Articles

Parents with Disabilities in the United States: Prevalence, Perspectives, and a Proposal for Legislative Change to Protect the Right to Family in the Disability Community

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I. INTRODUCTION

Children from families with parental disability are unnecessarily removed from the custody of their parents at alarming rates. Frequently, the only basis for removal is the parent's disability and a baseless speculative concern that the parent will not be able to provide practically, developmentally, or in some other way for the child. One movement, espousing above all the right to self-determination and independence ("Nothing About Us Without Us Ever!" being one movement motto), has discovered that sometimes no amount of determination or independence—or perceived financial or ethnic privilege—can protect the children of parents with disabilities once they become the object of custody litigation.[1]

The roots of this phenomenon are historical, but the consequences quite current. Whether in dependency or family law cases, such removals are devastating and traumatizing for the children and parents involved. For countless children, the trauma of losing their families—one of the most consequential traumas a child can endure—is heightened when they are abused or neglected in foster care settings or by co-parents or extended family members who have histories of violence, substance abuse, or neglect, and who would never have won custody from an able-bodied parent. Such suffering has repercussions not only for the children, but for society as well.

The rate of removal of children from families with parental disability is significantly higher than rates for children whose parents are not disabled, and the discrepancy is due to specific and avoidable problems within the social service and legal systems. The former are thus unfairly impacted and traumatized by removal and loss of familial integrity. Comprehensive legislative action that synthesizes other successful state and federal remedial legislation is needed to protect this population of children.

II. THE LAW AND HISTORY

A. Dependency Law

The freedom to parent without interference from the state is protected by the Fourteenth Amendment to the U.S. Constitution.[2] However, this right is balanced against the right of the state to protect its citizen children from harm.[3] The Supreme Court has struck a compromise: individuals cannot have their parental rights terminated by the state unless they are found "unfit."[4] Each state has its own rules on what constitutes a "fit" parent.[5] Typically a "fit" parent meets the

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[1] Interview with Judith Rogers, Occupational Therapist, Robert Wood Johnson fellow and author of the *Disabled Women's Guide to Pregnancy and Birth* (2005) and the *Baby Care Assessment for Parents with Physical Limitations or Disabilities* tool, in Berkeley, Cal. (Apr. 25, 2008).

[2] Santosky v. Kramer, 455 U.S. 745, 753 (1982); Quilloin v. Walcott, 434 U.S. 246, 255 (1978); Moore v. City of E. Cleveland, 431 U.S. 494, 499 (1977).

[3] Reno v. Flores 507 U.S. 292, 303 (1993); Santosky, 455 U.S. at 766 (observing that the state has an "urgent interest in the welfare of the child") (quoting Lassiter v. Dep't of Soc. Servs., 452 U.S. 18, 27 (1981) (internal quotations omitted)); Prince v. Mass., 321 U.S. 158, 166 (1944).

[4] *See* Troxel v. Granville, 530 U.S. 57, 68 (2000) (plurality opinion) (emphasizing that as long as a parent is "fit[], there will normally be no reason for the State to inject itself into the private realm of family.").

[5] Elizabeth Lightfoot & Traci LaLiberte, *The Inclusion of Disability as Grounds for Termination of Parental Rights in State Codes*, 17 J. RES. & TRAINING CTR. ON CMTY. LIVING 2 (2006) [hereinafter

physical, emotional, and health and safety needs of the child.[6]

In order to receive federal funding, a state must provide maintenance services before terminating rights[7] or must provide reunification services after terminating rights.[8] Exceptions exist: the Adoption and Safe Families Act allows for state termination of parental rights without maintenance or reunification services if a parent has previously murdered or severely abused a sibling of the child in question, or has subjected the child to severe abuse.[9] More controversially, services can be omitted if it is found that a parent's disability renders him or her unable to care for or control the child presently and will continue to do so in the future.[10]

In order to terminate parental rights, first courts must find the reunification efforts to be reasonable, though this need only be proven by a "preponderance of the evidence."[11] Secondly, the state must prove by "clear and convincing evidence"[12] that the parent is unfit.[13] In some states and counties, after determining that a parent is unfit, the court must make a third determination: the termination of parental rights is in the best interest of the child.[14]

B. Family Law

As noted above, the freedom to parent without interference from the state is protected by the Fourteenth Amendment. However, this situation is complicated when it is not the *state* interfering with one's

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Lightfoot, *Inclusion of Disability*] ("In addition to the ASFA-related TPR grounds, most states have additional grounds for TPR, some which date back many decades. States vary in their non-ASFA related grounds, with some having extensive and explicit lists of grounds for termination and others having very limited and/or very broad grounds for termination. Examples of other common grounds include chronic substance abuse, failure to maintain contact with a child or failure to maintain support of a child.").

[6] *Cf.* Stanley v. Ill., 405 U.S. 645, 652 (1972) (approving of but not adopting Illinois's interest in the "moral, emotional, mental, and physical welfare of the minor" in fitness determinations) (quoting ILL. REV. STAT., c. 37, s 701–2) (internal quotations omitted).

[7] *See* 42 U.S.C. § 671(a)(1) (2006) ("In order for a State to be eligible for payments under this part, it shall have a plan approved by the Secretary which . . . provides for foster care maintenance payments . . . .").

[8] *See* 42 U.S.C. § 671(a)(15)(B)(ii) (2006) ("[R]easonable efforts shall be made to preserve and reunify families . . . to make it possible for a child to safely return to the child's home.").

[9] Adoption and Safe Families Act, 42 U.S.C. § 671(a)(15)(D)(ii); Kathleen S. Bean, *Aggravated Circumstances, Reasonable Efforts, and ASFA*, 29 B.C. THIRD WORLD L.J. 223, 228 (2009).

[10] CAL. FAM. CODE ANN. § 7827 (West 2003); Jennifer A. Culhane, *A Challenge of California Family Code Section 7827: Application of This Statute Violates the Fundamental Rights of Parents Who Have Been Labeled Mentally Disabled*, 3 WHITTIER J. CHILD. & FAM. ADVOC. 131 (2003–04).

[11] *See, e.g.*, State *ex rel.* Dep't of Human Serv. v. T.F., 175 P.3d 976, 978 (Or. Ct. App. 2007).

[12] *Santosky*, 455 U.S. at 748.

[13] *Id.* at 760; *Quilloin*, 434 U.S. at 255 (citing Smith v. Org. of Foster Families, 431 U.S. 816, 862–63 (1978) (Stewart, J., concurring).

[14] *E.g.*, N.Y. FAM. CT. ACT §§ 62–23, 631 (McKinney 2009); *T.F.*, 175 P.3d at 978.

parenting rights, but instead the *other parent* who possesses the same right. When parents cannot reach a custody agreement themselves, courts may decide custody based on the state's right to protect its citizen children from harm. The legal standard courts use to determine custody is the "best interest of the child."[15] Most states have developed their own factors to determine which custody arrangement is in the best interest of the child.

Typical factors include the following: which parent best meets the physical, emotional, intellectual, and basic health and safety needs of the child; what the child wants (if the age and maturity of the child render an expressed desire reliable); the length of the current custody arrangement and whether it is positive; whether the alternative arrangement is suitable and stable; primary caretaking history; evidence of domestic violence or substance abuse; evidence of lying to the court about domestic violence or other matters; or whether either placement involves a partner with a history of violence or dependency issues.[16] The best interest analysis always allows for a parent's own "health" to be considered.[17]

With such seemingly practical factors to determine custody in place, why are removal rates as much as 80% for children of parents with certain disabilities?[18] To understand this consideration, it is important to first examine the history of parenting with a disability in our country.

C. The History of Parenting in Communities of Disability

In the first half of the twentieth century, proponents of the eugenics movement influenced nearly thirty state legislatures to pass laws allowing the involuntary sterilization of people with developmental, mental, sensory, or physical disabilities.[19] This legislative trend was based on the belief that these and other "socially inadequate" populations[20] would produce offspring that would be burdensome to

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[15] *See, e.g.*, *Quilloin*, 434 U.S. at 255.

[16] Factors compiled from review of statutory and case law from the seven states with the largest disability population; CAL. FAM. CODE § 3011 (West 1999); CONN. GEN. STAT. ANN. § 46b–56 (West 2008); FLA. STAT. ANN. § 61.13 (West 2006); MINN. STAT. ANN. § 518.17 (West 1999); N.Y. DOM. REL. LAW §70 (McKinney 2008) *construed in* Eschbach v. Eschbach, 56 N.Y.2d 167, 171–74 (1982); OKLA. STAT. ANN. tit. 43, § 112 (West 1999); TEX. FAM. CODE § 153.002 (West 2009).

[17] Miller v. Pipia, 297 A.D.2d 362, 364 (N.Y. App. Div. 2002) (listing the factors to be considered in determining a child's best interests).

[18] Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2; MENTAL HEALTH AMERICA, WHEN A PARENT HAS A MENTAL ILLNESS: CHILD CUSTODY ISSUES (2011), http://www.nmha.org/go/information/get-info/strengthening-families/when-a-parent-has-a-mental-illness-child-custody-issues (last visited Dec. 23, 2011) [hereinafter Mental Health America].

[19] Michael G. Silver, Note, *Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History*, 72 GEO. WASH. L. REV. 862, 864 (2004).

[20] Paul A. Lombardo, *Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL'Y 1, 3 (1996).

society.[21] The result of this policy was the forced sterilization of sixty thousand American citizens, some as young as ten years old.[22]

The judiciary supported the legislative trend toward sterilization. The pinnacle of this support was the Supreme Court's ruling in the seminal case of *Buck v. Bell.*[23] The plaintiff in the case was Carrie Buck, an eighteen-year-old who was a resident in the Virginia State Colony for Epileptics and Feeble Minded.[24] Despite the fact that Ms. Buck was only found to be "deviant" after giving birth to a little girl as a result of being raped by an older relative,[25] the Supreme Court upheld the Virginia statute that authorized her sterilization.[26]

By the 1970s, most sterilization laws were struck down on procedural grounds and rules were adopted that prohibited sterilization by institutions receiving federal funding. However, parenting with a disability is still not guaranteed. Currently there are seven states that retain a judicial process by which people with disabilities can be sterilized involuntarily.[27] Moreover, the debate about whether people with disabilities should be allowed to reproduce has been complicated by the regular denial of access to Assisted Reproductive Technologies (ART).[28]

While the justification for sterilization was to protect society, the justification for denial of ART is to protect children. Physicians most often deny treatment where they feel that the disability is uncontrolled and could affect the health of the child (such as diabetes), the disability carries a risk of genetic transmission (such as Tay-Sachs syndrome), or where they feel that patients will be incapable of providing stable home environments for children (such as those with a psychiatric disability).[29] While some of these denials may be more palatable than others, what is clear is that "[b]ecause denials of treatment take place in private and may not be reported, it is likely that the extent of medically based treatment denials is greater than the few cases reported in the literature."[30]

The same bias, ignorance, and poor practice that led to mass population sterilizations seems apparent in denial of ART and extremely high rates of child removal from the disability community.

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[21] *Id.* at 1, 3.

[22] PHILIP R. REILLY, THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES 2 (1991).

[23] 274 U.S. 200 (1927).

[24] *Id.* at 205.

[25] Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 54 (1985).

[26] *Buck*, 274 U.S. at 207.

[27] Jana Leslie-Miller, *From Bell to Bell: Responsible Reproduction in the Twentieth Century*, 8 MD. J. CONTEMP. LEGAL ISSUES 123, 136–37 (1997).

[28] Carl H. Coleman, *Conceiving Harm: Disability Discrimination in Assisted Reproductive Technologies*, 50 UCLA L. REV. 17, 19 (2002).

[29] *Id.* at 29–31.

[30] *Id.* at 31.

III. THE POPULATION OF PARENTS WITH A DISABILITY AND RATES OF REMOVAL

Despite the social and practical barriers placed in their paths, people with disabilities do become parents. Six and one-half percent of all families with children under eighteen contain at least one parent with a disability.[31] The rates are even higher for some sub-groups of the population. For instance, 18.7% of African-American families, 16.3% of Hispanic families, and 24% of single-parent families contain at least one parent with a disability.[32]

The difficulty now is for parents with a disability to retain custody of their children. Statistics collected by independent organizations indicate that based on the disability population, removal ranges from 40–60% for parents with developmental disabilities[33] to as high as 70–80% for those with psychiatric disabilities.[34] Statistics on removal rates for parents with physical or sensory disabilities are not as readily available, though these communities report significantly heightened rates of removal. In one study of 1,000 predominantly physically disabled parents, 15% reported experiencing pathological, discriminatory treatment related to custody litigation.[35] This means that custody loss by parents with disabilities is affecting thousands of American children.

The National Child Abuse and Neglect Data Set (NCANDS), completed in 2011, identifies the portion of the child welfare population that is comprised of families where at least one parent has a disability. The NCANDS identifies caretakers, not specifically parents, in the study. In 2010, 95.9% of children had parents as their caretakers.[36] Based on a conservative sample of the nineteen most consistently reporting states, the organization Through the Looking Glass (TLG) found that in 2010, at least 12.9% of the children in child welfare cases have at least one parent with a disability.[37] This is a low estimate because, similar to the

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[31] H. Stephen Kaye, 2011 American Community Survey (2011) (unpublished tabulations) (on file with the Disability Statistics Center, University of California San Francisco).

[32] *Id.*

[33] DIFFERENT MOMS (The ARC of the United States and Lifetime Television 1999); Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2; Mental Health America, *supra* note 18.

[34] Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2; Mental Health America, *supra* note 18.

[35] LINDA TOMS BARKER & VIDA MARALANI, CHALLENGES AND STRATEGIES OF DISABLED PARENTS: FINDINGS FROM A NATIONAL SURVEY OF PARENTS WITH DISABILITIES 4-8, B-28 (1997). Of interest is the fact that most of the survey participants tended to be European-American, middle-income, and educated. These are not the demographics expected to report high levels of discrimination or involvement with custody litigation with the state.

[36] FEDERAL INTERAGENCY FORUM ON CHILD AND FAMILY STATISTICS, AMERICA'S CHILDREN: KEY NATIONAL INDICATORS OF WELL-BEING, 2011 (2011), http://www.childstats.gov/americaschildren/Famsoc1.asp (last visited Dec. 23, 2011).

[37] Ella Callow, Alison Gemmill, Jean Jacob & Sharon Riley, *Parents with Disabilities and their Families in Child Protective Services Systems: Practice and Prevalence* 2011. (unpublished) (Nat'l Center for Parents with Disabilities at Through the Looking Glass) (Study funded by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education, Grant

treatment of children with disabilities in the child welfare system, adults with disabilities are not clinically assessed upon entering the system and are therefore often under-identified.[38]

As a companion to the NCANDS study, the TLG Legal Program conducted a qualitative study of 102 parents and grandparents with disabilities who contacted the program for technical assistance in a child custody case over the course of eighteen months. Calls came in from nineteen states including all states on both coasts. One hundred and fifty-five children were involved in the 102 reported proceedings. The distribution of parental disability was as follows: 38% of calls addressed a physical disability, 33% of calls addressed a psychiatric disability, 13% addressed an intellectual disability, 9% addressed a cognitive/intellectual disability, 5% addressed a visual disability, and 2% of calls addressed deafness.[39] Fifty percent of the calls related to the family court system, while 42% concerned the dependency system, and 8% concerned the probate court.[40] Probate court cases, including adoption and guardianship matters, accounted for 8% of all calls.[41] Three percent of calls were pre-emptive (no case yet filed) and 1.5% of callers could not explain the type of case with which they were involved.[42]

Some of the parents with disabilities believed that their children were secure from removal because their disability was not "as serious" or "as obvious" as other disabilities.[43] Some parents with disabilities believed that their financial resources, or the fact that they were not minorities, would protect them from losing custody to the state.[44] Still other parents felt that their gender, or perhaps the fact they lived in a more "progressive" state might protect them if they went through a divorce or even if they needed the help of social services.[45] The data,

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#H133A08003) (data on file with Through the Looking Glass) [hereinafter Demographic & Statistical Study].

[38] U.S. DEP'T OF HEALTH & HUMAN SERVS, ADMIN. ON CHILD., YOUTH & FAMILIES, CHILD MALTREATMENT (2008), *available at* http://www.acf.hhs.gov/programs/cb/pubs/cm08/cm08.pdf; Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2 ("Likewise, parents with disabilities are increasingly involved in the child welfare system, *though the overall prevalence of such involvement is unknown due to inadequate record-keeping and the paucity of research.*").

[39] Ella Callow & Jean Jacob, The Perspectives and Demographics of Parents with Disabilities Contacting Through the Looking Glass' Legal Program Regarding Custody Issues (unpublished tabulations from the 2008-2011 study) (data on file with Through the Looking Glass). While 92% of calls implicated parent responsibilities, 8% involved another family member/caretaker. Fathers/male relatives constituted 29% of the calls, and mothers/female relatives constituted the other 71% of the calls. Of callers reporting ethnicity, 50% were European American, 18% were African American, 12% were Latino/a-Hispanic American, and 4% were Native American.

[40] *Id.* at 1.

[41] *Id.*

[42] Demographic & Statistical Study, *supra* note 37.

[43] Ella Callow, Legal Program Director, The National Center for Parents with Disabilities and their Families, Address at the National Council on Disability Living Forum (May 6, 2011); Ella Callow, Legal Program Director, The National Center for Parents with Disabilities and their Families, Address at the 2011 Jacobus tenBroek Disability Law Symposium (April 14, 2011).

[44] *Id.*

[45] *Id.*

however, says otherwise. Research suggests that no child from a family with parental disability is safe from inappropriate removal.[46] The existence of a parental disability renders all such children more vulnerable.

IV. THE CAUSES OF UNNECESSARY REMOVALS

Looking at the removal statistics, it is clear that the legal system is not protecting the children of parents with disabilities from the maladies associated with such a traumatic removal procedure.

Two-thirds of dependency statutes allow the court to determine that a parent is unfit—a determination necessary to terminate parental rights—based exclusively on the parent's disability.[47] In every state, disability may be considered when determining the best interest of a child for purposes of a custody determination in family court or dependency court.[48] In theory, there should always be a nexus shown between the disability and harm to the child, so that a child is only taken from a custodial parent when the parent's disability is creating detriment that cannot be alleviated. However, this is not the reality.

Six major barriers to preventing unnecessary removals have been identified.

A. Attitudinal Bias

Defined loosely as a general belief in the pathology of people with disabilities, attitudinal bias is still prevalent in American society.[49] Attitudinal bias leads to speculation by neighbors, family members, and medical personnel that a parent with a disability cannot be a safe parent. These are the individuals most likely to report a parent with a disability to a child welfare agency for no reason other than the disability, thus starting the family's dependency proceedings and often leading to termination of parental rights. Attitudinal bias also leads non-disabled

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[46] *See* Demographic & Statistical Study, *supra* note 37.

[47] Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2.

[48] Factors compiled from review of statutory and case law from the seven states with the largest disability population; CAL. FAM. CODE § 3011 (West 1999); CONN. GEN. STAT. ANN. § 46b–56 (West 2008); FLA. STAT. ANN. § 61.13 (West 2006); MINN. STAT. ANN. § 518.17 (West 1999); OKLA. STAT. ANN. tit. 43, § 112 (West 1999); TEX. FAM. CODE § 153.002 (West 2009); N.Y. DOM. REL. LAW §70 (McKinney 2008) *construed in* Eschbach v. Eschbach, 56 N.Y.2d 167, 171–74 (1982); *see also* Miller v. Pipia, 297 A.D.2d 362, 364 (N.Y. App. Div. 2002) (listing the factors to be considered in determining a child's best interests).

[49] Megan Kirshbaum et al., *Parents with Disabilities: Problems in Family Court Practice*, 4 J. CTR. FOR FAM. CHILD. & CTS. 27, 37–39 (2003).

co-parents or extended family members—even those with substance abuse or violence issues—to become emboldened in their actions to move for custody in family court, sometimes doing so entirely on the basis of the custodial parent's disability. Professionals involved with custody cases, such as social workers, officers of the court, and legal and mental health professionals are not immune to this attitudinal bias.

In one example, a Georgia stay-at-home dad became a walking paraplegic[50] after sustaining an injury during a shooting while on police duty. After sustaining this injury, he was ordered by a family court judge to maintain a 24-hour-a-day nanny whenever he had custody of his three-year old daughter, Molly.[51] There was no evidence of any danger to the child, nor any past injuries or incidents giving cause for concern about her safety in his care. Despite being Molly's primary caretaker from her birth, this father was relegated to what amounted to supervised visitation because a judge assumed his parenting would be deficient based solely on his disability; at the same time, Molly was put into daycare for full days by her mother who chose to work. After the court reviewed the Adapted Baby Care assessment and expert testimony, the father ultimately received a successful adjudication.

In another instance, in a Wisconsin dependency case, a grandmother in her early sixties had arthritis that necessitated use of a walker.[52] She had custody of her two-year-old grandson, Bobby, since his birth. She was told by a social worker that she could keep Bobby until his third birthday (three weeks from the day of the conversation) because there was no immediate need for removal. However, the social worker added that she would not advocate for him to stay with the grandmother long-term because it was more appropriate to permanency planning to place Bobby with a young, healthy family, rather than with his grandmother who was "old and handicapped." She lost custody and Bobby was adopted after a harrowing experience in the foster care system (to be discussed later in this Article).

B. Lack of Disability Awareness and Knowledge Regarding Adaptive Equipment and Services

Most people do not know that adaptive equipment and adapted services, assessments, and evaluations can be critical in proper assessment for custody litigation, nor do they know what the terms

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[50] A walking paraplegic is someone who is diagnosed as a paraplegic, but has retained enough function to walk using walking canes or a walker.

[51] Telephone interviews with Allen James, Father with a disability, Ga. (Mar. 3, 2005–April 19, 2008).

[52] Telephone interviews with Eloise Holt, Grandmother with a disability, Wis. (Sept. 18, 2004–Feb. 15, 2005). All identifying information has been altered to protect confidentiality.

"adaptive equipment" or "adapted services" mean.[53]

Adaptive equipment can be used by parents with diverse disabilities to enable or strengthen their parenting of their child.[54] For example, a parent with a physical disability, such as a wheelchair user, can use a changing table modified to allow them to roll the wheelchair beneath the surface. A parent with a sensory disability, such as blindness, may use an adaptive device for measuring a child's medication. A parent with an intellectual disability may use an alarm or prompting system to remember to give a child medication.

Adapted services can be used by professionals to maximize the benefit of the service for the involved family.[55] For example, adapted parenting education for parents with intellectual disabilities often involves work inside the family's home, with higher frequency and duration of sessions than typically found in parenting classes. This service would also be expanded to focus on disability-specific issues such as modifying communication, facilitating the parent-child relationship and helping the parent to feel secure as a parent despite experiencing discrimination and abuse by this population throughout their lives. Finally, adapted services can include basic things such as an interpreter at a parenting class for a parent who is deaf, or referring a parent in a wheelchair to a therapist that is in an accessible location.

One type of adapted parenting assessment is the Adapted Baby Care Assessment for parents with physical limitations or disabilities.[56] This assessment involves multiple days of observation of the parent caring for the child in the home and on outings into the community.[57] The occupational therapist assesses the parenting for current functioning and aims to improve parenting wherever possible with adaptive equipment and parenting strategies and services.[58] The occupational therapist then produces a report that documents the parent's current functioning, decides which equipment or strategies and services could improve childcare, and determines whether it is a safe placement currently or with the adaptations in place.[59]

Adapted services, assessments, and evaluations for parents with disabilities that properly assess their parenting capacity are effective because they include the use of Adapted Baby Care equipment and adapted approaches to parenting. Adapted parenting evaluations for

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[53] Interview with Judith Rogers, Occupational Therapist, Robert Wood Johnson fellow and author of the *Disabled Women's Guide to Pregnancy and Birth* (2005) and the *Baby Care Assessment for Parents with Physical Limitations or Disabilities* tool, in Berkeley, Cal. (Apr. 25, 2008).

[54] *Id.*

[55] Interviews with Christi Tuleja, Director, Through the Looking Glass infant development/early intervention services, in Berkeley, Cal. (Aug. 2004–Jan. 2005).

[56] *Id.*

[57] *Id.*

[58] *Id.*

[59] *Id.*

parents with physical or sensory disabilities focus on observation in the home, where adaptive equipment and child safety equipment is already set up for use by the parent.[60] Evaluations should not include measures that skew the result for parents, such as I.Q. testing for parents who have cognitive or learning disabilities.[61] The timing of a test should allow a parent with a psychiatric disability to adjust to new medications, or the test should be administered at a time of day when the parent is most able to undergo testing since some psychotropic medications leave the user feeling more tired and less focused at certain times of the day.

It is TLG's experience that because many social workers, mediators, evaluators, attorneys, and judges tend not to know about adaptive equipment, services and assessments, they take a defeatist view of parents with disabilities, assuming they cannot parent successfully. This defeatist view colors the process and the outcome of custody litigation. But, information regarding adaptive services can change that.

In one example, a California mother who was a wheelchair user faced removal of her medically fragile newborn, Kyle, based solely on the social worker's impression that because she was a wheelchair user and had some limited muscle control in her upper body, she could not care for her child.[62] After the social worker learned of the multiple forms of adaptive equipment that could be used to enable the mother to transfer, lift, diaper, and feed her newborn, Kyle was able to remain with his mother.[63]

In another example, four-year-old Kiara was removed from her grandmother in Utah because her grandmother was obese and had mobility impairment.[64] After the court ordered social services to pay for an Adapted Baby Care assessment, a favorable report was provided to the court.[65] Kiara was not only able to return to her grandmother, the grandmother was also able to adopt her.[66]

C. Barriers to Meaningful Participation in the Process

Because of inaccessible, inappropriate, or non-existent services, parents with disabilities are often prevented from meaningful

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[60] Interviews with Christi Tuleja, Director, Through the Looking Glass infant development/early intervention services, in Berkeley, Cal. (Aug. 2004–Jan. 2005).

[61] *Id.*

[62] Telephone interviews with Adrianna Terry, Mother with a disability, Cal. (Nov. 20, 2004–Jan. 24, 2005). All identifying information has been altered to protect confidentiality.

[63] *Id.*

[64] Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005). All identifying information has been altered to protect confidentiality.

[65] *Id.*

[66] *Id.*

participation in evaluations, mediations, case plan services, and court hearings.

In one example, a mother who was deaf was involved in family court mediation with her hearing husband, who had abused her.[67] The mediator chose to use the husband to interpret for the deaf mother rather than secure a professional interpreter.[68]

In another instance, a mother in Oklahoma experienced chronic pain and needed to make a telephonic appearance to participate in the hearing.[69] She could not get an answer on whether this would be allowed.[70] When TLG contacted the local court and requested to speak with the Americans with Disabilities Act (ADA) coordinator (required by federal law), the clerk not only did not know who the ADA coordinator was, she did not know what the ADA was.[71]

In numerous cases every year, parents with developmental and psychiatric disabilities are unable to truly participate in the family court process because they did not have an attorney and did not understand or were unable to communicate effectively with the court. In dependency cases, the parents may not receive state sponsored counsel until later in the process; however, in family court, it is uncommon for parents to receive state sponsored counsel.[72] This is a major problem and one reason why some civil version of *Gideon v. Wainwright*,[73] such as the right to counsel afforded to those accused of a crime, must be made available to parents with developmental or psychiatric disabilities in family and dependency court *from the time a case has begun.*[74]

D. Evidence

There is a failure of the bar to rise to the occasion and zealously work to win on evidence in parental rights cases. Evidence, such as Adapted Baby Care evaluation reports, or facts showing adaptive equipment that will enable a parent to care for a child or tackle emergency situations (like bed-shaking smoke alarms for parents who

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[67] Telephone interviews with Elain Diaz, Mother with a disability, Ill. (Apr. 22, 2008–Oct. 26, 2010). All identifying information has been altered to protect confidentiality.

[68] *Id.*

[69] Telephone interview with Jaden Oldford, Mother with a disability, Okla. (May 12, 2008). All identifying information has been altered to protect confidentiality.

[70] *Id.*

[71] *Id.*

[72] Bruce Boyer, *Justice, Access to the Courts, and the Right to Free Counsel for Indigent Parents: The Continuing Scourge of* Lassiter v. Department of Social Services of Durham, 36 LOY. U. CHI. L.J. 363, 366–67 (2005).

[73] 372 U.S. 335, 345 (1963) (holding that indigent defendants in criminal cases have a due process right to appointed counsel).

[74] *See* Lisa Brodoff et al., *The ADA: One Avenue to Appointed Counsel Before a Full Civil Gideon*, 2 SEATTLE J. SOC. JUST. 609 (2004).

are deaf), is rarely presented to the court. Finally, attorneys fail to challenge a biased and/or un-adapted parenting evaluation that recommends termination of rights or a switch in custody from a parent with a disability.

In a case in Washington, a mother with Friedreich's ataxia[75] who was a wheelchair user was faced with loss of custody of her three-year-old son, Jesse.[76] Her parents had called child protective services and simultaneously drove her to a nursing home and left her there because they did not want to assist her or her son any further.[77] The mother's attorney refused to arrange for an occupational therapy assessment because she feared the results would be negative.[78] TLG's staff felt that the attorney was so unfamiliar with adaptive equipment and adapted services that she could not envision a successful ending.

This failure to utilize experts to share evidence underestimates the professionalism of the bench and deprives the court of the opportunity to receive a fair account of the case.

E. Law

As discussed above, both dependency and family law statutes allow consideration of parental disability, and some specifically allow termination of parental rights based on disability. While case law has fleshed out the need to show a nexus between disability and detriment to the welfare of a child in some states,[79] the fact remains that such a nexus is often not shown, and few cases are ever appealed. In addition to these problems with substantive laws, there are also procedural aspects of laws that adversely impact the disability population.

The Adoption and Safe Families Act of 1997 mandates strict timelines in dependency cases that disparately impact parents with disabilities.[80] These timelines often present special difficulties for parents who must secure adaptive equipment and services that are more involved than those for non-disabled parents. In the case of parents with psychiatric disabilities, these timelines may be impossible because of the need for psychiatric inpatient care and treatment at some point in the dependency process.

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[75] Friedreich's ataxia is a disease that causes nervous system damage and results in impaired muscle coordination.

[76] Telephone interviews with Lorelei Gorman, Mother with a disability, Wash. (Jan. 18, 2005–Jan. 23, 2006). All identifying information has been altered to protect confidentiality.

[77] *Id.*

[78] *Id.*

[79] ELLA CALLOW ET AL., SUMMARIES OF LEGAL PRECEDENTS AND LAW REVIEW ARTICLES CONCERNING PARENTS WITH DISABILITIES, (Through the Looking Glass 2004 rev. 2005).

[80] Pub. L. No. 105-89, 111 Stat. 2115 (1997).

Often, TLG's Legal Program is contacted at the point in the dependency process where the court must determine whether further services should be provided to parents or if services should be ended and rights terminated (i.e., a permanency planning hearing). TLG is asked to produce an assessment of a parent with a disability in time for a hearing that is scheduled within ten to fourteen days of the request. However, because the disability may involve the need for an Adapted Baby Care assessment, the utilization of adaptive equipment, or a six to ten week series of observations for a parenting assessment, TLG is unable to work within this timeline to assist the court in making a fair determination.

F. Cost

Other than California, there is no known state that includes adaptive parenting equipment in its statutory definition of durable medical equipment that impoverished parents with disabilities qualify to receive. Since the cost of equipment is often prohibitive to parents with disabilities, their children are sometimes removed because of small financial shortfalls of a few hundred dollars.

V. THE EFFECT OF UNNECESSARY REMOVALS ON CHILDREN

A. Separation from the Primary Caretaker

Almost every child taken from a parent with a disability, whether in dependency or family court, experiences separation from his or her primary caretaker. This separation is a serious cause for concern. Researchers in the fields of psychology and cognitive science have documented a much clearer picture of the severe emotional and psychological damage infants and young children experience when separated from their primary caregivers.[81] In fact, the most significant issue for a child's development is now known to be a secure attachment to a sensitive, responsive, and reliable caregiver.[82]

When children are removed from their primary caregivers, they experience specific emotional phases.[83] The child will first express

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[81] *See generally* HANDBOOK OF ATTACHMENT: THEORY, RESEARCH, AND CLINICAL APPLICATIONS (Jude Cassidy & Philip R. Shaver eds. 1999).

[82] *Id.*

[83] JOHN BOWLBY, A SECURE BASE: PARENT-CHILD ATTACHMENT AND HEALTHY HUMAN DEVELOPMENT 32 (1988).

"protest" and do everything possible to try to get back to the caregiver.[84] The next phase is "despair," as the child begins to fear he or she will not be reunited with the caregiver.[85] Finally, the child will experience "detachment," at which point he or she gives up hope.[86] The pain is so great that many children lose hope of ever having that security and love again.[87]

The immediate result of this process can be pathological attachments to the old caregiver if reunited, or toward new caregivers during separations.[88] Insecure attachment, the more severe disorganized attachment–where a child wants but cannot bring himself to seek fully the soothing and comfort of a caregiver–and reactive attachment disorder–which is mentally and emotionally disabling, both fall within the spectrum of predictable outcomes from traumatic and/or repeated separations.[89]

The long-term effects are equally formidable. Traumatic or repeated separations from caregivers place children at an increased risk of conduct disturbances, disruptive behavioral problems, attention disorders, and mood disorders.[90] Children who are denied secure attachment due to separation are less able to cope with psychological trauma, self-regulate their behavior, handle social interactions, and build positive self-esteem and self-reliance.[91]

B. Special Issues in Dependency Cases

Despite the now established knowledge regarding the danger of removal and multiple-placements for young children, such procedures are still the norm for children involved in the dependency process. In TLG's experience, removal and reunification is more common than maintenance and services with the children in the home. Removal of a child usually results in many foster care placements for the child. For example, in Los Angeles, the nation's largest dependency system, 24.3% of children younger than one year old, 33.5% of children aged one to

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[84] *Id.*

[85] *Id.*

[86] *Id.*

[87] *Id.* at 32.

[88] BOWLBY, *supra* note 83, at 29.

[89] *See* Douglas F. Goldsmith et al., *Separation and Reunification: Using Attachment Theory and Research to Inform Decisions Affecting the Placements of Children in Foster Care*, 55 JUV. & FAM. CT. J. 1, 2 (2004), *available at* http://www.ncjfcj.org/images/stories/dept/ppcd/pdf/spr%2004_1%20goldsmith%20et%20al.pdf.

[90] L. Allen Sroufe et al., *Relationships, Development, and Psychopathology*, *in* HANDBOOK OF DEVELOPMENTAL PSYCHOPATHOLOGY 75, 80 (Arnold J. Sameroff, Michael Lewis, & Suzanne M. Miller eds, 2d ed. Kluwer Academic / Plenum Publishers 2000) (1990).

[91] Goldsmith, *supra* note 90, at 2.

two, and 38.8% of children aged three to five experienced three or more caretakers within a thirteen to twenty-three month stay in foster care.[92]

Moreover, after removal, children placed in foster care are two times more likely to die of abuse.[93] They are two to four times more likely to be sexually abused.[94] They are three times more likely to be physically abused.[95] They may be placed in the care of persons who have not had adequate criminal background checks.[96] They may be neglected, lost, or murdered.[97] Despite such dire outcomes, children are denied the legal protections and remedies against the foster system that are afforded to prisoners against the prison system, largely because the foster care system is considered benign.[98]

Earlier in this Article, two cases were discussed: four-year-old Kiara who was removed and quickly returned to her grandmother, and three-year-old Bobby who was kept in foster care and later adopted.[99] These cases contrast the effects of the foster care system on the well-being of young children removed from a non-offending parent with a disability.

In Kiara's case, she was taken from her pre-school by a social worker without any explanation of why she was being taken or when she would see her grandmother again.[100] She quickly moved from crying and fighting in protest, to despair.[101] Within days she withdrew from all playing, eating, and emoting.[102] Fortunately, Kiara's mother secured counsel who applied immediately for the court to order her back home and for TLG to conduct an Adapted Baby Care assessment.[103] She was then able to return home permanently soon after, and had only one outside placement.[104] She has since been adopted by her grandmother and she has shown no signs of subsequent maladjustment.[105]

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[92] CAL. DEP'T OF SOC. SERV. & UNIV. OF CAL. AT BERKELEY, CHILD WELFARE DYNAMIC REPORT SYSTEM (2011), http://cssr.berkeley.edu/ucb_childwelfare/default.aspx (last visited Dec. 23, 2011).

[93] Kurt Mundorff, *Children as Chattel: Invoking the Thirteenth Amendment to Reform Child Welfare*, 1 CARDOZO PUB. L. POL'Y & ETHICS J. 131, 150 (2003).

[94] *Id.*

[95] *Id.*

[96] Ella Callow, Legal Program Director, The National Center for Parents with Disabilities and their Families, Address at the National Council on Disability Living Forum (May 6, 2011); Ella Callow, Legal Program Director, The National Center for Parents with Disabilities and their Families, Address at the 2011 Jacobus tenBroek Disability Law Symposium (Apr. 14, 2011).

[97] Michael B. Mushlin, *Unsafe Havens: The Case for Constitutional Protection of Foster Children from Abuse and Neglect*, 23 HARV. C.R.-C.L. L. REV. 199, 205–07 (1988).

[98] *See id.* at 231–32.

[99] Telephone interviews with Eloise Holt, Grandmother with a disability, Wisc. (Sept. 18, 2004–Feb. 15, 2005); Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005). All identifying information has been altered to protect confidentiality.

[100] Telephone interviews with Eloise Holt, Grandmother with a disability, Wisc. (Sept. 18, 2004–Feb. 15, 2005). All identifying information has been altered to protect confidentiality.

[101] *Id.*

[102] *Id.*

[103] *Id.*

[104] *Id.*

[105] Telephone interview with Eloise Holt, Grandmother with a disability, Wisc. (Sept. 18, 2004–Feb.

In Bobby's case, his grandmother did her best in the weeks between being told he would be removed and his actual removal to try to explain the unexplainable—why social services was taking him and when he could come home.[106] Bobby had just turned three at removal and continued in the protest phase for an extended period afterwards.[107] His behavior was viewed as pathological by the social worker who supervised visitation with his grandmother.[108] The social worker would repeatedly drag Bobby away from his grandmother at the end of visitation and threaten to end contact if he did not "behave."[109] Eventually, the social worker acted on that threat.[110] Bobby then became despairing and detached quite quickly.[111] He refused to eat, and when he did eat, he would throw up.[112] Social services placed Bobby in a hospital for barium treatments to see if there was a physiological cause for his behavior; there was not.[113] He then was injured in foster care and had to be hospitalized for the injury.[114] His grandmother was denied the chance to be with him (she had highly circumscribed visitation at this point) and his foster parents chose not to visit him.[115] As a result he spent his hospitalization alone in a crib with a top to prevent his getting out surrounded by IVs and other invasive equipment.[116]

After this point Bobby was labeled as "willful" and was considered a high-needs and difficult child.[117] This label was used as another reason not to return him to his grandmother.[118] Bobby was eventually adopted out of foster care.[119] The adoptive parents have kept some contact with the grandmother.[120] Her knowledge of what he experienced in foster care helps Bobby's adoptive parents understand the psychiatric work he now requires to deal with his reactive attachment disorder, claustrophobia, and ongoing nightmares.[121]

The following case of Jennifer underscores the abuse that children

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15, 2005).

[106] Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005). All identifying information has been altered to protect confidentiality.

[107] *Id.*

[108] *Id.*

[109] *Id.*

[110] *Id.*

[111] Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005).

[112] *Id.*

[113] *Id.*

[114] *Id.*

[115] *Id.*

[116] Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005).

[117] *Id.*

[118] *Id.*

[119] *Id.*

[120] *Id.*

[121] Telephone interviews with Johanna Sutton, Grandmother with a disability, Utah (July 1, 2005–Aug. 26, 2005).

removed from parents with disabilities suffer after damaging removals.

In Minnesota, five-year-old Jennifer was being reintroduced to her estranged, biological father over the protests of her developmentally disabled mother.[122] The mother opposed reintroduction because she knew almost nothing about the biological father.[123] However, social workers in the case felt that it would be positive to support the child by having a relationship with her father, who was not disabled.[124] Jennifer began showing regressive behavior upon returning from visits with her father and showing anxiety and fear before visitation times.[125] Her mother noticed Jennifer's behaviors, reported these phenomena to the social worker, and renewed her protests.[126] The social workers, however, were fixated on having a non-disabled parent-child relationship for Jennifer.[127] Eventually, Jennifer returned home with physical evidence of severe sexual abuse, the father was prosecuted for the crime, and his rights were terminated.[128]

Had the mother not been developmentally disabled, it is likely that the social worker would not have been so inclined to promote the relationship between Jennifer and her father and disregard the mother's objective *and* intuitive resistance.

C. What About Family Law Cases?

Children removed from parents because of disability in family law cases not only suffer the same trauma from separation and loss of the primary caretaker, they also have a greatly increased risk for post-removal maltreatment.

TLG staffers have observed that court officers, evaluators, and mediators, as a biased response to a parent's disability, are frequently in a rush to justify a move from the parent with a disability to an able-bodied caregiver. This leads the courts to accept alternative placements that would be unacceptable were the disability not a factor. Unlike TLG's experiences with the general population in family court cases, children with a disabled parent are more frequently placed with the non-disabled parent or extended family member, regardless of whether that individual has a history of abuse, addiction, poor decision-making, or

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[122] Telephone interview with Keri Rogers, Mother with a disability, Alaska (July 4, 2004–Apr. 29, 2005). All identifying information has been altered to protect confidentiality.

[123] *Id.*

[124] *Id.*

[125] *Id.*

[126] *Id.*

[127] Telephone interview with Keri Rogers, Mother with a disability, Alaska (July 4, 2004–Apr. 29, 2005).

[128] *Id.*

parenting. This individual may also have had little or no contact with the child, or will not be a "friendly parent"—i.e., one who will facilitate an ongoing relationship between the child and the parent with a disability.

VI. REMEDIAL STATE AND FEDERAL LEGISLATION OF INTEREST

The challenges and barriers discussed above have led to radical efforts to enact legislation affecting custody. Grassroots disability rights organizations in a number of states, including Idaho, Kansas, and California have altered their state statutes governing custody of children in a variety of ways. These disability-specific legislative changes should be models for similar legislation at the state or federal level. Some of the causes for unnecessary removal have not been addressed in specific legislation, yet they have been addressed in more general legislation in California and at the federal level.

A. Idaho

The pioneering effort to change legislation that victimized the children of parents with disabilities was undertaken by the Idaho State Independent Living Council's Committee on Fathers and Mothers Independently Living with their Youth (FAMILY).[129] The Idaho State Independent Living Council (SILC) is part of the cross-disability umbrella organization, National Council on Independent Living (NCIL), an organization that grew out of the Disability Rights Movement.[130]

As a grassroots organization, the Idaho SILC collects information on what consumers are most concerned about and includes these issues into the State Plan on Independent Living. In 2000, Idaho SILC reported that there was a growing fear of unwarranted removals of children from their parents with disabilities. The FAMILY Committee, headed by then Idaho SILC Executive Director Kelly Buckland, was formed to address this problem.[131] Buckland, who himself is a person with a disability,

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[129] IDAHO STATE INDEPENDENT LIVING COUNCIL, http://www.silc.idaho.gov. (last visited Dec. 23, 2011).

[130] THE NATIONAL COUNCIL ON INDEPENDENT LIVING—ABOUT, http://www.ncil.org/about.html (last visited Dec. 23, 2011). NCIL is the oldest existing cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), individuals with disabilities, and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.

[131] The FAMILY Committee worked closely with TLG during the process. TLG provided training and technical assistance, expertise with adaptive equipment and supportive services, and experience of working *specifically* with parents with disabilities. Dr. Megan Kirshbaum considered the process one of the most successful collaborations in the organization's history because of the tangible results

became a parent during the process, making the issue especially personal for him.

The FAMILY Committee worked with State Senator Robbi Barrutia, Representative Thomas Loertscher (the chairman of the Idaho House Health and Welfare Committee), and the Idaho Supreme Court. Over the course of two legislative sessions, the bills were defeated in House Committee. [132] But Chairman Loertscher had a change of heart after watching Sean Penn's depiction of a developmentally disabled dad fighting to keep his daughter.[133] As a result, four successful bills were passed over the 2002 and 2003 legislative sessions which have modified every custody-related section of the Idaho Statutes.

Cumulatively, these bills accomplished an enormous amount. They addressed: attitudinal bias, lack of knowledge of disability, adaptive equipment and services, problems in the production of good evidence and the challenge of bad evidence, and laws leading to discrimination by allowing the removal of children without showing a nexus between the disability and detriment to the child. These changes were accomplished by making the following additions and removals in the divorce, separation, and dependency statutes:

> 1. Adding non-discrimination statements regarding parents with disabilities;[134]
>
> 2. Adding definitions of "disability," "supportive services," and "adaptive equipment;"[135]
>
> 3. Adding a new section that specifically makes relevant and admissible evidence a parent with a disability may have regarding the services and adaptive equipment available to enable him or her to care for their child;[136]
>
> 4. Adding new language requiring any individual conducting a parenting evaluation to consider the use of adaptive equipment and supportive services for parents with disabilities and requiring that individual to have, or be assisted by

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achieved and the FAMILY Committee's ability to become experts in the phenomenon they sought to remedy.

[132] S.B. 1526, 55th Leg., 2d Reg. Sess. (Idaho 2000); Idaho State Independent Living Council, *SILC 2000 Post Legislative Update*, http://www.silc.idaho.gov/BLR/Apr00.htm (last visited Dec. 23, 2011); S.B. 1073, 56th Leg., 1st Reg. Sess. (Idaho 2001); S.B. 1074, 56th Leg., 1st Reg. Sess. (Idaho 2001); IDAHO STATE INDEPENDENT LIVING COUNCIL, *SILC 2001 Post Legislative Update*, http://www.silc.idaho.gov/BLR/May01.htm (last visited Dec. 23, 2011).

[133] I AM SAM (New Line Cinema 2001).

[134] IDAHO CODE ANN. §§ 16-1601, 16-2001(2), 32-717(5), 32-1005(3) (2011).

[135] *Id.* at §§ 16-1602(3), (14), (33), 16-2002(17)-(19), 32-717(4)(a)-(c), 32-1005(2)(a)-(c).

[136] *Id.* at §§ 16-1609(A), 16-2005(6).

> someone having, expertise in such equipment and services;[137]
>
> 5. Removing references to disability as a factor to be considered in custody determinations;[138] and
>
> 6. Adding a new section requiring a written statement by the court should it determine that disability is a relevant factor in a custody determination.[139]

The FAMILY Committee similarly lobbied for modifications of those statutes governing adoption and probate guardianships of children.[140]

Thus far, two cases involving the new legislation have reached the appellate level. In the first, *Doe v. Doe,* the court was unable to reach the merits of the case because it determined that the new legislation was not to be applied retroactively.[141] In the second, *Lieurance-Ross v. Ross,* a father appealed the decision of a family court magistrate finding that he could not be awarded custody of his children because he had a general guardianship as a result of stroke-impaired cognitive functioning.[142] In a decision that showed how much the court had learned from the new legislation, the conclusion included a discussion of adaptive parenting equipment and services and stated:

> [I]n light of our conclusion that a parent with a guardian is not precluded from seeking custody of his or her child, we see no reason to apply Section 32-717(2) differently in situations where a parent with a disability has a guardian from those situations where a parent with a disability does not have a guardian. In either scenario, the court is required to make findings regarding the effect the disability has on the parent's ability to carry out parenting responsibilities and whether adaptive equipment or supportive services can compensate for those aspects of the disability, which affect the parent's ability to care for his or her child.[143]

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[137] *Id.* at §§ 16-2008(b), 32-717(2).

[138] *Id.* at §§ 16-2008(b), 32-717(2); H.B. 557, 56th Leg., Reg. Sess. (Idaho 2002).

[139] IDAHO CODE ANN. § 32-717(5).

[140] *Id.* at §§ 15-5, 16-1500.

[141] 71 P.3d 1040, 1052 (Idaho 2003).

[142] 129 P.3d 1285, 1287-88 (Ct. App. Idaho 2006).

[143] *Id.* at 1291.

B. Kansas

Soon after the success in Idaho, the process of legislative amendment was facilitated by another SILC: the State Independent Living Council of Kansas (SILCK) under Executive Director Shannon Jones. The vehicle, Senate Bill 230, passed during the 2005 legislative session and went into effect in 2006.[144] This legislation included four major safeguards for parents with disabilities in the Revised Kansas Code for Care of Children, the new Article 22 of Chapter 38.[145] These four safeguards addressed issues of attitudinal bias; lack of knowledge of adaptive equipment; problems in the production of good evidence and the challenge of bad evidence; and laws leading to discrimination by allowing the removal of children without showing a nexus between the disability and detriment to the child. The legislation accomplished this through the following mechanisms:

> 1. A non-discrimination statement regarding parents with disabilities, thereby more fully encompassing them in the policy directive to protect the privacy and unity of the family;[146]
>
> 2. A statement that the disability of a parent will not constitute a ground for finding the child dependent or for removal of the child from the parent, without a specific showing of a causal relationship between the disability and harm to the child;[147]
>
> 3. A statement that the disability of a parent will not constitute a ground for terminating the parental rights of a parent with a disability, without a specific showing of a causal relationship between the disability and harm to the child;[148] and
>
> 4. A mandate that determinations regarding custody under the code will consider the availability and use of accommodations, specifically adaptive equipment and support services.[149]

Although more limited in scope (due to the fact that it was picked up as part of a revision of one specific code—the dependency code), the

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[144] S.B. 230, 81st Leg., 2005 Reg. Sess., (2006) (enacted), *available at* www.kansas.gov/government/legislative/bills/2006/230.pdf.

[145] Revised Kansas Code for Care of Children, KAN. STAT. ANN. § 38-2201 (2006).

[146] *Id.* at § 38-2201(c).

[147] *Id.* at § 38-2201(c)(1).

[148] *Id.*

[149] *Id.* at § 38-2201(c)(2).

Kansas legislation includes some of the most important protections for parents with disabilities. By requiring demonstration of the causation between harm to the child and the disability, the code, essentially, requires that proper services and adapted evaluations and assessments be performed. Moreover, these legislative changes set the stage for modification of other relevant Kansas codes, such as those effecting domestic relations, adoption, and guardianship.[150]

C. California

In 2010, *In re Marriage of Carney*[151] was codified.[152] *Carney* was a landmark case for parents with disabilities. The *Carney* court held as follows:

> [I]f a person has a physical handicap it is impermissible for the court [in a ruling on a custody matter] simply to rely on that condition as prima facie evidence of the person's unfitness as a parent or of probable detriment to the child; rather, in all cases the court must view the handicapped person as an individual and the family as a whole.[153]

The court also noted that the father's physical handicap, which affected his ability to participate with his children in purely physical activities, did not constitute a changed circumstance of sufficient relevance and materiality to render it either "essential or expedient" for the children's welfare that they be taken from his custody.[154]

The codification is now contained as California Family Law § 3049 and specifies that "[i]t is the intent of the Legislature in enacting this section to codify the decision of the California Supreme Court in *In re Marriage of Carney*, with respect to custody and visitation determinations by the court involving a disabled parent."[155]

This was not the first time that efforts were made to address the

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[150] As in Idaho, TLG worked closely with SILCK, providing training, technical assistance and expertise during this process. One of the most interesting parts of the project was accessing the handbook and protocols used by social services in Kansas. For those in the legal program, it was the first time these types of documents had been available for review and exposed another area that should be reviewed for disability bias. As with Idaho, TLG found the determination of the Kansas SILC to utilize this opportunity heartening.

[151] 598 P.2d 36 (Cal. 1979).

[152] TLG's Legal Program provided technical assistance and public support for a successful collaborative effort by two policy organizations—Fathers and Families and Disability Rights California—to codify *Carney*.

[153] *Carney*, 598 P.2d. at 42.

[154] *Id.* at 44.

[155] CAL. FAM. CODE § 3049 (West 2011). Legal Program consumers in California are often provided reference to this code section for inclusion in pleadings or submissions to family law mediators during the course of family law proceedings.

needs of this population through legislative change in California. In 2000, changes to the California Welfare and Institutions Code caused Adapted Baby Care equipment to be included in the list of durable medical equipment covered by Medi-Cal (state means tested insurance program).[156] The landmark legislation expanded references to "conditions that interfere with normal activity" to include those that interfere with the ability to parent, identified such conditions as meeting the definition of "significant disability" rendering services medically necessary, and expanded the rights of Medi-Cal beneficiaries to include receiving adaptive parenting equipment within the definition of durable medical equipment.[157]

This legislation also addressed the problem of the cost-prohibitive nature of some adaptive equipment. Unfortunately, there has been no test case. There was a funding crisis at the time the legislation was passed that resulted in confusion about whether the new legislation would be funded. But within the last year, the state government has indicated that the legislation can be acted upon.[158]

D. The Indian Child Welfare Act

While the Indian Child Welfare Act (ICWA) is clearly not aimed at the disability community, the impetus for ICWA arose from circumstances similar to those surrounding families with parents who are disabled.[159] Both Native Americans and people with disabilities are historically oppressed minorities denied civil and human rights in this country. Both groups were systemically isolated from other sectors of society until mid-way through the last century. Both groups suffer extreme levels of poverty. Little is understood about their cultures, leading to generalized stereotyping and discrimination. Most importantly, both groups have been subjected to involuntary sterilization programs and massive removal of their children.

Congress passed ICWA in 1978 because Native American nations were losing custody of their children at an alarming and genocidal rate.[160] At the time, 25%–35% of Native children were being removed from their

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[156] *See id.* at §§ 14132, 14059 (West 2011). TLG teamed with the Los Angeles Office of Protection and Advocacy Inc. to create legislation affecting the California Welfare and Institutions Code.

[157] *See id.*

[158] Interview with Representative, Sacramento Medi-Cal, in Cal. (Aug. 2006).

[159] *Indian Child Welfare Program: Hearings Before the Subcomm. on Indian Affairs of the S. Comm. on the Interior and Insular Affairs,* 93d Cong. 15 (1974) (statement of William Byler, Executive Director, Association of American Indian Affairs, Inc.) (stating that studies undertaken by the Association on American Indian Affairs in 1969 and 1974, and presented in the Senate hearings, showed that 25% to 35% of all Indian children had been separated from their families and placed in adoptive families, foster care, or institutions).

[160] *See id.*

families.[161] It was determined that a major cause of the removal of these children was the belief among Anglos that systemic removal of Native children from Native communities was always in the best interest of the Native child, as well as the pathologizing of childcare practices that were culturally healthy within the context of Native communities.[162] A common example is Anglo normalization of the nuclear family leading to the labeling of extended family childcare as "abandonment" or "neglect" by the Native parent for whom extended family care is the norm.[163] Indeed, Congress made the following findings:

> Congress . . . has assumed the responsibility for the protection and preservation of Indian tribes and their resources . . . (3) that there is no resource that is more vital to the continued existence and integrity of Indian tribes than their children . . . (4) that an alarmingly high percentage of Indian families are broken up by the removal[s] . . . and (5) that the States . . . have often failed to recognize the essential tribal relations of Indian people and the cultural and social standards prevailing in Indian communities and families.[164]

Lack of knowledge about the culture and parenting techniques of Native American people is very similar to lack of knowledge about the culture, adaptive equipment, supportive services, strengths, and parenting techniques of the disabled community. Because of this and other similarities between the causes of custody loss in the two communities—poverty, illiteracy, bias and discrimination—portions of the very successful ICWA that provide remedies for the Native American community should be borrowed to strengthen new legislation to protect the children of parents with disabilities.

The following selection of both substantive and procedural portions of ICWA, with attention to necessary disability adaptations (such as adaptations for parents who are non-readers or blind), can be applied in remedial legislation to address the following issues: lack of knowledge about adaptive equipment, services, and assessments; problems with the mandated timelines in dependency cases; lack of adequate legal counsel in the family courts and in portions of the dependency process; and a lack of adequate and timely adapted services in the dependency courts. Such portions include:

> 1. Mandatory written notification—with return receipt requested—must be provided to parents when a dependency

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[161] *Id.*

[162] Paul David Kouri, Note, In re M.J.J., J.P.L., & J.P.G.: *The "Qualified Expert Witness" Requirements of the Indian Child Welfare Act*, 29 AM. INDIAN L. REV. 403, 404–05 (2004).

[163] Ester C. Kim, Comment, *Mississippi Ban of* Choctaw Indians v. Holyfield: *The Contemplation of All, the Best Interests of None*, 43 RUTGERS L. REV. 761, 765–66 (1991).

[164] 25 U.S.C. § 1901 (2011).

> action is instituted. No action can be taken until ten days after receipt of the notice by the parent. Upon request, the parents shall have the right to an additional twenty days to prepare for any such proceeding;[165]
>
> 2. Mandatory appointment of counsel for the parent at the time of any removal, placement, or termination proceeding;[166]
>
> 3. A requirement that states provide evidence of active efforts to prevent the removal of a child or the termination of a parent's rights.[167] Active efforts have been interpreted in case law to require more vigorous intervention than reasonable efforts, the standard set forth in the Adoption and Safe Families Act;[168] and
>
> 4. A requirement that no removals or terminations may occur in the absence of a determination.[169] This must be supported by clear and convincing evidence in the cases of removals and by reasonable doubt in the cases of terminations.[170] Failure to remove or terminate will result in serious emotional or physical damage to the child.[171] Part of the showing must include the testimony of a qualified expert witness.[172]

VII. PROPOSED LEGISLATION: SUBSTANCE AND PROCEDURE

Together, the contents of the above section provide four tools to create comprehensive legislation.

A. Components of Future Legislation

Future legislation must combine the work of Idaho, Kansas, and California with the work done in ICWA. Together, the language of these statutes provides cohesive and comprehensive remedies to the six

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[165] 25 U.S.C. § 1912 (a) (2006).

[166] *Id.* at § 1912 (b).

[167] *Id.* at § 1912 (d).

[168] *Indian Child Welfare Act (ICWA) FAQ*, NATIONAL INDIAN CHILD WELFARE ASSOCIATION, http://www.nicwa.org/Indian_Child_Welfare_Act/faq/ (last visited Dec. 23, 2011).

[169] 25 U.S.C. § 1912 (e)–(f) (2006).

[170] *Id.*

[171] *Id.*

[172] *Id.*

common causes of children being removed from parent(s) with disabilities in family or dependency court and offers real protection for children of parents with disabilities.[173]

The following elements should be included in any future remedial legislation intended to prevent the unnecessary removal of children from disabled parents:

1. A non-discrimination statement with regard to parents with disabilities, utilizing the Kansas,[174] Idaho,[175] and California[176] models;

2. Definitions of "disability," and "supportive services," and "adaptive equipment" utilizing the Idaho model;[177]

3. Language requiring a showing of causation between the disability and detriment to the child when disability is a basis for removal of a child in dependency court or a determination to remove custody from a parent with a disability in family court utilizing the Kansas and Idaho models;[178]

4. Language requiring appointed counsel in family law court for parents with mental or intellectual disabilities, and that counsel in both dependency and family law cases be assigned at the outset of the case, utilizing the ICWA model;[179]

5. Language requiring active efforts to prevent removal or termination in dependency cases to the level of clear and convincing evidence, and especially noting that failure to provide parenting adaptations or adaptive equipment and supportive services will result in a finding that active efforts did not occur using the ICWA model;[180]

6. Language codifying the right of parents to (a) be notified of the availability of parenting adaptations/adaptive equipment and supportive services, and (b) have a person knowledgeable about parenting adaptations/adaptive equipment and

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[173] *See supra* Part IV.

[174] KAN. STAT. ANN. § 38-2201 to -2283 (2006).

[175] IDAHO CODE ANN. §§ 16-1601; 16-2001, 32-717 (5), 32-1005 (3) (2010).

[176] CAL. FAM. CODE § 16509.2 (West 2011) ("The physical or mental incapacity, or both, in itself, of a parent or a child, shall not result in a presumption of need for child welfare services.").

[177] *See* IDAHO CODE ANN. § 32-717(4)(a)–(c) (2007).

[178] *See* Kansas Code for Care of Children, KAN. STAT. ANN. § 38-2201(c)(1) (2010); IDAHO CODE ANN. § 32-717(2) (2007).

[179] *See* 25 U.S.C. § 1912(b) (2006).

[180] *See id.* at § 1912(d).

> supportive services included in cases as an expert in both dependency and family court, using the Idaho model;[181]
>
> 7. Language codifying the right of parents with disabilities to present evidence to the dependency or family court regarding the parenting adaptations/adaptive equipment and supportive services available to them, using the Idaho and Kansas models;[182]
>
> 8. Language requiring parenting adaptations/adaptive equipment to be included in the durable medical equipment available to disabled recipients of state medical coverage, and language requiring parenting to be categorized as a major activity of daily living using the California model;[183] and
>
> 9. Language requiring a judge to issue a written ruling whenever disability is a basis for loss of custody in the dependency or family court, using the Idaho model.[184]

There are currently other efforts to address dependency codes separately, most notably by the Research and Training Center on Community Living (a program of the University of Minnesota), detailed in their policy research brief entitled "The Inclusion of Disability as Grounds for Termination of Parental Rights in State Codes."[185] As previously discussed in Part VI, addressing dependency cases separately was a first step in both the Kansas and Idaho legislative efforts.

However, simply removing disability as a grounds for termination will be a limited accomplishment—a paper tiger. Even if disability is removed as an explicit basis for removal of children in dependency court, the court, using the standard of parental fitness, may consider *anything* that impacts that parent's ability to care for the child. Moreover, 44% of TLG's Legal Program consumers enrolled in the 2011 *Perspectives* study were involved in family court cases—more than in dependency court. And, it is family court, using the best interest of the child standard, which may consider *anything* that could impact the well-being of the child. Meaningful substantive and procedural protections must be put in place; the changes cannot just trim away politically incorrect language.

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[181] *See* IDAHO CODE ANN. § 32-717(2) (2007).

[182] *See* KAN. STAT. ANN. § 38-2201(c)(2) (2010); *see also* IDAHO CODE ANN. § 32-717(4)(c) (2007).

[183] *See* CAL. WELF. & INST. CODE § 14132(m) (West 2011).

[184] *See* IDAHO CODE ANN. § 32-717(5)(a)–(c) (2007).

[185] Lightfoot, *Inclusion of Disability*, *supra* note 5, at 2.

B. State or Federal?

Legislation with meaningful substantive and procedural protections for parents with disabilities is addressable at the state level—Kansas, Idaho, and California's successes are evidence of this. However, advocates are interested in pursuing remedial legislation at the federal level. The benefits of a federal fix would include addressing a national problem at the national level and providing consistency for families with a disabled parent. Federal legislation would avoid the difficulties of making changes in states with large populations, like California and New York, or in states that are less politically accessible to the disability community, and would allow the national disability community to pool its resources and "people power" to lobby for one law instead of many.

Traditionally, the possibility of federal legislation has been met with resistance because of the view of family law as a matter for state governance. This notion grew out of *Barber v. Barber.*[186] *Barber* involved a wife trying to use the federal courts to enforce a judgment for divorce against her husband.[187] The court in dicta noted that it "disclaim[ed] altogether any jurisdiction in the courts of the United States" over the actual granting of divorce or alimony decrees.[188]

Almost a century and a half later, in 1992, the Supreme Court noted in *Ankenbrandt v. Richards* that the "domestic relations exception" was, in effect, not based on the accuracy of the historic justifications, but on the fact that Congress had apparently accepted this construction since 1859.[189]

Despite this, the federal government routinely *does* make policy that affects families directly. Among these policies are the Family Medical Leave Act of 1993,[190] the Adoption and Safe Families Act, [191] and federal laws requiring the states to adopt child support and enforcement schemes. Congress passed these laws using its powers under the Commerce Clause[192] and the Spending Clause.[193]

Recent cases have limited Congress's power to promulgate laws under the Commerce Clause to cases where the laws will do the following: 1) regulate the use of the channels of interstate commerce; 2) regulate and protect the instrumentalities of interstate commerce, or persons or things in interstate commerce; or 3) regulate those activities

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[186] 62 U.S. 582 (1858).

[187] *Id.* at 583–84.

[188] *Id.* at 584.

[189] 504 U.S. 689, 700 (1992).

[190] 29 U.S.C. § 2601 (2006).

[191] 42 U.S.C. §§ 673b, 678, 679b (2006).

[192] U.S. CONST. art. I, § 8, cl. 3.

[193] U.S. CONST. art. I, § 8, cl. 1.

having a substantial relation to interstate commerce.[194] However, child support collection and enforcement is generally accepted as an appropriate use of the Commerce Clause.[195] Less restricted, the Spending Clause allows Congress to spend money for the general welfare of the citizenry, and includes the power to force the states to abide by national standards through the threat of withholding federal funds. The Adoption and Safe Families Act[196] is generally accepted as an appropriate use of the Spending Clause.[197]

Either clause may be a route to a federal fix for the loss of familial integrity experienced by the children of people with disabilities. However, it seems that the Commerce Clause is a less likely vehicle than the Spending Clause. An involved discussion of which power, or what other powers (such as Section 5 of the Fourteenth Amendment) might allow a federal fix are beyond the parameters of this Article. Pursuant to *Santosky v. Kramer*,[198] parenting rights are protected under the Fourteenth Amendment as a fundamental liberty interest. If, as is posited herein, parents are being deprived of this fundamental right without due process of law, or are being denied "the equal protection of the laws" based on their status as disabled, then Section 5 of the Fourteenth Amendment provides that "Congress shall have power to enforce, by appropriate legislation, the provisions of this article."[199] However, it is imperative that the possibility of a fix not be thrown out merely because of historic "hoary"[200] notions that the family is beyond the purview of the federal government.

Another logical starting point would explore how an amendment to the powerful American with Disabilities Act might be promulgated under these powers to protect the children of parents with disabilities from unnecessary removals.

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[194] United States v. Lopez, 514 U.S. 549, 558–59 (1995); United States v. Morrison, 529 U.S. 598, 608–09 (2000).

[195] *See, e.g.*, U.S. v. Parker, 108 F.3d 28, 30 (3d Cir. 1997); U.S. v. Hampshire, 95 F.3d 999, 1003–04 (10th Cir. 1996); U.S. v. Mussari, 95 F.3d 787, 790 (9th Cir. 1996); U.S. v. Sage, 92 F.3d 101, 104–07 (2d Cir. 1996).

[196] 42 U.S.C. §§ 620–29, 670–79 (2006).

[197] Mo. Child Care Ass'n v. Cross, 294 F.3d 1034, 1036 (8th Cir. 2002) (holding that the Adoption and Safe Families Act of 1997, which amended the Adoption Assistance and Child Welfare Act of 1980, was a valid exercise of the Spending Power and that through the Supremacy Clause preempted state law).

[198] 455 U.S. at 753.

[199] U.S. CONST. amend. XIV, §§ 1, 5. For scholarship debating the scope of Congress's Section Five power, *see* Larry D. Kramer, *The Supreme Court, 2000 Term – Foreword: We the Court*, 115 HARV. L. REV. 5, 136–53 (2001); Robert C. Post & Reva B. Siegel, *Equal Protection by Law: Federal Antidiscrimination Legislation After* Morrison *and* Kimel, 110 YALE L.J. 441 (2000); Robert C. Post & Reva B. Siegel, *Legislative Constitutionalism and Section Five Power: Policentric Interpretation of the Family and Medical Leave Act*, 112 YALE L.J. 1943 (2003).

[200] Sylvia Law, *Families and Federalism*, 4 WASH. U.J.L. & POL'Y 175, 179 (2000).

VIII. CONCLUSION

Millions of children of parents with disabilities are being removed from their families at alarming rates and are suffering the maladies that accompany such removals. The vast majority of these removals are unnecessary. They are based on a handful of major causes that can be remedied legislatively. Whether state or federal, it is imperative that legislation to remedy this problem be promulgated within this generation.

Unnecessary removal is not just an issue for American children of parents with disabilities. There is nothing specific to our culture that lends itself to this injustice. The United Nations General Assembly adoption of the Convention on the Rights of Persons with Disabilities (UNCRPD) features Article 23: Respect for home and the family, which alludes to adaptive equipment and services and emphasizes preventing a *child's loss of her parents*:[201]

> 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 . . . .
>
> . . . .
>
> 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.
>
> . . . .
>
> 4. 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

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[201] Convention on the Rights of Persons with Disabilities, art. 23, *adopted* Dec. 13, 2006, 2515 U.N.T.S. 3.

disability of either the child or one or both of the parents.[202]

In 2011, Legal Program Director (and one of the authors of this Article) Ella Callow presented a portion of the raw data contained in this Article to an audience of hundreds of disability activists, researchers and U.N. members gathered at the Nordic Network on Disability Research Conference, in Reykjavik, Iceland. The purpose of the conference was to bring the international disability community together to envision and discuss what the UNCRPD meant for people with disabilities, including families that contain a parent with a disability. Throughout the conference, people from other nations expressed how important it is, and how hopeful their communities are, that America will join with the 151 other nations that have ratified the UNCPRD as of 2011. Clearly, this is a global issue for which the time has come.

The American disability rights movement is still a young movement, but it has been breathtakingly successful for many individuals with disabilities. Protecting the rights of parents with disabilities and their children will be an important step in the movement's history. It will be very difficult; yet, what more important step can there be in a movement than to secure for its members the basic right to family, and to protect its children against wrongful removal, trauma, and great harm? We must be willing to take on great challenges for the sake of our children.

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[202] *Id.*