**Chapter 1. Introduction**

*“Parenting knows no barrier…all it takes is love.”endnote**[[1](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end1)]*

**The Evolution of Parenting in the Disability Community**

The desire to become a parent traverses all cultural, physical, and political boundaries. However, for people with disabilities—including intellectual and developmental, psychiatric, sensory, and physical disabilities—this innate desire has long been forestalled by societal bias. Today, people with disabilities continue to encounter significant legal, medical, and familial resistance to their decision to become parents.endnote[[2](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end2)] This opposition has profound and disconcerting roots.

**Parenting with a Disability in the 20th Century**

The first half of the 20th century was characterized by the eugenics movement, during which more than 30 states legalized involuntary sterilization.endnote[[3](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end3)] This legislative trend was premised on the belief that people with disabilities and other “socially inadequate” populations would produce offspring who would be burdensome to society.endnote[[4](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end4)] Because of these state statutes, more than 65,000 Americans were involuntarily sterilized by 1970.endnote[[5](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end5)]

Forced sterilization gained the blessing of the U.S. Supreme Court in the 1927 *Buck v. Bell* decision.endnote[[6](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end6)] Carrie Buck was an institutionalized woman in Virginia who was deemed “feebleminded.”endnote[[7](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end7)] She was the daughter of a “feebleminded” mother who was committed to the same institution. At age 17, Buck became pregnant after being raped; her daughter Vivian allegedly also had an intellectual disability and was also deemed feebleminded.endnote[[8](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end8)] After the birth of Vivian, the institution sought to sterilize Buck in accordance with Virginia’s sterilization statute. Following a series of appeals, Virginia’s sterilization statute was upheld on the premise that it served “the best interests of the patient and of society.”endnote[[9](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end9)] Concluding this historical decision, Justice Oliver Wendell Holmes, Jr., declared, “Three generations of imbeciles are enough.”1endnote[[0](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end0)]

Despite receiving severe criticism, *Bell* has never been overruled. In fact, in 1995, the Supreme Court denied the petition for certiorari of a woman with an intellectual disability challenging Pennsylvania’s involuntary sterilization statute.endnote[[11](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end11)] Bell was cited by a federal appeals court as recently as 2001, in *Vaughn v. Ruoff*.endnote[[12](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end12)] In this case, the plaintiff had a “mild” intellectual disability and both of her children were removed by the state. Immediately following the birth of her second child, the social worker told the mother that if she agreed to be sterilized, her chances of regaining custody of her children would improve. The mother agreed to sterilization, but approximately three months later, the state informed her that it would recommend termination of parental rights. The district court found that the plaintiff had a protected liberty interest in the 14th Amendment and that the social worker’s conduct violated her due process rights. The judgment was affirmed by the U.S. Court of Appeals for the Eighth Circuit. However, the appeals court, citing *Bell*, acknowledged that “involuntary sterilization is not always unconstitutional if it is a narrowly tailored means to achieve a compelling government interest.”endnote[[13](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end13)]

**Parenting with a Disability Today: The Eugenics Movement’s Backdoor?**

Even today, 22 years after the passage of the ADA, several states still have some form of involuntary sterilization laws on their books. A few even retain the original statutory language, which labels the targets of these procedures as possessing hereditary forms of “idiocy” and “imbecility,” and state that the best interests of society would be served by preventing them from procreating.endnote[[14](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end14)]

In fact, there appears to be a growing trend nationally and internationally toward sterilizing people with intellectual or psychiatric disabilities. Five years ago, a nine-year-old American girl with developmental disabilities was forced to undergo a procedure to, among other things, stunt her growth and remove her reproductive organs. Since then, more than 100 families have reportedly subjected their disabled children to similar treatment, while thousands more have considered doing so.endnote[[15](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end15)]

In the fall of 2011, the Massachusetts Department of Mental Health filed a petition to have the parents of a woman with a psychiatric disability appointed as temporary guardians for the purpose of consenting to an abortion, despite the fact that the woman had refused such a procedure, citing her religious beliefs.endnote[[16](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end16)] The court ordered that the woman’s parents be appointed as co-guardians and said she could be “coaxed, bribed, or even enticed ... by ruse” into a hospital where she would be sedated and an abortion would be performed. The judge also ordered the facility that performed the abortion to sterilize the woman “to avoid this painful situation from recurring in the future.” The decision was reversed on appeal. With regard to the sterilization order, the appeals court ruled, “No party requested this measure, none of the attendant procedural requirements has been met, and the judge appears to have simply produced the requirement out of thin air.” In overturning the order to terminate the pregnancy, the court stated, “The personal decision whether to bear or beget a child is a right so fundamental that it must be extended to all persons, including those who are incompetent.” The appropriate result of the proceedings does not erase its troubling genesis—a state agency that intervened to terminate a pregnancy on the basis of the disability of the pregnant woman, despite her objection to having an abortion.

The familial rights of people with disabilities appear to be declining rapidly. In 1989, 29 states restricted the rights of people with psychiatric disabilities to marry.endnote[[17](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end17)] Ten years later, this number had increased to 33.endnote[[18](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end18)] Further, in 1989, 23 states restricted the parenting rights of people with psychiatric disabilities; by 1999, 27 states had enacted restrictions.

Unquestionably, the power of eugenics ideology persists. Today, women with disabilities contend with coercive tactics designed to encourage sterilization or abortions because they are deemed not fit for motherhood.endnote[[19](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end19)] Similarly, there is a pervasive myth that people with disabilities are either sexually unwilling or unable.endnote[[20](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end20)] According to Michael Stein, internationally recognized expert on disability law and policy, “Mainstream society’s discomfort with the notion of people with disabilities’ relational intimacy is well documented. One poll found that 46 percent of nondisabled people stated they ‘would be concerned’ if their teenage son or daughter dated a person with a disability, and 34 percent ‘would be concerned’ if a friend or relative married a person with a disability.”endnote[[21](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end21)] Stein says, “The main consequences of the disabled non-sexuality myth are (1) difficulty in the formation of intimate interpersonal relationships between disabled and nondisabled people; (2) limited awareness and availability of health care services to women with disabilities; and (3) as a corollary to the myth, severe misperceptions about and often prejudices against individuals with disabilities acting in parental or guardianship capacities.”endnote[[22](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end22)]

Indeed, despite the increasing numbers of people with disabilities becoming parents, most still struggle with family, community, and social ambivalence about this choice.endnote[[23](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end23)] According to Corbett Joan O’Toole and Tanis Doe, international disability activists, “In general, with rare exceptions, people with disabilities do not get asked if they want to have children. They don’t get asked if they want to be sexual. The silence around sexuality includes their parents, their counselors, their teachers, and most health professionals. Yet these same people sometimes counsel in favor of involuntary sterilization.”endnote[[24](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end24)] Lindsay,endnote[[25](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end25)] a woman with physical and cognitive disabilities and a mother of two, reflects on this: “I was first discouraged from being a mother by family and community’s attitudes toward sex and disability, especially by their belief, which I internalized, that my difference (my scarred face and starfish-shaped hands) made me ugly, and therefore less desirable.”

As Carrie Killoran, a mother with a physical disability, recalls, “Before I got pregnant, I was told by my father that it would be irresponsible of me to have a baby because I would be an unfit mother. This is the view of most of society.… On the contrary, I turned out to be one of the fittest mothers I know. The ability to be a good mother does not reside in the ability to chase around after a toddler, nor in the ability to teach your child how to ride a bike. Neither does it include protecting your child from being teased about her parent’s disability; all children find something to tease each other about and a sturdy, self-confident child will emerge unscathed.”endnote[[26](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end26)]

People with disabilities face these negative attitudes even after becoming parents. O’Toole and Doe state, “If we do have a child we get asked if it is ours, ‘Who is the parent?’ ‘Where is the parent?’ or ‘Why are you holding it?’”endnote[[27](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end27)] When Jessica,endnote[[28](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end28)] a woman with cerebral palsy, told her mother that she was pregnant with twins, her mother responded, “Now your husband has three babies.” Cassandra,endnote[[29](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end29)] a woman with significant physical disabilities and a mother of one, frequently has strangers approach her and question her ability to be a parent.

According to another mother with a physical disability, “The most difficult preparations were those to mentally ready ourselves for the likely probability that there would be—and will always be—people who doubted our abilities and worth as parents.”endnote[[30](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end30)] The mother recalls, “I learned long ago that the stereotypes and judgments held by people about [my husband] and me aren’t usually encased in their words. It’s often what is not said. Several of our friends were married around the same time we were. Almost immediately after our celebrations, my fellow brides would complain about the annoyance they felt when people peppered them with questions about when they were going to have a baby. That certainly wasn’t a question that people lined up to ask us.”endnote[[31](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end31)]

People with disabilities also face resistance to procreate if their disability is hereditary. Ora Prilletensky, professor, author, and mother with a disability, writes:

“In addition to the myth of asexuality and skepticism regarding their ability to attract partners, women with disabilities have been discouraged from having children for a variety of other reasons. Concerns that they will give birth to ‘defective’ babies and prejudicial assumptions about their capacity to care for children often underpin the resistance that they may encounter. The growing sophistication of prenatal tests, coupled with societal disdain for imperfection, translates into increased pressure on all women to ensure the infallibility of their offspring. Women choosing to forgo prenatal testing often have to contend with the clear disapproval of their doctors and may even run the risk of losing their medical insurance if they choose to bring to term rather than abort the ‘flawed’ (and expensive) fetus. Indeed, there is an estimated 80 percent rate of abortion of fetuses diagnosed as having a condition that could result in a significant disability.”endnote[[32](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end32)]

Kathryn,endnote[[33](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end33)] a wheelchair user and little person, reports that she and her husband, who has a similar disability, were encouraged to adopt because there was a chance their child could have their disability. In fact, many people did not express happiness regarding Kathryn’s pregnancy until tests revealed that their baby did not have their disability.

Although the right to be a parent is generally regarded as fundamental, this right is not always assumed for people with disabilities. According to Megan Kirshbaum and Rhoda Olkin of Through the Looking Glass (TLG), “Parenting has been the last frontier for people with disabilities and an arena in which parents are likely to encounter prejudice.”endnote[[34](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end34)] Indeed, carrying on a shameful tradition of discrimination against people with disabilities, states continue to erect legislative, administrative, and judicial obstacles to impede people with disabilities from creating and maintaining families.

As discussed in this report, the rate of removal of children from families with parental disability—particularly psychiatric, intellectual, or developmental disability—is ominously higher than rates for children whose parents are not disabled. And this removal is carried out with far less cause, owing to specific, preventable problems in the child welfare system. Further, parents with disabilities are more likely to lose custody of their children after divorce, have more difficulty in accessing reproductive health care, and face significant barriers to adopting children.

**Current Data on Parents with Disabilities and Their Families**

Parents with disabilities and their families exist in substantial numbers throughout the world, yet documentation of this population is extremely limited. A significant obstacle to ascertaining the number of parents with disabilities as well as their demographic characteristics is the absence of data. While some census data provide estimates of the number of people with disabilities or the number of parents within a given locale, almost no regional or national data consider the combination of these two characteristics.endnote[[35](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end35)] National estimates of the number of parents with disabilities are usually based on projections from much fewer data or estimated by complex extrapolations.endnote[[36](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end36)] Even at the regional or local level, most disability service providers fail to collect data on the number of parents with disabilities in their purview.endnote[[37](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end37)] O’Toole notes, “Sometimes it is the lack of questioning that is the genesis of the research gap.”endnote[[38](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end38)] Because of the scarcity of substantive data at the local and national levels, parents with disabilities remain mostly invisible. According to Paul Preston, co-director of the National Center for Parents with Disabilities TLG, “Erroneous assumptions about the low prevalence of parents with disabilities affect the availability of resources or the motivation to create new resources specifically for parents with disabilities and their families.”endnote[[39](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end39)]

TLG, home to the National Center for Parents with Disabilities and Their Families, recently completed a study that gathered data on parents with disabilities and their families.endnote[[40](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end40)] Analyzing data from the 2010 American Community Survey, TLG estimates that at least 4.1 million parents with reported disabilities in the United States have children under age 18; meaning that at least 6.2 percent of American parents who have children under age 18 have at least one reported disability. The rates are even higher for some subgroups of this population; for instance, 13.9 percent of American Indian/Alaska Native parents and 8.8 percent of African American parents have a disability. Further, 6 percent of white, 5.5 percent Latino/Hispanic, and 3.3 percent of Asian/Pacific Islander parents have a disability. Of these parents, 2.8 percent have a mobility disability, 2.3 percent have a cognitive disability, 2.3 percent have a daily activity limitation, 1.4 percent have a hearing disability, and 1.2 percent have a vision disability.

Another recent study conducted by TLG revealed significant differences in education and income between parents with and without disabilities.endnote[[41](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end41)] For instance, only 12.6 percent of parents with disabilities have college degrees, compared with 30.8 percent of those without disabilities. Further, only 76.5 percent of parents with disabilities have a high school diploma (includes people with college degrees and beyond), compared with 87.2 percent of those without disabilities. The median family income for parents with disabilities is $35,000, compared with $65,000 for parents without disabilities.

Finally, TLG estimates that at least 6.1 million children in the United States have parents with disabilities; that is 9.1 percent of children in this country.endnote[[42](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end42)]

In its broadest sense, “parents with disabilities” also includes those who may not identify themselves as having a disability, such as a deaf parent, a parent of short stature, or a parent with diabetes.endnote[[43](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end43)] An additional population to consider is grandparents and other relatives who have a disability and are a child’s primary caretaker. According to Preston:

“In the United States, there is an especially rapid increase in the number of grandparents in parenting roles; a 1999 study found that caregiving grandparents had greater than 50 percent chance of having a limitation in an activity of daily living (ADL) compared to non-caregiving grandparents. Although grandparents and other relatives may not be legally recognized as a child’s ‘parent,’ nonetheless these primary caregivers and their children face many of the same issues as families of biological and adoptive mothers and fathers with disabilities. Another consideration in defining this population is whether to exclude parents whose child does not live with them; this is an especially salient issue in that many children of parents with disabilities are inappropriately removed from their parents’ care, and most parents with disabilities have few financial and social resources to retain or regain custody of their children. Finally, non-disabled parents may develop a disability long after their children have grown and left home, and the impact of disability may not be comparable to those families in which the parent has had a disability prior to or during the early parenting years.”endnote[[44](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end44)]

Millions of parents throughout the United States have disabilities, and this number is likely to grow as people with disabilities become increasingly independent and integrated into their communities. For instance, recent data from the CDC reveal that 1 in 88 children qualify for a diagnosis of autism spectrum disorder (ASD).endnote[[45](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end45)] Likewise, there has been a dramatic increase in the number of veterans who are returning from war with service-connected disabilities,endnote[[46](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end46)] some of whom may already be parents and others who will become parents after acquiring their disability.

Despite more and more people with disabilities creating families, there are few data and little research on the prevalence of parents with disabilities, their needs, and their experiences. Reasons for this lack of information include the lack of attention to the needs and experiences of parents with disabilities and their families, the lack of administrative and research data on parents with disabilities, and the lack of funding for research. Adequate policy development and program planning to address the issues and meet the needs of parents with disabilities and their children cannot occur without accurate prevalence data and more detailed information about the circumstances, goals, and needs of these families.

**Fundamental Principles of Parenting Rights in the United States**

The United States Supreme Court has avowed continuously and with conviction that parents’ rights to the care and custody of their children are protected under the Due Process Clause of the 14th Amendment. Beginning with the seminal 1923 decision in *Meyer v. Nebraska*,endnote[[47](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end47)] in which the Court held that parents have the due process right to see to the education of their children together with the duty to give children a suitable education, parental rights have long been held as fundamental. Two years after *Meyer*, the Court, in *Pierce v. Society of Sisters*, ruled that parents have the liberty “to direct the upbringing and education of children under their control.”endnote[[48](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end48)] In this landmark case, the Supreme Court found, “The child is not the mere creature of the State; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.”endnote[[49](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end49)] Subsequent decisions have further defined the contours of the law’s protections of parental rights.

In 1972, in *Stanley v. Illinois*, the Supreme Court struck down an Illinois statute that provided for removal of children born out of wedlock from the care of their father without a hearing because unwed fathers were presumed unfit; the Court held that parental unfitness may not be presumed but must be proven in a hearing in each case.endnote[[50](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end50)] According to the decision, the interest of a parent in his or her children “undeniably warrants deference and, absent a powerful countervailing interest, protection.”endnote[[51](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end51)] The Court reiterated the due process protection for parents’ rights five years later.endnote[[52](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end52)]

In 1978, the Court, quoting its opinion in *Prince v. Massachusetts*,endnote[[53](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end53)] said, “It is cardinal with us that ‘the custody, care and nurture of the child resides first with the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder.’”endnote[[54](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end54)]

More recent Supreme Court cases have continued to recognize substantive due process protection for parents’ rights, unfailingly holding that the right to one’s children is more substantial than a property right.endnote[[55](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end55)] “Choices about marriage, family life, and the upbringing of children are among associational rights this Court has ranked as of basic importance in our society, rights sheltered by the 14th Amendment against the State’s unwarranted usurpation, disregard, or disrespect.”endnote[[56](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end56)] The Court also has noted that when access to justice is at issue, equal protection and due process concerns converge and are implicated.endnote[[57](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end57)] Specifically, in *M.L.B. v. S.L.J*, the Court held that the ability to pay should not determine access to justice, such access being protected by the equal protection clause, and that there are due process concerns as well about the essential fairness of state-ordered proceedings.endnote[[58](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end58)]

The most recent Supreme Court case to address parental rights is the 2000 case of *Troxel v. Granville*, in which the Court ruled that a Washington state grandparent-visitation statute failed to respect “the fundamental right of parents to make decisions concerning the care, custody, and control of their children.”endnote[[59](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end59)] Citing extensive case precedent, the plurality decision of the Court declared that the right of parents to direct the upbringing and education of their children is a fundamental right. The Court also found that the grandparent-visitation statute did not respect the fundamental rights of parents, but instead gave preference to what the state deemed to be in the child’s best interest. Because of the fundamental nature of parental rights, the government could not overrule a parent’s decision simply by questioning that decision. Although six Supreme Court justices ultimately sided with the parent in *Troxel*, the Court had difficulty agreeing on the precise legal status of parental rights. Only four of the justices (one short of the five required for a majority) agreed in the opinion that parental rights were fundamental, implied rights protected by the Constitution.

Thus, despite the conclusion that the substantive liberty interest of parents requires strict scrutiny of any government intervention into the family,endnote[[60](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end60)] Justice O’Connor’s plurality opinion in *Troxel* does not apply strict scrutiny.endnote[[61](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end61)] In his concurrence, Justice Thomas stated that the Court must apply strict scrutiny to any infringement of the constitutional rights of parents.endnote[[62](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end62)] In another concurrence, Justice Souter recognized the due process protection of parents’ rights but did not adopt Justice Thomas’s strong stance regarding strict scrutiny.endnote[[63](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end63)] Therefore, despite the recognition of substantive due process protection of parental rights, it appears that intervention by the government into family life is not subject to strict scrutiny. Given that differential treatment of people with disabilities is also not subject to strict scrutiny,endnote[[64](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end64)] parents with disabilities may not seek strict scrutiny of state decisions to interfere in the lives of their families.

Attorney Dave Shade, in his 1998 *Law & Equity* article, wrote, “The right to establish a home and raise children is among the most basic of civil rights, long recognized as essential to the orderly pursuit of happiness. Cherished as this right may be, however, it has been violated, abused or just ignored for people with disabilities. Although persons with disabilities have made significant gains in recent years in overcoming the invidious discrimination with which they have long been burdened, the legal rights of parents with disabilities remain in question.”endnote[[65](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end65)]

**Dependency Law**

While the freedom to parent without interference from the state is a fundamental right protected by the 14th Amendment, that right is balanced by the right of the state to protect its citizen children from harm. Indeed, the Supreme Court stated in *Wisconsin v. Yoder* et al.,endnote[[66](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end66)] “To be sure, the power of the parents ... may be subject to limitation ... if it appears that parental decisions will jeopardize the health or safety of the child, or have a potential for significant social burdens.”endnote[[67](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end67)]

Under the legal doctrine of *parens patriae*, the state has a fundamental interest in protecting the interests of children.endnote[[68](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end68)] Accordingly, states claim the authority to protect the best interests of children by limiting or, under extreme circumstances, severing the parents’ rights.endnote[[69](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end69)] Typically, “extreme circumstances” involve instances of child abuse and neglect.

As early as 1839, in upholding the removal of a child from her parents’ custody, the Pennsylvania Supreme Court recognized a tension between parental rights and the state’s interest in protecting its childrens’ welfare: “The right of parental control is a natural, but not an inalienable one. It is not accepted by the declaration of rights out of the subjects of ordinary legislation; and it consequently remains subject to the ordinary legislative power.”endnote[[70](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end70)]

The Supreme Court has affirmed that while the state may completely dissolve the parent-child relationship without the parent’s consent, the state must comply with standards of due process. For instance, when states have attempted to terminate parental rights solely on the basis of ascribed status, the Supreme Court has intervened. In 1972, in *Stanley v. Illinois*,endnote[[71](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end71)] the Court held that both due process and equal protection dictated that Illinois could not terminate an unwed father’s rights to his children before a hearing on his parental fitness. In contending that the plaintiff must receive an individual hearing, the Court articulated at least one limitation on the state’s power to terminate parental rights: The state must prove unfitness through individual inquiry rather than through presumptions based on ascribed status. Arguably, this reasoning must also be applied in decisions vis-à-vis the termination of parental rights on the basis of disability.

In 1981, the Court directly addressed the issue of termination of parental rights, stating that termination is “a unique kind of deprivation” and that a “parent’s interest in the accuracy and justice of the decision to terminate his or her parental status is, therefore, a commanding one.”endnote[[72](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end72)] Conversely, the Court noted that “the State has an urgent interest in the welfare of the child.”endnote[[73](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end73)] The question before the Court was whether indigent parents have a right to appointed counsel in termination proceedings, and the answer was that there is no absolute right to counsel in these proceedings, but there may be a right to counsel depending on the circumstances of the case and the due process implications of those circumstances.endnote[[74](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end74)]

One year later, in 1982, in *Santosky v. Kramer*,endnote[[75](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end75)] the Court avowed that the state must overcome a strong presumption against termination because “the child and his parents share a vital interest in preventing erroneous termination of their natural relationship.”endnote[[76](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end76)] The Court held that before terminating a parent’s rights, the state must prove parental unfitness by *clear and convincing evidence*; if this burden cannot be met, the child must remain with his or her parents.endnote[[77](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end77)] Moreover, even where the parent-child relationship appears to be strained or problematic, natural parents enjoy a fundamental liberty interest in rearing their children: “The fundamental liberty interest of natural parents in the care, custody, and management of their child does not evaporate simply because they have not been model parents or have lost temporary custody of their child to the State.”endnote[[78](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end78)]

In 1973, Congress took the first steps toward enacting federal legislation to address the issue of child abuse. The Child Abuse Prevention and Treatment Act (CAPTA), passed in 1974, required states “to prevent, identify and treat child abuse and neglect.”endnote[[79](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end79)]

Shortly thereafter, in 1978, the ICWA was passedendnote[[80](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end80)] in response to concerns that Native American children were being separated from their tribes and placed in foster care at disproportionately high rates.endnote[[81](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end81)]

In 1980, Congress passed the Adoption Assistance and Child Welfare Act (AACWA), Public Law 96-272, in an attempt to drastically reform the child welfare system in every state.endnote[[82](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end82)] AACWA required that “reasonable efforts” be made to keep children with their parents, both to prevent or eliminate the need for removal of the child from his or her family, and to make it possible for the child to return to his or her family following removal.endnote[[83](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end83)] The primary objective of AACWA was to respond to the needs of children in foster care and to promote permanency through reunification or adoption.endnote[[84](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end84)] However, many professionals in the field, like Laureen D’Ambra, found that this resulted in the unintended interpretation by many states as “reasonable efforts at all costs.”endnote[[85](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end85)] While programs worked to preserve or reunite many families, AACWA failed relative to permanency planning.endnote[[86](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end86)] AACWA did not provide a specific definition of “reasonable efforts,” nor did HHS promulgate formal regulations and guidance.endnote[[87](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end87)] Further, AACWA failed to establish time frames for completing the reunification process, and automatic mandates were not enacted for filing TPR cases when parents’ conduct was not beneficial to efforts to reunify.endnote[[88](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end88)] This vagueness convinced many, including Senator Mike DeWine of Ohio, that “some, some of the tragedies in the child welfare system are the unintended consequence of a small part of [the Child Welfare Act].”endnote[[89](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end89)] More pointedly, Senator DeWine stated, “There is strong evidence to suggest that, in practice, reasonable efforts have become many times, extraordinary efforts—efforts to keep families together at all costs.”endnote[[90](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end90)]

On November 19, 1997, President Bill Clinton signed the Adoption and Safe Families Act of 1997, Public Law 105-89, promoting child safety, permanency, and well-being.endnote[[91](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end91)] Through ASFA, Congress sought to strengthen the child welfare system’s response to a child’s need for safety and permanency at every point along the continuum of care.endnote[[92](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end92)] ASFA made safety the “paramount concern” in the delivery of child welfare services and decision making, and clarified when reasonable efforts to prevent removal or to reunify a child with his or her family are not required. To promote permanency, ASFA shortened the time frames for conducting permanency hearings, created a requirement for states to make reasonable efforts to finalize a permanent placement, and established time frames for filing petitions to terminate the parental rights for certain children in foster care.endnote[[93](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end93)] ASFA also introduced concurrent planning, which allows states to provide reunification efforts with parents while also developing a simultaneous plan for a permanent home for the child if reunification fails.endnote[[94](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end94)]

**Family Law**

Family law involves a variety of domestic relation matters, such as marriage, divorce, domestic abuse, prenuptial agreements, child support, and child custody and visitation. This section focuses on family law as it relates child custody and visitation.

The Constitution protects the fundamental right to parent without interference from the state, and case law has established that unfitness must be proved before the state can terminate parental rights. However, when parents are unable to reach a custody or visitation agreement between *themselves*, it is the family law courts that decide child custody—without the constitutional mandates—based on the best interest of the child standard.

Historically, American law treated children as chattel or property and gave strong preference to fathers when there was a dispute over custody.endnote[[95](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end95)] As society changed from an agrarian to an industrial base, this presumption shifted to what was termed the “tender years doctrine:” the idea that young children should be raised by their mothers, rather than their fathers, because of the nurturing nature of the mother-child relationship.endnote[[96](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end96)] This presumption gave way to the best interest of the child standard in the 1970s, in response to changing gender roles and the divorce revolution.endnote[[97](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end97)]

Family law cases are governed by individual state statutes. When parents cannot reach a custody agreement, courts may decide custody on the basis of the state’s right to protect its citizen children from harm.endnote[[98](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end98)] The legal standard courts use to determine custody is the best interest of the child.endnote[[99](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end99)] Most states have developed their own factors to determine which custody arrangement is in the best interest of the child. Typical factors include 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; and whether either placement involves a significant other with a history of violence or dependency issues.endnote[[100](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end100)] The best interest analysis always allows for a parent’s own health to be considered.

**Adoption Law**

Adoption law, both domestic and international, creates the legal relationship of parent and child and bestows on the adoptive parents all the rights and responsibilities of that role.endnote[[101](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end101)] That is, adoptive parents play the same role as biological parents in the life of their child.endnote[[102](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end102)] There is no inherent right to adopt a child or to become a foster parent; unlike parenting biologically, parenting by adoption is not guaranteed in the United States Constitution or any state constitution.endnote[[103](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end103)]

During the adoption process, courts and agencies consider a list of criteria to determine whether an individual or couple will be suitable parents for a child. Criteria typically include “age, religion, financial stability, emotional health, capacity for parenthood, physical health, marital status, infertility, adjustment to sterility, quality of the marital relationship, motives for adoption, attitudes toward nonmarital parenthood, the attitude of significant others, total personality, emotional maturity, and feelings about children.”endnote[[104](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end104)] “Where the couple lives and whether they have other children are also factors that agencies may consider when deciding among prospective adoptive families.”endnote[[105](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end105)] With international adoption, each country has its own criteria.

**Domestic Adoption**

Domestic adoption is largely governed by state law, with federal laws providing overarching standards with which state adoption laws must comply.endnote[[106](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end106)] Massachusetts passed the first adoption statute in the United States.endnote[[107](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end107)] By 1929, all states had enacted similar laws, emphasizing the best interest of the child standard.

Domestic adoptions can be accomplished through many different routes, but all must be approved by a presiding judge. endnote[[108](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end108)] There are five types of domestic adoption in the United States: public agency adoptions, licensed private agency adoptions, independent adoptions (often referred to as attorney adoptions), adoptions through a facilitator (allowed in some states), and unlicensed private agency adoptions.endnote[[109](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end109)]

Regulated by federal legislation, domestic adoptions often take place across state lines.endnote[[110](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end110)] Interstate adoptions are affected by agreements between the “sending” and “receiving” states. These agreements carry the force of law: namely, the Interstate Compact on Adoption and Medical Assistance (ICAMA) and the Interstate Compact on the Placement of Children (ICPC).endnote[[111](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end111)] Currently, 42 states participate in the ICAMA, which regulates and coordinates the payment of benefits to children with special needs, children who are adopted pursuant to an adoption assistance agreement, those who are adopted from one state by a family in another state, and those whose adoptive family moves from one state to another. The ICPC is an agreement among all 50 states, the District of Columbia, and the U.S. Virgin Islands, and is covered by legal statute in all states. It applies to the placement of minor children made from one state to another by public and private agencies, the courts, independent placers (e.g., physicians and attorneys), and individuals.

**International Adoption**

International adoption (also referred to as intercountry adoption) differs from domestic adoption in several significant ways.endnote[[112](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end112)] Children who are eligible for intercountry adoption must have lost their birth parents to death or abandonment, or the birth parents must prove that they are incapable of caring for the children.endnote[[113](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end113)] In some cases, children adopted through intercountry adoption come from orphanages or institutional settings.endnote[[114](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end114)] The placement process for international adoption underwent significant change following the United States’ ratification of the Hague Convention on Protection of Children and Co-operation in Respect of Inter-Country Adoption on April 1, 2008.endnote[[115](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end115)] The Hague Convention is “designed to protect the best interests of children and prevent the abduction, sale, and trafficking of children.”endnote[[116](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end116)] In the United States, the Department of State has overall responsibility for implementing the Convention, although the U.S. Citizenship and Immigration Services (USCIS) in the Department of Homeland Security also play a significant role.endnote[[117](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end117)] The United States is one of 85 nations that are parties to the Hague Convention.endnote[[118](http://www.ncd.gov/publications/2012/Sep272012/Endnotes#end118)] When a U.S. citizen wants to adopt a child from any of these nations, convention rules apply. In adopting a child from a country that is not a party to the convention, some rules vary.endnote[[119](http://www.ncd.gov/publications/2012/Sep272012/Endnotes" \l "end119)]

**Purpose and Structure of Report**

The purpose of this report is to comprehensively examine the barriers and facilitators people with disabilities experience in exercising their fundamental right to create and maintain families, and to highlight the persistent, systemic, and pervasive discrimination against parents with disabilities. In particular, the report analyzes how U.S. federal disability law and policy apply to parents with disabilities within the child welfare system and the family law system, and the systems’ disparate treatment of parents with disabilities and their children. The report examines the impediments prospective parents with disabilities encounter when they attempt to adopt children, either domestically or internationally, and when they attempt to access assisted reproductive technologies.

The report is divided into 17 chapters. Chapter 2 lays out the research methodology used in the study. Chapter 3 considers U.S. federal disability rights laws and their application to parents with disabilities and their children. Chapter 4 analyzes the United Nations Convention on the Rights of Persons with Disabilities and its promotion of parenting rights. Chapter 5 examines the child welfare system, focusing on removal, reunification, and termination of parental rights. Chapter 6 explores parental disability and child welfare in the Native American community. Chapter 7 focuses on the family law system, specifically custody and visitation. Chapter 8 reviews inappropriate and unadapted parenting assessments and their impact on the child welfare and family law systems. Chapter 9 examines the lack of adapted services, adapted equipment, and parenting techniques in child welfare and family court. Chapter 10 analyzes the adoption law system and the barriers prospective parents with disabilities face.

Chapter 11 explores access to assisted reproductive technologies for people with disabilities. Chapter 12 focuses on the impact of disability on parenting. Chapter 13 considers various opportunities for supporting parents with disabilities and their children. Chapter 14 reviews promising practices to prevent the unnecessary removal and loss of children. Chapter 15 examines remedial state and federal legislation of interest. Chapter 16 proposes federal and state legislation to address the systemic and pervasive discrimination that parents with disabilities and their children regularly encounter. The report concludes by setting forth recommendations that will ensure the rights of people with disabilities to create and maintain families, and support them in their endeavors to do so.