. [Research and Training Center on Community Living, University of Minnesota]; Joseph, J.G., et al. "Characteristics and Perceived Needs of Mothers with Serious Mental Illness." *Psychiatric Services* 50(10), 1999, 1357-1359; Mowbray, C.T, et al. "Motherhood for Women with Serious Mental Illness: Pregnancy, Childbirth, and the Postpartum Period." *American Journal of Orthopsychiatry* 65(1), 1995, 21-38; Toms Barker, L. and V. Maralani. Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities, Berkeley, CA: TLG Publications, 1997. Notably, most survey participants tended to be European American, middle-income and educated, not the demographic expected to report experiencing high levels of discrimination or involvement with custody litigation with the state.

<sup>6</sup> Silver, Michael G. "Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History." *George Washington Law Review* 72, 2004, 862, 864; Lombardo, Paul A. "Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom." *Journal of Contemporary Health & Policy* 13, 1996, 1, 3; Reilly, Phillip R. *The Surgical Solution: A History of Involuntary Sterilization in the United States*, 1991, 2.

<sup>7</sup> Americans with Disabilities Act, 42 U.S.C. §12101 et seq.; Section 504 of the Rehabilitation Act, 29 U.S.C. §724.