Rocking the Cradle:

Ensuring the Rights of Parents with Disabilities and Their Children

National Council on Disability

September 27, 2012

National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

September 27, 2012

The President
The White House
Washington, DC 20500

Dear Mr. President:

The National Council on Disability is pleased to submit the enclosed report, "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children."

Despite a dark history marked by the eugenics movement, increasing numbers of people with disabilities are choosing to become parents. Recent research reveals that more than 4 million parents—6 percent of American mothers and fathers—are disabled. This number will unquestionably increase as more people with disabilities exercise a broader range of lifestyle options as a result of social integration, civil rights, and new adaptive technologies. Likewise, there has been a dramatic increase in the number of veterans who are returning from war with service-connected disabilities, some of whom may already be parents and others who will enter parenthood after acquiring their disability.

The right to parent without interference is protected by the U.S. Constitution and balanced by the judicially recognized power of the state to interfere to protect the well-being of its children. The factors used in both dependency court and family court proceedings to determine whether children need to become wards of the state and which parent is the most competent custodian may be reasonable. Nonetheless, these rules are not objectively or justly applied to parents with disabilities and their children.

Even today, 22 years after the passage of the Americans with Disabilities Act, parents with disabilities are the only distinct community of Americans who must struggle to retain custody of their children. Removal rates where parents have a psychiatric disability have been found to be as high as 70 percent to 80 percent; where the parent has an intellectual disability, 40 percent to 80 percent. In families where the parental disability is physical, 13 percent have reported discriminatory treatment in custody cases. Parents who are deaf or blind report extremely high rates of child removal and loss of parental rights. Parents with disabilities are more likely to lose custody of their children after divorce. In addition, prospective parents with disabilities have more difficulty when it comes to accessing reproductive health care such as assisted reproductive technologies, and they face significant barriers to adopting children.

Clearly, the legal system is not protecting the rights of parents with disabilities and their children. Fully two-thirds of dependency statutes allow the court to reach the determination that a parent is unfit (a determination necessary to terminate parental rights) on the basis of the parent's disability.

In every state, disability may be considered when determining the best interest of a child for purposes of a custody determination in family or dependency court. A nexus should always be shown between the disability and harm to the child, so that a child is taken from a custodial parent only when the parent's disability is creating a detriment that cannot be alleviated. However, this is not the reality.

NCD undertook this groundbreaking study to advance understanding and promote the rights of parents with disabilities and their children. This report provides a comprehensive review of the barriers and facilitators people with diverse disabilities—including intellectual and developmental disabilities, psychiatric disabilities, sensory disabilities, and physical disabilities—experience when they are exercising their fundamental right to create and maintain families. The report also describes the persistent, systemic, and pervasive discrimination against parents with disabilities. It analyzes how U.S. disability law and policy apply to parents with disabilities within the child welfare and family law systems, and the disparate treatment of parents with disabilities and their children. Examination of the impediments prospective parents with disabilities encounter when adopting or accessing assisted reproductive technologies provides further examples of the need for comprehensive protection of these rights.

This report sets forth suggested action to ensure the rights of parents with disabilities and their children. Whether such action is taken at the state or federal level—as an amendment or a new law—the need for action could not be more timely or clear.

In closing, NCD commends your Administration for its commitment to family values. Parents with disabilities and their children deserve support, not stigma. We look forward to working with you to ensure that the recommendations in this report are implemented.

Sincerely,

Jonathan Young, PhD, JD
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate, the Speaker of the U.S. House of Representatives, and the Director of the Office of Management and Budget.)

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The National Council on Disability (NCD), and particularly Robyn Powell, express appreciation to Through the Looking Glass, the NIDRR-funded National Center for Parents with Disabilities and Their Families—specifically Ella Callow, Megan Kirshbaum, and Paul Preston—for their assistance in writing sections of this report, as well as their insight and guidance throughout the research and drafting of the report. NCD also recognizes Lindsey Coffey, associate at Ropes and Gray, for her assistance and guidance in drafting the chapter on assisted reproductive technologies. NCD thanks the key informants who provided varied perspectives and valuable contributions. Finally, NCD expresses its gratitude to the parents and prospective parents who shared their stories and experiences.

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List of Acronyms

AACWA	Adoption Assistance and Child Welfare Act
AAMC	Association of American Medical Colleges
ABA	American Bar Association
ACF	Administration for Children and Families (HHS)
ACL	Administration for Community Living (HHS)
ADA	Americans with Disabilities Act—1990
ADAAA	ADA Amendments Act—2008
ADLs	activities of daily living
AFCARS	Adoption and Foster Care Analysis and Reporting System
AHRQ	Agency for Healthcare Research and Quality
AI	American Indian
AIDD	Administration on Intellectual and Developmental Disabilities
AN	Alaskan Native
APA	American Psychological Association
ART	assisted reproductive technologies
ASD	autism spectrum disorder
ASFA	Adoption and Safe Families Act—1997
ASRM	American Society for Reproductive Medicine
CAPTA	Child Abuse Prevention and Treatment Act—1974
CASCW	Center for Advanced Studies in Child Welfare
CBPA	competence-based parenting assessment
CDC	Centers for Disease Control and Prevention
CI	Office of Children's Issues (Bureau of Consular Affairs, Department of State)
CIL	Center for Independent Living
CMS	Centers for Medicare and Medicaid Services
CPS	child protective services
CRPD	Convention on the Rights of Persons with Disabilities
DD	developmental disability
DME	durable medical equipment
DOJ	Department of Justice
DOL	Department of Labor
DOT	Department of Transportation
ED	Department of Education
EI	early intervention
EHS	Early Head Start

ETA	Employment and Training Administration (DOL)
FTA	Federal Transit Administration (DOT)
GAO	Government Accountability Office
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HS	Head Start
HUD	Department of Housing and Urban Development
IADLs	instrumental activities of daily living
ICAMA	Interstate Compact on Adoption and Medical Assistance
ICDR	Interagency Committee on Disability Research
ICPC	Interstate Compact on the Placement of Children
ICWA	Indian Child Welfare Act—1978
ID	intellectual disability
IDEA	Individuals with Disabilities Education Act
IUI	intrauterine insemination
IVF	in vitro fertilization
LCME	Liaison Committee on Medical Education
MDT	multidisciplinary team
MEPA	Multiethnic Placement Act—1994
NA	Native American
NCANDS	National Child Abuse and Neglect Data System
NCD	National Council on Disability
NIDRR	National Institute for Disability and Rehabilitation Research
NIH	National Institutes of Health
ODEP	Office of Disability Employment Policy (DOL)
P&A	Protection and Advocacy
PAS	personal assistance services
PATH	Projects for Assistance in Transition from Homelessness
PHA	public housing agency
PRWORA	Personal Responsibility and Work Opportunity Reconciliation Act—1996
RFP	request for proposals
RSA	Rehabilitation Services Administration
SAMHSA	Substance Abuse and Mental Health Services Administration
SART	Society for Reproductive Technologies
SNAP	Supplemental Nutrition Assistance Program
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SSIS	Social Service Information System

TANF	Temporary Assistance for Needy Families
TLG	Through the Looking Glass
TPR	termination of parental rights
UFAS	Uniform Federal Accessibility Standards
USCIS	U.S. Citizenship and Immigration Services
USDA	Department of Agriculture
VA	Department of Veterans Affairs

Executive Summary

The goal of this report is to advance understanding and promote the rights of parents with disabilities and their children. The report provides a comprehensive review of the barriers and facilitators people with diverse disabilities—including intellectual and developmental, psychiatric, sensory, and physical disabilities—experience when exercising their fundamental right to create and maintain families, as well as persistent, systemic, and pervasive discrimination against parents with disabilities. The report analyzes how U.S. disability law and policy apply to parents with disabilities in the child welfare and family law systems, and the disparate treatment of parents with disabilities and their children. Examination of the impediments prospective parents with disabilities encounter when accessing assisted reproductive technologies or adopting provides further examples of the need for comprehensive protection of these rights.

The fundamental right to parent without interference is protected by the U.S. Constitution and balanced by the judicially recognized power of the state to interfere to protect the well-being of its children. Factors used in both dependency court and family court proceedings to determine whether children need to become wards of the state and to determine which parent is the more competent custodian may be reasonable. Nonetheless, these rules have not been objectively or justly applied to parents with disabilities.

The first half of the 20th century was plagued by the eugenics movement, which resulted in more than 30 states passing legislation permitting involuntary sterilization. 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. The Supreme Court endorsed the legislative trend toward forced sterilization; as a result of these state statutes, by 1970 more than 65,000 Americans had been involuntarily sterilized. Even today, 22 years after the passage of the Americans with Disabilities Act, several states still have some form of involuntary sterilization law on their books.

The power of the eugenics ideology persists. Women with disabilities still contend with coercive tactics designed to encourage sterilization or abortion because they are not deemed fit for motherhood. Equally alarming, a growing trend is emerging toward sterilizing people with intellectual or psychiatric disabilities.

Despite this harrowing history, many people with disabilities still choose to become parents. Current research reveals that there are 4.1 million parents with disabilities in the United States, roughly 6.2 percent of all American

parents with children under the age of 18. The rates are even higher for some subgroups of this population. For example, 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 of Latino/Hispanic, and 3.3 percent of Asian/Pacific Islander parents have a disability. Of the parents with disabilities, 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. Because of the paucity of data and research on the prevalence of parents with disabilities, these statistics likely underestimate the number of parents with disabilities significantly.

These parents are the only distinct community of Americans who must struggle to retain custody of their children. Removal rates where parents have a psychiatric disability have been found to be as high as 70 percent to 80 percent; where the parent has an intellectual disability, 40 percent to 80 percent. In families where the parental disability is physical, 13 percent have reported discriminatory treatment in custody cases. Parents who are deaf or blind report extremely high rates of child removal and loss of parental rights. 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.

Clearly, the legal system is not protecting the rights of parents with disabilities and their children. Fully two-thirds of dependency statutes allow the court to reach the determination that a parent is unfit (a determination necessary to terminate parental rights) on the basis of the parent's disability. In every state, disability may be considered in determining the best interest of a child for purposes of a custody determination in family or dependency court. In theory, a nexus should always be shown between the disability and harm to the child, so that a child is taken from a custodial parent only when the parent's disability is creating a detriment that cannot be alleviated. However, this is not the reality.

Discrimination against parents with disabilities is all too common throughout history, and it remains an obstacle to full equality for people with disabilities in the present. Furthermore, this problem is not limited to traditional categories of disability, such as physical or sensory impairments. Discrimination by legal authorities and in child custody proceedings against parents with emerging disabilities is common as well. For example, as improved diagnosis and expanding diagnostic criteria have enhanced identification of children and adults on the autism spectrum, discrimination against parents diagnosed as autistic has emerged as a serious and ongoing systemic problem. As our society recognizes autism and other newly identified disabilities in a greater percentage of the next generation, the percentage of the American public susceptible to discrimination will increase. Parents who belong to these groups will experience the same abuses of their civil rights that parents with psychiatric disabilities currently experience; notably, status-based removals and deprivation of due process protections such as reunification services.

This report recommends actions that should be taken immediately to ensure the rights of parents with disabilities and their children. Whether action is taken at the state or federal level, as an amendment or a new law, the need for action could not be more timely or clear.

Summary of Methodology

This report provides a comprehensive overview of the current state of knowledge, attitudes, and practices toward parents with disabilities and their children. The study was designed to elicit information from a range of stakeholders in the field of parenting rights of people with disabilities. The research methodology for the report included key informant interviews, informal conversations with parents and prospective parents with disabilities, and extensive desk-based document review. The research also included a legal analysis of federal disability laws and their implications for parents and prospective parents with disabilities, as well as a review of key case precedent. The research included a review of federal and state legislation concerning child welfare, family law, and adoption to determine the extent to which people with disabilities are included, to identify problems and gaps as they relate to parents and prospective parents with disabilities, and to identify opportunities for increasing their participation. Moreover, the research included a review of federal agencies, departments, centers, and offices whose missions relate to parents with disabilities and their children, and the extent to which issues related to these populations have been identified and focused upon. Finally, the research examined programs that currently serve parents with disabilities and their children.

Findings and Recommendations

FINDING 1: There are few accurate and comprehensive sources of information on the prevalence of parents with disabilities.

Despite increasing numbers of people with disabilities creating families, there is a paucity of data and research on the prevalence of parents with disabilities, their needs, and their experiences. Reasons for this lack of information include the lack of attention given to the needs and experiences of parents with disabilities and their families, the dearth 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.

Recommendations

- **The Administration should issue an Executive Order establishing an Interagency Committee on Parents with Disabilities.**

  NCD recommends that the Administration issue an Executive Order establishing an Interagency Committee on Parents with Disabilities. Members of this committee should include NCD; the Department Health and Human Services (HHS), specifically the Administration for Community Living (ACL), including the Administration on Intellectual and Developmental Disabilities (AIDD) and the Administration for Children and Families (ACF); Department of Labor (DOL), specifically the Office of Disability Employment Policy (ODEP)

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and Employment and Training Administration (ETA); Department of Justice (DOJ); Substance Abuse and Mental Health Services Administration (SAMHSA); Social Security Administration (SSA); Department of Agriculture (USDA); Department of Transportation (DOT); Centers for Medicare and Medicaid Services (CMS); Department of Housing and Urban Development (HUD); National Institute for Disability and Rehabilitation Research (NIDRR); Department of Education (ED); Department of Veterans Affairs (VA); and Rehabilitation Services Administration (RSA).

- **Congress, the Administration, and federal agencies should gather effective data on parents with disabilities and their families.**

  NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on parents with disabilities and their families. Federal agencies—including but not limited to the Federal Interagency Forum on Child and Family Statistics, HHS, SAMHSA, SSA, USDA, CMS, VA, and HUD—should collect data on the parents with disabilities and the families they serve. The Centers for Disease Control and Prevention (CDC) should conduct a surveillance survey to determine the prevalence of parents with disabilities. Similarly, key systems that serve people with disabilities—such as state disability and veterans agencies, Centers for Independent Living, disability and mental health providers, and paratransit agencies—must collect data on the parental status of their clients/consumers.

- **Congress, the Administration, and federal agencies should fund research on parents with disabilities and their families.**

  NCD recommends that Congress appropriate funding specifically for research on parents with disabilities and their families. Further, NCD recommends that federal agencies such as the Interagency Committee on Disability Research (ICDR), AIDD, the National Institutes of Health (NIH), and SAMHSA emulate and collaborate with NIDRR in dedicating funding to research on parents with disabilities and their families, focusing on their needs and how best to support them. This will necessarily involve demonstration projects and evaluative service models.

FINDING 2: The child welfare system is ill-equipped to support parents with disabilities and their families, resulting in disproportionately high rates of involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights.

Parents with disabilities and their children are overly, and often inappropriately, referred to child welfare services and, once involved, are permanently separated at disproportionately high rates. The children of parents with disabilities are removed at disproportionately high rates owing to a number of factors, including (1) state

statutes that include disability as grounds for termination of parental rights (TPR); (2) the disparate impact of certain provisions of the Adoption and Safe Families Act of 1997 (ASFA); (3) perceived limits on the application of the Americans with Disabilities Act (ADA), especially at the termination phase; (4) bias, speculation, and the "unfit parent" standard; and (5) a lack of training in relevant systems regarding parents with disabilities.

Recommendations

- **States must eliminate disability from their statutes as grounds for termination of parental rights and enact legislation that ensures the rights of parents with disabilities.**

  NCD recommends that states eliminate disability from their dependency statutes as grounds for TPR. Further, NCD recommends that all states enact legislation, in accordance with the language set forth in Appendix C of this report, to ensure the rights of parents with disabilities.

- **Congress should address the disparate treatment experienced by parents with disabilities by adding specific protections for parents with disabilities in the Adoption and Safe Families Act.**

  NCD recommends that Congress amend ASFA by adding specific protections for parents with disabilities. Specifically, language must be added to the (1) "15/22" rule, allowing for additional time for parents with disabilities; and (2) the "reasonable efforts" provision to keep children with their parents, both to prevent or eliminate the need for removal of the child from the family and to make it possible for the child to return to the family following removal by eliminating the bypass provision (which allows states to bypass efforts to reunify families in certain situations) as applied to parents with disabilities and ensuring that child welfare agencies comply with the law and make reasonable efforts to prevent the removal of children and provide reunification services for parents with disabilities and their families.

- **Congress should address the disparate treatment experienced by parents with disabilities resulting from the focus on permanency by shifting funding priorities at the federal level so that states have a greater incentive to provide prevention and preservation services.**

  NCD recommends that Congress shift funding priorities at the federal level so that states have a greater incentive to provide services to families while the children are maintained in the home, as research has shown that in-home services are most effective, particularly for people with disabilities.

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- **DOJ, in collaboration with HHS, should issue guidance to states (specifically child welfare agencies and dependency courts) on their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ, in collaboration with HHS, issue guidance to states (specifically child welfare agencies and dependency courts) reinforcing their legal obligations pursuant to the ADA. Such guidance must address the (1) applicability of the ADA to TPR proceedings; (2) duty of child welfare agencies and dependency courts to provide reasonable accommodations to parents with disabilities; and (3) presumptions of parental incompetence based on disability violate the ADA.

- **HHS and DOJ should gather data on parents with disabilities and their interaction with child welfare and dependency court systems.**

  NCD recommends that HHS and DOJ collect annual data on parents with disabilities and their interaction with child welfare agencies and dependency courts. Such data must include (1) disability, (2) exact involvement, (3) services and reasonable accommodations provided, and (4) outcome.

- **DOJ, in collaboration with HHS, must investigate all reported allegations of child welfare agencies or dependency courts that violate federal disability laws and enforce them as appropriate.**

  NCD recommends that DOJ include such matters in its enforcement priorities; violations of parental rights must be considered violations of civil rights. HHS (which has institutional expertise in the functioning of the child welfare system and courts) and DOJ's Civil Rights Division should collaborate to enrich investigations into alleged violations of the Rehabilitation Act or the ADA by these entities with respect to parents with disabilities and their children. This could be effected through a memorandum of understanding establishing a synergistic partnership (such as the interagency agreement between the DOJ Civil Rights Division and the Department of Transportation) or the creation of a special section integrating expertise from the two departments (such as the Housing and Civil Enforcement Section of the DOJ Civil Rights Division).

- **The HHS Children's Bureau should collaborate with NIDRR in funding and directing NIDRR's National Center for Parents with Disabilities and Their Families.**

  NCD recommends that the HHS Children's Bureau collaborate with NIDRR in funding and directing NIDRR's National Center for Parents with Disabilities and Their Families. NIDRR has funded such centers since 1990, with regular competition for awards every three to five years. The added funding and direction would allow the National Center to develop additional knowledge and provide additional technical assistance to federal, state, and local agencies and tribes to improve outcomes for families with parents with disabilities in the child welfare and family court systems.

FINDING 3: Parents with disabilities who are engaged in custody or visitation disputes in the family law system regularly encounter discriminatory practices.

Parents with disabilities who are seeking or defending custody or visitation rights often encounter a family law system that is riddled with practices that discriminate against them. Such practices include (1) a system that is pervaded with bias; (2) inconsistent state laws, many that overtly discriminate against parents with disabilities, others that fail to protect them from unsupported allegations that they are unfit or create a detrimental impact on their children solely on the basis of presumption or speculation regarding the parental disability; and (3) a lack of expertise or even familiarity regarding parents with disabilities and their children.

Recommendations

- **Family court professionals—including judges, attorneys, and evaluation personnel—should receive training related to parenting with a disability.**

  NCD recommends that all family court professionals—including judges, attorneys, and evaluation personnel— receive training on a regular basis on parents with disabilities and their children. This training should be a mandatory component of continuing education requirements for such professionals.

- **DOJ should issue guidance to family courts on their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ issue guidance to family courts, reinforcing their legal obligations pursuant to the ADA. Such guidance must address (1) the applicability of the ADA to custody and visitation proceedings; (2) the courts' duty to provide reasonable accommodations to parents with disabilities; and (3) presumptions of parental incompetence based on disability violates the ADA.

- **States must modify their custody and visitation statutes to eliminate language that discriminates against parents with disabilities.**

  NCD recommends that states eliminate parental disability as a factor that courts can consider when determining the "best interest of the child" in custody and visitation disputes. Further, NCD recommends that all states enact legislation, in accordance with the language set forth in Appendix C of this report, to ensure the rights of parents with disabilities.

FINDING 4: Parents with disabilities who are involved in dependency or family proceedings regularly face evidence regarding their parental fitness that is developed using inappropriate and unadapted parenting assessments. Resources are lacking to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques.

Parents with disabilities who are involved in dependency or family proceedings regularly face (1) evidence regarding their parental fitness that is developed using inappropriate and unadapted parenting assessments; and (2) a national dearth of resources to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques. Even when such resources exist, dependency and family courts do not often use them.

Recommendations

- **State statutes, rules of court, and professional standards must require that parenting assessments are fully accessible to parents with disabilities.**

  NCD recommends that state statutes, rules of court, and professional standards require evaluators to thoroughly investigate whether they are in compliance with the 2012 American Psychological Association's Guidelines for Assessment of and Intervention With Persons With Disabilities, and whether they need to modify the evaluation process or incorporate parenting adaptations to provide a more valid, reliable assessment of a parent's capacities in the context of child welfare and child custody cases. Such standards must require adapted naturalistic observations—for instance, in the parent's modified home setting rather than in an unfamiliar setting—instead of leaving the venue for observation open to the evaluator's discretion; must require explicit evidentiary support for statements about a parent's capacity; and must prohibit the use of speculation and global diagnostic or disability labels as grounds for limiting custody or visitation. Professional standards must address the problem of using standardized testing to assess parenting capacity in parents with disabilities. Further, evaluators must use tools that have been developed specifically to assess the capabilities and needs of parents with disabilities, particularly intellectual and developmental disabilities, and should include existing and natural supports in the assessment.

- **States must mandate training for custody evaluators on parents with disabilities and their children.**

  NCD recommends that state legislatures mandate training for current custody evaluators to teach them the skills necessary to conduct competent disability-related custody evaluations. Such training must include valid methods that directly evaluate parenting knowledge and skills, and must consider the role of adaptations or environmental factors that can impede or support positive outcomes.

- **CMS must expand the definition of durable medical equipment (DME) to include adaptive parenting equipment.**

  NCD recommends that CMS expand its definition of DME to include adaptive parenting equipment for parents with disabilities who receive Medicaid or Medicare.

- **States should establish adaptive parenting equipment reuse and loan programs.**

  NCD recommends that states establish adaptive parenting equipment reuse and loan programs similar to the programs states now have pursuant to the Assistive Technology Act of 2004.

FINDING 5: Prospective adoptive parents with disabilities face significant barriers to adopting children, both domestically and internationally.

Despite a growing need for adoptive parents, people with disabilities regularly encounter discriminatory practices that eliminate them solely because of their disabilities.

Recommendations

- **DOJ should issue guidance to domestic public and private adoption agencies, as well as private adoption agencies engaging in international adoption on U.S. soil, regarding their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ issue guidance to domestic public and private adoption agencies, as well as private adoption agencies engaging in international adoption on U.S. soil, regarding their legal obligations pursuant to the ADA. Such guidance must address the agencies' duty to provide reasonable accommodations to prospective adoptive parents with disabilities throughout all phases of the process and state that presumptions of parental incompetence based on disability violate the ADA.

- **DOJ must investigate all reported allegations of public and private adoption agencies violating the ADA and enforce the law as appropriate.**

  NCD recommends that DOJ investigate all reported allegations of domestic public and private adoption agencies violating the ADA and enforce the law as appropriate. Discrimination in the adoption process against prospective parents with disabilities must be considered a violation of civil rights.

- **The Department of State should dedicate resources to expanding the rights of people with disabilities to adopt internationally.**

  NCD recommends that the Office of Children's Issues (CI), part of the Bureau of Consular Affairs at the Department of State, and the Department of State's Office of the Special Advisor for International Disability Rights work together to expand the rights of people with disabilities to adopt internationally, particularly from those nations that have ratified the

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Hague Convention. Such work will require educating state and private adoption agencies in other countries on the capacity of people with disabilities to parent, with or without adaptive parenting equipment, techniques, or supportive services.

- **Adoption agency staff must undergo training on how to fully assess prospective parents with disabilities.**

  NCD recommends that adoption agency staff who are responsible for evaluating prospective adoptive parents or conducting home studies to assess fitness for adoptive placement be provided with training regarding parents with disabilities, adaptive equipment, techniques, and supportive services.

FINDING 6: People with disabilities face significant barriers to receiving assisted reproductive technologies (ART), despite its importance for many people with disabilities who want to procreate.

ART can enable many people with disabilities to procreate who would otherwise be unable to do so. However, many people with disabilities face significant, and sometimes insurmountable, barriers to receiving ART. ART providers regularly engage in discriminatory practices against people with disabilities, and the growing costs of ART, combined with the limited insurance coverage for these treatments, leave many people with disabilities unable to afford the treatment.

Recommendations

- **DOJ, in collaboration with HHS, should issue guidance to ART providers on their legal obligations pursuant to the ADA and the Rehabilitation Act.**

  NCD recommends that DOJ, in collaboration with HHS, issue guidance to ART providers regarding their legal obligations pursuant to the ADA and the Rehabilitation Act. Such guidance must address the providers' duty to provide access and reasonable accommodations throughout all phases of the process and must state that presumptions of parenting ability based on disability violate the ADA.

- **DOJ, in collaboration with HHS, must investigate all reported allegations of ART providers violating the ADA and the Rehabilitation Act, and enforce the law as appropriate.**

  NCD recommends that DOJ investigate all reported allegations of ADA and Rehabilitation Act violations by ART providers and enforce them as appropriate.

- **HHS must issue guidance to ART providers on treating patients with disabilities and make training available on parenting capacity.**

  NCD recommends that HHS—collectively the ACL, CDC, NIH, Office for Civil Rights, and the Office of the Surgeon General—issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations. ART office staff responsible for evaluating prospective parents to assess fitness should be provided with training regarding parents with diverse disabilities, adaptive parenting equipment and techniques, and supportive services.

- **ART professional organizations must issue guidance to their members on treating patients with disabilities.**

  NCD recommends that ART professional organizations, such as the Society for Reproductive Technologies (SART) and the American Society for Reproductive Medicine (ASRM), issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations.

- **Medicaid and Medicare must fund ART for people with disabilities.**

  NCD recommends that CMS identify and implement mechanisms to pay for ART for Medicaid and Medicare beneficiaries with disabilities.

FINDING 7: Personal assistance services (PAS) are a crucial support for many people with disabilities but usually may not be used to assist them with their parenting activities.
PAS are a crucial support for more than 13.2 million people with disabilities. They help people with disabilities with activities of daily living (ADLs, such as eating, bathing, dressing, and toileting) and with instrumental activities of daily living (IADLs, such as grocery shopping, cooking, and cleaning). Cost is undoubtedly the most significant barrier for parents with disabilities who need PAS. They face significant challenges because no government program assists them in caring for their nondisabled children. PAS are considered beyond the purview of assistance that may be provided as they do not assist the people with disabilities themselves. Other Western nations provide this service to consumers, successfully funding and implementing the program in a variety of ways. PAS oriented

Recommendation

- **CMS must expand its definition of ADLs to include parenting activities.**

  NCD recommends that CMS expand its definition of ADLs to include parenting activities so that funded PAS can help consumers with their parenting responsibilities.

toward parenting tasks would greatly assist parents with disabilities and their families. The benefits of PAS go beyond improving quality of life—they have also been found to be cost-effective.

FINDING 8: Parents with disabilities face significant barriers to obtaining accessible, affordable, and appropriate housing for their families.

Having a home is crucial to creating and maintaining a family. However, many parents with disabilities face significant barriers in securing accessible, affordable, and appropriate housing.

Recommendations

- **HUD must require that public housing agencies (PHAs) provide at least 50 percent of their accessible units in family housing developments.**

  NCD recommends that HUD require PHAs to provide at least 50 percent of their accessible units in family housing developments. Such units must comply with all relevant federal disability access requirements and must include the same family-oriented space and appointments found in other units.

- **HUD should establish a national modification fund to pay for reasonable modifications to make private units accessible.**

  NCD recommends that HUD develop a national modification fund to pay for reasonable modifications to make private units accessible for parents with disabilities and their families.

- **HUD should develop a program for parents with disabilities who are first-time homeowners.**

  NCD recommends HUD develop a program for parents with disabilities who are first-time homeowners. This program should include counseling and low-interest loans.

FINDING 9: Many parents with disabilities face barriers to traveling with their families using paratransit services.

Transportation affects all areas of the lives of parents with disabilities and their families—from child care to housing to participating in a child's education and meeting a child's medical needs. Nevertheless, it remains one of the most challenging areas for many parents with disabilities and their families. Paratransit services—a support used by many parents with disabilities—have many barriers related to parents traveling with their families.

FINDING 10: Parents with disabilities have significantly less income and more frequently receive public benefits.

The financial status of parents with disabilities and their families is bleak. In fact, the most significant difference between parents with and without disabilities is economic. Parents with disabilities are more likely to receive

Recommendation

- **The Department of Transportation must issue guidance to paratransit providers on their legal obligations to transport parents with disabilities and their families to support the parenting and employment by people with disabilities.**

  NCD recommends that DOT issue guidance to paratransit providers that reflect its findings in Letter of Findings for FTA Complaint #99096 regarding their obligation to facilitate the use of the system by parents with disabilities and their children without additional charges or discriminatory conditions.

public benefits. A recent survey found that 52 percent of parents with disabilities receive Supplemental Security Income (SSI), and a substantial number of parents with disabilities and their families receive Social Security Disability Insurance (SSDI), Supplemental Nutrition Assistance Program (SNAP, commonly known as food stamps), and Temporary Assistance for Needy Families (TANF). Unfortunately, many parents with disabilities find that these programs do not adequately meet their families' needs.

Recommendations

- **SSA must explore ways to serve SSI and SSDI beneficiaries who are parents more effectively.**

  NCD recommends that SSA begin an exploratory project to determine how to serve SSI and SSDI beneficiaries more effectively, focusing on ways to increase financial assistance to parents with disabilities and their families.

- **The HHS Administration for Children and Families (ACF) must provide additional supports to parents with disabilities who receive TANF. Such efforts will require collaboration with the Rehabilitation Services Administration (RSA) and state vocational rehabilitation agencies.**

  NCD recommends that ACF provide additional supports to parents with disabilities who receive TANF. Pursuant to the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), parents who receive TANF must work a specific number of hours (determined by the age of their children). PRWORA also imposes a five-year lifetime limit on assistance. Without appropriate family and work supports to overcome barriers to

(continued)

employment, parents with disabilities, especially single mothers, may be unable to comply with the PRWORA/TANF regulations, resulting in a loss of benefits to families. The programs' work requirements do not consider disabilities as a barrier to work. Low-paying work and lack of job training programs for people with disabilities are common obstacles to employment, and people with disabilities face significant discrimination in the hiring process, further hindering their ability to comply with the work requirements. Finally, some parents with disabilities—such as those with intellectual or developmental disabilities—may need long-term employment support, such as career planning and training. ACF must provide support to parents with disabilities who receive TANF, including job training, child care, and transportation. Such efforts will require collaboration with RSA, DOL, ODEP, ETA, and state vocational rehabilitation agencies.

FINDING 11: People with disabilities, especially women, face significant barriers to receiving proper reproductive health care. Proper health care, especially reproductive health care, is crucial for people who want to create and maintain families. People with disabilities, particularly women, face significant barriers to receiving accessible, affordable, and appropriate health care.

Recommendations

- **The Agency for Healthcare Research and Quality (AHRQ), within its mandate to undertake research on priority populations, should promote research that clearly identifies the barriers encountered by women with disabilities who are seeking reproductive health care.**

  NCD recommends that AHRQ, within its mandate to undertake research on priority populations, promote research that clearly identifies the barriers encountered by women with disabilities who are seeking reproductive health care. Such research would help disability health policy researchers and other stakeholders to paint an accurate picture of, for example, the extent to which reproductive health care technologies, facilities, and equipment remain inaccessible to women with disabilities, and would bolster efforts to effect change.

- **The Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education (LCME) should convene a work group charged with identifying specific disability competencies that should be required of health care professionals**

before they graduate from medical and residency training programs, and should translate these competencies into specific course recommendations that can be adopted by medical training programs.

NCD recommends that AAMC and LCME convene a work group charged with identifying specific disability competencies that should be required of health care professionals before they graduate from medical and residency training programs, and should translate these competencies into specific course recommendations that can be adopted by medical training programs. Competencies should include the core knowledge and skills required to provide appropriate health care to people with diverse disabilities, as well as general awareness of reproductive health care issues and concerns of women with disabilities. Such training should also address parenting with a disability.

- **DOJ, in collaboration with HHS, must increase its monitoring and enforcement of the ADA and Section 504 of the Rehabilitation Act for health care facilities and programs.**

  NCD recommends that DOJ, in collaboration with HHS, increase its monitoring and enforcement of the ADA and Section 504 of the Rehabilitation Act for health care facilities and programs. DOJ must focus additional resources on compliance monitoring and investigation of Title III complaints concerning programmatic access violations of the ADA and Section 504 by health care providers.

- **CMS must identify and implement mechanisms to pay for comprehensive preconception care for Medicaid and Medicare beneficiaries with disabilities.**

  NCD recommends that CMS identify and implement mechanisms to pay for comprehensive preconception care for Medicaid and Medicare beneficiaries with disabilities.

FINDING 12: Parents and prospective parents with disabilities face a significant lack of peer supports.

Peer supports for parents and prospective parents with disabilities are important because of the limited availability of information on parenting with a disability. Parents with disabilities often lack positive parenting role models. Moreover, social isolation is a significant issue for many parents with disabilities, particularly parents with intellectual and developmental disabilities, owing to learning difficulties, transportation challenges, and discrimination by nondisabled parents. Peer support networks can be easily developed or expanded at a minimal cost and would be supportive for many parents.

Recommendation

- **Congress should appropriate funding to establish a national parenting network for parents with disabilities.**

  NCD recommends that Congress appropriate funding to establish a national parenting network for parents with disabilities. A primary national network should include peer staffing, provide peer-to-peer links, gather information, and provide links to other networking efforts, including those in proposed state sites. The network should maintain an accessible Web site and a "warm line" (during business hours) with cross-disability, legal, and crisis intervention expertise. Proposed state sites should include peer staffing and peer-to-peer networking as well as links to the national network. State sites could also maintain an accessible Web site and warm lines during business hours with cross-disability and crisis intervention expertise and links to resources in their regions. Additionally, peer support groups could be located in independent living centers and in programs that specialize in parents with disabilities or deafness. These local parent support groups could provide the ongoing peer connections that are important to alleviate isolation in communities. Collaboration among the national, state, and local services—including training and dissemination of information—should be a priority.

FINDING 13: Social service providers regularly overlook the parenting role of their consumers.

Disability, mental health, child welfare, housing, transportation, and other service providers play a significant role in the lives of many people with disabilities. The services these agencies provide typically overlook the parenting needs of the consumer or client. In fact, research demonstrates that the majority of providers have no idea which of their clients are parents.

Recommendations

- **Service providers must gather data on the parenting status of the people they serve.**

  NCD recommends that service providers under the authority of the Department of Education, Equal Employment Opportunity Commission, HHS, HUD, Department of the Interior, DOJ, and DOT gather and report annual data on the parenting status of the people with disabilities they serve through state and federally administered programs that include this population.

- **States must develop and implement mechanisms that support integrated, family-centered, strengths-based care for parents with disabilities and their children.**

  NCD recommends that states develop and implement mechanisms to support integrated, family-centered, strengths-based care for parents with disabilities and their children. Agencies and service providers that work with parents and their families need to communicate and coordinate with each other. Coordination across agencies should facilitate the provision of more appropriate services in a more cost-effective fashion. Further, funding for adult and child services must be family-centered and not siloed. This will require a reorganization of the administration and funding of disability services to support the system's capacity to respond to family needs whether the "identified client" is the adult or the child, and encourage a "family wraparound approach." States will have to modify interagency agreements and vendor contracts to permit the inclusion of language and expectations for integrated, family-centered, strengths-based care for parents with disabilities and their children.

FINDING 14: Formal Individuals with Disabilities Education Act (IDEA) Part C Early Intervention (EI) programs and other non-Part C early intervention and prevention model programs are an appropriate service option for many children of parents with disabilities.

Early intervention and prevention model programs have the potential to fully accommodate parents with disabilities; thus, efforts must be made to ensure that parents with disabilities and their families are considered for services.

Recommendation

- **The Department of Education and HHS must identify and implement mechanisms for Part C Early Intervention programs, other early intervention and prevention model programs, and Early Head Start to serve the needs of parents with disabilities and their families.**

  NCD recommends that the Department of Education and HHS identify and implement mechanisms for early intervention and prevention programs, including Early Head Start and Head Start, to serve the needs of parents with disabilities and their families. Further, early intervention and prevention model program service providers require education about the needs of parents with disabilities and their families, including how to remediate barriers to full participation in services.

FINDING 15: Parents with disabilities involved in dependency or family law proceedings face significant barriers to retaining effective and affordable legal representation.
Parents with disabilities face significant barriers to retaining effective and affordable legal representation for dependency and family law proceedings. Many attorneys lack the skills and experience to meet the needs of parents with disabilities. Parents with disabilities are often represented by court-appointed legal representatives who typically have excessive caseloads and little if any training in disability. Research demonstrates that attorneys who represent parents with disabilities in these matters often fail to represent the parents' best interests; they may harbor stereotypes about parents with disabilities that can reinforce their impression that such cases are unwinnable, and many fail to understand the implications of the ADA in these cases.

Recommendation

- **Protection and Advocacy (P&A) agencies must establish parenting rights as a formal priority, and funding must be appropriated accordingly.**

  NCD recommends that P&A agencies establish protection of custody and parenting rights as a formal national priority. To that end, Congress should establish and authorize additional funding for P&A systems nationally to meet the legal needs of parents with disabilities and their children in child welfare and child custody cases.

FINDING 16: Centers for Independent Living (CILs), with appropriate training, can provide services to parents with disabilities.
Given the breadth and importance of CILs and the supports they provide, with training they have the potential to support parents with disabilities, especially to advocate regarding transportation, housing, financial advocacy, and assistive technology issues, and to offer parent support groups.

Recommendation

- **CILs must make serving the needs of parents with disabilities a national priority and funding must be appropriated accordingly.**

  NCD recommends that CILs make serving the needs of parents with disabilities a national priority. To that end, Congress and RSA must appropriate additional funding to support this unmet need.

FINDING 17: Despite limited funding and little national attention given to parents with disabilities and their families, a number of programs and support services have begun to emerge across the nation; they must be replicated nationally to provide consistent capacity to support parents with disabilities and their children. Programs that serve the needs of parents with disabilities remain scarce. Nevertheless, despite limited funding and little national attention given to parents with disabilities and their families, a number of programs and support services have begun to emerge across the nation. Several programs show promise, long-term sustainable impact, and the potential for replication. Generally, they are small, local programs that are part of larger disability services organizations. The programs, for the most part, are specific disability focused, meaning they provide services to parents with a certain disability (e.g., intellectual disabilities or psychiatric disabilities) but not cross-disability. Despite their small size and limited focus, these programs show enormous potential for serving parents with disabilities. With greater funding, programs similar to those discussed in this report can grow and develop nationwide, and adequately serve a currently underserved segment of the United States: parents with disabilities and their families. Additional funding will enable these programs to create systems that can consistently support families proactively rather than approaching intervention through child removal and other punitive measures.

Recommendations

- **Congress, the Administration, and federal agencies should fund the development of state multidisciplinary teams (MDTs) to support parents with disabilities and their children.**

  NCD recommends that multidisciplinary programs be established in each state. Moreover, funding must be available for MDTs to train and facilitate collaboration among relevant professional communities, systems, and organizations to increase regional capacity to serve parents with disabilities and their families. Further investigation is needed into how to use a more sustained and robust version of the 360 Project funding and development model, as well as requests for proposals, to achieve this goal preliminarily in 10 to 12 states while working toward a national system akin to the Healthy Start system in Australia. Ultimately, these projects should reflect the best of the promising practices highlighted here, with multidisciplinary, cross-disability, and infant mental health features to maximize the well-being of children with parents who have disabilities.

- **Congress, the Administration, and federal agencies should fund research to analyze existing policies, guidelines, performance standards, and data collection practices of national organizations serving parents with disabilities and their families.**

NCD recommends that Congress, the Administration, and federal agencies fund research specifically to analyze the existing policies, guidelines, performance standards, and data collection practices of national organizations serving parents with disabilities and their families.

FINDING 18: The impact of disability on the integrity of American Indian/Alaskan Native (AI/AN) families has been utterly neglected by professionals in the fields of law, policy, and research.

This issue has been neglected despite these communities having twice the disability rate of the general population and a tragic history of government-sponsored removal of their children so severe that it prompted the creation of the Indian Child Welfare Act (ICWA).

Recommendations

- **The Health and Human Services Administration for Native Americans, ACF Native Affairs Work Group, and Intra-Departmental Council on Native American Affairs member agencies should create a task force to investigate and secure funding for research concerning the impact of disability on familial integrity in Indian Country.**

  NCD recommends that these interrelated entities create a task force to investigate the impact of parental and extended family caregiver disability and its associated legal and social implications for preserving AI/AN families; identify the barriers to conducting research with this population; and procure funding for such research. In many child welfare cases involving Indian children, the parents have disabilities; the inability or unwillingness of child welfare systems to meaningfully accommodate these families represents an end-run around ICWA, defeating the spirit and power of the legislation at a time of great peril for AI/AN communities.

- **Pursuant to §805 of the Native Americans Program Act of 1975, this same task force should procure funding for pilot projects to develop supports for AI/AN parents and extended family caregivers with disabilities and thereby support family integrity in Indian Country.**

  NCD recommends that these interrelated entities create a research task force to investigate how best to develop the capacity to deliver the supports AI/AN parents and extended family caregivers require to care for their children and prevent entry

into the child welfare system. These supports should be delivered through existing tribal and urban Indian community programs or by developing new programs. The community supports that can prevent entry into the child welfare system or can support positive outcomes in these cases are not often present in reservation or urban Indian communities. Funding should be procured for a cross-disability, multidisciplinary model program similar to the AFC 360 initiative process to allow reservation and urban Indian communities to maximize their cultural and social relevance and take advantage of their deep understanding of the functioning of their own government and social service delivery systems.

- **Grants and funding should be made available under the Indian Tribal Justice Technical and Legal Assistance Act of 2000 to support technical assistance and training for tribal courts that focuses on parents with disabilities and child welfare and custody cases.**

  NCD recommends that the Bureau of Justice Assistance, as part of DOJ's Indian Country Law Enforcement Initiative, create and administer grants to support the development and implementation of tribal legal services training and technical assistance to the court programs to enhance understanding in of the capacity of parent and extended family caregivers with disabilities to care for minor children and the interplay of ADA and ICWA cases in state court proceedings involving their tribal citizens. This is important not only to support nonbiased outcomes in tribal courts, but to ensure that, where possible, they accept jurisdiction in cases where discrimination is occurring in state courts or have sufficient facility with this issue to withhold endorsement of "active efforts" by state child welfare entities where accommodation has not been provided. Existing disability and Native American child welfare organizations (including tribally administered organizations) should be encouraged to collaborate in submitting requests for proposals (RFPs) and developing projects to be funded. Native American disability organizations can provide technical information and knowledge regarding parents with disabilities and how to support them in their own communities; outreach for RFPs should be directed to them. Long-standing organizations such as the Native American Independent Living Services (which serves AI/AN people in New Mexico) and the Native American Disability Law Center (which works with the tribal communities in the Southwest) represent different types of Native American disability programs and are well positioned to assist both reservation and urban Indian communities.

FINDING 19: Federal legislation, similar to the Indian Child Welfare Act, must be enacted to address the systemically disparate treatment faced by parents with disabilities throughout the country.

To fully protect the rights of parents with disabilities, federal legislation akin to the ICWA must be enacted. While the ICWA is not aimed at the disability community, the impetus for the ICWA arose from circumstances similar to those surrounding families with parents who have disabilities. Both Native Americans and people with disabilities are historically oppressed minorities who have been denied civil and human rights in this country. Both groups were systemically isolated from other sectors of society until midway through the last century. Both groups suffer extreme levels of poverty, and little is understood about their cultures, leading to stereotyping and discrimination. Most important, both groups have been subjected to involuntary sterilization programs and massive removals of their children. Lack of knowledge about the culture of Native American people and how they parent is very similar to lack of knowledge about the culture, adaptive equipment, supportive services, and strengths of the disability community and how people with disabilities parent. Because of this and the other similarities between the causes of custody loss in the two communities—such as poverty, illiteracy, bias, and discrimination—portions of the ICWA that provide remedy for the Native American community should be borrowed to strengthen new legislation to protect the children of parents with disabilities.

Recommendation

- **Congress should address the disparate treatment experienced by parents with disabilities through legislation similar to the ICWA that will protect the rights of parents with disabilities and their families.**

  NCD recommends that Congress enact legislation similar to the ICWA, in accordance with the language set forth in Appendix C of this report, to protect the rights of parents with disabilities. Alternatively, legislative amendment of the ADA and other relevant federal acts governing child welfare, child custody, adoption, and assisted reproductive technologies will be necessary to advance the intention of the ADA at the national level.

FINDING 20: The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the rights of people with disabilities to create and maintain families.

The CRPD protects the rights of people with disabilities to create and maintain families in several Articles, particularly Articles 23 and 25. Additionally, the CRPD reinforces the reproductive rights of women with disabilities.

Recommendation

- **The United States should ratify the CRPD.**

  NCD recommends that the Senate consider and expeditiously provide its advice and consent to ratification of the CRPD. U.S. ratification of the CRPD would reinforce American leadership in disability rights and support American efforts to promote the rights of parents with disabilities around the world.

> Current research reveals that there are 4.1 million parents with disabilities in the United States... These parents are the only distinct community of Americans who must struggle to retain custody of their children.

Chapter 1. Introduction

"Parenting knows no barrier…all it takes is love."[1]

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.[2] 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.[3] 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.[4] Because of these state statutes, more than 65,000 Americans were involuntarily sterilized by 1970.[5]

Forced sterilization gained the blessing of the U.S. Supreme Court in the 1927 *Buck v. Bell* decision.[6] Carrie Buck was an institutionalized woman in Virginia who was deemed "feebleminded."[7] 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.[8] 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."[9] Concluding this historical decision, Justice Oliver Wendell Holmes, Jr., declared, "Three generations of imbeciles are enough."[10]

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.[11] *Bell* was cited by a federal appeals court as recently as 2001, in *Vaughn v. Ruoff*.[12] 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

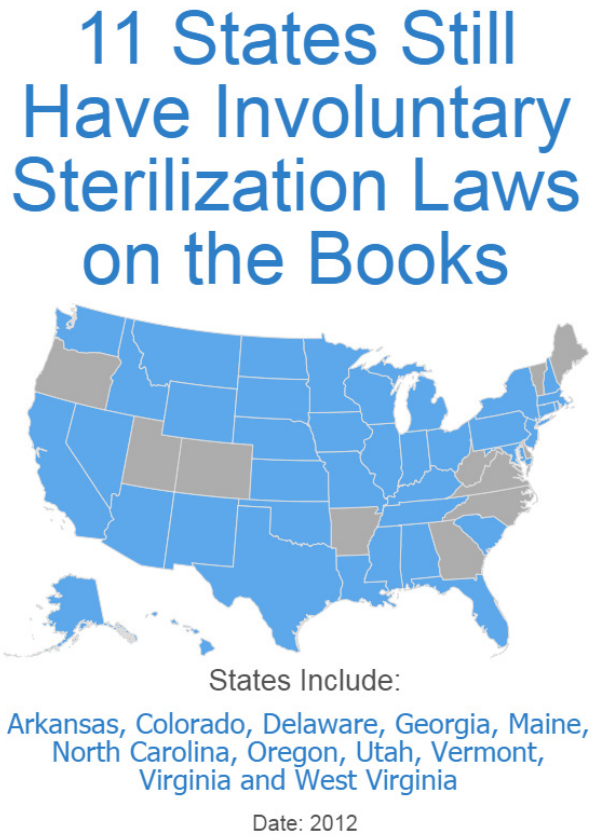
would recommend termination of parental rights. The district court found that the plaintiff had a protected liberty interest in the 14th Amendment and that the social worker's conduct violated her due process rights. The judgment was affirmed by the U.S. Court of Appeals for the Eighth Circuit. However, 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."[13]

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.[14]

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.[15]

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.[16] 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.[17] Ten years later, this number had increased to 33.[18] 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.[19] Similarly, there is a pervasive myth that people with disabilities are either sexually unwilling or unable.[20] 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."[21] 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."[22]

Indeed, despite the increasing numbers of people with disabilities becoming parents, most still struggle with family, community, and social ambivalence about this choice.[23] 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."[24] Lindsay,[25] 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."[26]

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.

—Carrie Killoran

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?'"[27] When Jessica,[28] a woman with cerebral palsy, told her mother that she was pregnant with twins, her mother responded, "Now your husband has three babies." Cassandra,[29] 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."[30] 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."[31]

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."[32]

Kathryn,[33] 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."[34] 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.[35] National estimates of the number of parents with disabilities are usually based on projections from much fewer data or estimated by complex extrapolations.[36] 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.[37] O'Toole notes, "Sometimes it is the lack of questioning that is the genesis of the research gap."[38] 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."[39]

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.[40] 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.[41] 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.[42]

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.[43] 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."[44]

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).[45] Likewise, there has been a dramatic increase in the number of veterans who are returning from war with service-connected disabilities,[46] 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*,[47] 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."[48] 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."[49] 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.[50] According to the decision, the interest of a parent in his or her children "undeniably warrants deference and, absent a powerful countervailing interest, protection."[51] The Court reiterated the due process protection for parents' rights five years later.[52]

> *"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.'"*
>
> *—U.S. Supreme Court, Prince v. Massachusetts (1978)*

In 1978, the Court, quoting its opinion in *Prince v. Massachusetts*,[53] 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.'"[54]

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.[55] "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."[56] The Court also has noted that when access to justice is at issue, equal protection and due process concerns converge and are implicated.[57] 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.[58]

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."[59] 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,[60] Justice O'Connor's plurality opinion in *Troxel* does not apply strict scrutiny.[61] In his concurrence, Justice Thomas stated that the Court must apply strict scrutiny to any infringement of the constitutional rights of parents.[62] 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.[63] 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,[64] 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."[65]

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.*,[66] "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."[67]

Under the legal doctrine of *parens patriae*, the state has a fundamental interest in protecting the interests of children.[68] Accordingly, states claim the authority to protect the best interests of children by limiting or, under extreme circumstances, severing the parents' rights.[69] 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."[70]

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*,[71] 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."[72] Conversely, the Court noted that "the State has an urgent interest in the welfare of the child."[73] 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.[74]

One year later, in 1982, in *Santosky v. Kramer*,[75] 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."[76] 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.[77] 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."[78]

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."[79]

Shortly thereafter, in 1978, the ICWA was passed[80] in response to concerns that Native American children were being separated from their tribes and placed in foster care at disproportionately high rates.[81]

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.[82] 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.[83] The primary objective of AACWA was to respond to the needs of children in foster care and to promote permanency through reunification or adoption.[84] 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."[85] While programs worked to preserve or reunite many

families, AACWA failed relative to permanency planning.[86] AACWA did not provide a specific definition of "reasonable efforts," nor did HHS promulgate formal regulations and guidance.[87] 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.[88] 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]."[89] 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."[90]

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.[91] 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.[92] 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.[93] 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.[94]

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.[95] 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.[96] 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.[97]

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.[98] The legal standard

courts use to determine custody is the best interest of the child.[99] 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.[100] 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.[101] That is, adoptive parents play the same role as biological parents in the life of their child.[102] 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.[103]

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."[104] "Where the couple lives and whether they have other children are also factors that agencies may consider when deciding among prospective adoptive families."[105] 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.[106] Massachusetts passed the first adoption statute in the United States.[107] 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.[108] 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.[109]

Regulated by federal legislation, domestic adoptions often take place across state lines.[110] 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).[111] 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.[112] 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.[113] In some cases, children adopted through intercountry adoption come from orphanages or institutional settings.[114] 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.[115] The Hague Convention is "designed to protect the best interests of children and prevent the abduction, sale, and trafficking of children."[116] 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.[117] The United States is one of 85 nations that are parties to the Hague Convention.[118] 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.[119]

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.

Chapter 2. Research Methodology

In the development of a comprehensive overview of the current state of knowledge, attitudes, and practices toward parents with disabilities and their children, NCD undertook a variety of activities to collect and evaluate information for the report.

An extensive desk-based document review was undertaken to examine scholarly literature, journal articles, studies, commentaries, conference proceedings, popular newspapers and magazines, Web sites and blogs, and other materials related to parents with disabilities and their families. NCD consulted primary sources—including electronic databases, federal agency resources, and a variety of academic journals—and spoke with key informants who identified specific reports and related documents.

Semistructured key informant telephone or in-person interviews were conducted with 22 subject matter experts concerned with parents with disabilities and their children. Informants included social science researchers, advocates, and service providers. All the persons identified and interviewed had expertise in this field.

In addition to the key informant interviews, informal interviews were conducted with 13 people with disabilities, 12 who are parents and 1 who is trying to create a family through assisted reproductive technologies. These interviews were completed via telephone, email, or instant messaging, depending on the needs and preferences of the interviewees. Pseudonyms are used throughout the report to ensure anonymity. Vignettes were provided by TLG. Collectively, these stories exemplify the experiences of parents with diverse disabilities and their children.

NCD summarized the applicability, effectiveness, and impact of the Americans with Disabilities Act and the Rehabilitation Act on parents with disabilities and their children, and conducted a review of key cases under each law and their impact.

NCD reviewed the federal and state legislation concerning child welfare, family law, and adoption to determine the extent to which people with disabilities are included, to identify problems and gaps as they relate parents and prospective parents with disabilities, and to identify opportunities for increasing their participation.

NCD identified key federal agencies, departments, centers, and offices whose missions relate to parents with disabilities and their children. NCD then determined the extent to which issues related to these populations—including accessibility, enforcement of disability laws, and supports for parents with disabilities—had been identified and addressed.

Finally, NCD identified examples of effective models that serve and support parents with

disabilities and their children. Programs are included that meet three general criteria: (1) they respond to specific needs that have been defined either by parents with disabilities or by others who are very familiar with the needs of parents with disabilities; (2) they are well established in terms of factors including longevity, funding, and institutional commitment; and (3) they have conducted customer satisfaction or other evaluations that were available for review to determine their effectiveness and to make improvements.

Chapter 3. Disability Law Framework

This chapter examines federal disability rights laws and provides an overview of their applicability to the parenting rights of Americans with disabilities. Specifically, the chapter examines the protections afforded by the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 and their application to the efforts of people with disabilities to create and maintain families.

Federal Disability Rights Laws: An Overview

The landmark ADA and its predecessor, the Rehabilitation Act of 1973, established comprehensive national mandates prohibiting discrimination on the basis of disability. Collectively, these two laws prohibit public and private entities from discriminating against people with disabilities and ensure equal opportunity to participate in and benefit from a wide range of services and programs.

Under federal law, a person is defined as having a disability if he or she (a) has a physical or mental impairment that substantially limits one or more major life activities; (b) has a record of such impairment; or (c) is regarded as having such impairment.[120] Pursuant to the 2008 ADA amendments, major life activities include but are not limited to seeing, walking, and learning, as well as the operation of major bodily functions, such as the reproductive system.[121] The amendments clarify that the ADA covers people with episodic conditions, such as epilepsy. Today, a person is protected under the ADA if he or she has a disability that substantially limits a life activity when the condition is in an active state, even if the condition is not evident or does not limit a life activity at all times.[122] Furthermore, public entities and places of public accommodation may not discriminate against an "individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association."[123]

Rehabilitation Act of 1973

The first federal civil rights law protecting people with disabilities was the Rehabilitation Act of 1973.[124] The intent of the Rehabilitation Act is to "Empower individuals with disabilities to maximize employment, economic self-sufficiency, independence and inclusion and integration into society through…the guarantee of equal opportunity."[125]

The most well-known provision of the Rehabilitation Act is Section 504, which states,

> "No otherwise qualified individual with a disability . . . Shall, *solely by reason of her or his disability*, be excluded from the participation in, be denied the benefits of, or be

> subjected to discrimination under any program or activity receiving Federal financial assistance…."[126]

Section 504 prohibits discrimination against people with disabilities by programs conducted by federal agencies as well as any program or activity that receives federal financial assistance.[127] Section 504 applies to nearly all public schools, public and private colleges, human services programs (including the child welfare system and adoption agencies), and public housing agencies. Notably, Section 504 applies to all health care entities and providers that receive federal monies, including through Medicaid, Medicare, or federal block grants.

The Rehabilitation Act includes other significant provisions as well. Section 501 requires affirmative action and nondiscrimination in employment by federal agencies.[128]

Section 503 requires affirmative action and prohibits employment discrimination by federal government contractors and subcontractors with contracts of more than $10,000.[129] Section 508 requires that all electronic and information technology developed, maintained, procured, or used by the Federal Government must be accessible to people with disabilities, including employees.[130]

Americans with Disabilities Act

On July 26, 1990, President George W. Bush signed into law the Americans with Disabilities Act, which extended the protections and prohibitions of the Rehabilitation Act to private conduct, with the goal of reducing the social discrimination and stigma experienced by people with disabilities.[131] In passing the ADA, Congress recognized that "historically, society tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."[132] In furtherance of the objective of eliminating discrimination, Congress stated that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals."[133] In light of the ADA's intended "clear and comprehensive national mandate for the elimination of discrimination,"[134] the ADA ensures the rights of people with disabilities to create and maintain families in a variety of ways. Indeed, before the passage of the ADA, Congress gathered an unprecedented amount of testimony concerning discrimination against people with disabilities, including stories of people with disabilities who had lost custody of their children[135] and people with disabilities who were denied the opportunity to adopt children.[136]

The ADA is divided into five titles that cover the various protections afforded by the law:

- Title I covers employment.[137]
- Title II Part A covers public entities: state and local government.[138]
- Title II Part B covers public transportation provided by public entities.[139]
- Title III covers private entities: public accommodations, commercial facilities, examinations and courses related to licensing or certification, and transportation provided to the public by private entities.[140]
- Title IV covers telecommunications.[141]
- Title V contains miscellaneous provisions.[142]

Titles II and III are most relevant here because they govern access to public entities run by state and local governments, and places of public accommodation, respectively.

Title II of the Americans with Disabilities Act

Title II of the ADA prohibits discrimination by public entities run or funded by state and local governments.[143] It mandates, "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[144] The ADA defines public entity to include "any department, agency, special purpose district, or other instrumentality of a State or States or local government."[145] Examples of covered programs and entities include state courts, state legislatures, town meetings, police and fire departments, and state and local offices and programs. Entities that receive federal financial assistance from DOJ, including state judicial systems, are also prohibited from discriminating on the basis of disability under Section 504 of the Rehabilitation Act.[146] Further, the Supreme Court has held that providing people with disabilities access to courts is a mandate of Title II. According to the Court, "Unequal treatment of disabled persons in the administration of judicial services has a long history," which the ADA seeks to redress.[147] Title II (and Section 504) are thus crucial, because they mandate access for people with disabilities to the child welfare system, family law courts, and public adoption agencies.

Title II requires the following of public entities:

- Public entities must provide people with disabilities an equal opportunity to participate in programs, services or activities.[148] To implement this mandate, public entities must make reasonable modifications in policies, practices, or procedures unless such modifications would fundamentally alter the nature of the service, program or activity.[149]
- Public entities shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities;[150]
- Public entities shall not impose or apply eligibility criteria that screen out or tend to screen out any individual with a disability from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered;[151]
- Public entities must furnish auxiliary aids and services when necessary to ensure effective communication, unless an undue burden or fundamental alteration would result;[152]
- Public entities may provide benefits, services, or advantages, beyond those required by the regulation, to people with disabilities;[153]
- Public entities may not place surcharges on individuals with disabilities to cover the costs of measures to ensure nondiscriminatory treatment, such as making necessary modifications required to provide program accessibility or providing qualified interpreters;[154]

Patrick Cokley reads an ABC book to Jackson Cokley (age 3), while Rebecca Cokley, NCD Executive Director, looks on.

- Public entities may not deny the benefits of programs, activities, and services to individuals with disabilities because entities' facilities are inaccessible.[155] A public entity's services, programs or activities, when viewed in their entirety, must be readily accessible to, and usable by, people with disabilities.[156]

Title II also requires newly constructed or altered facilities to comply with the ADA's 2010 Standards for Accessible Design (2010 Standards), if the start date for construction is on or after March 15, 2012.[157] If elements in existing facilities already comply with corresponding elements in the 1991 Standards or the Uniform Federal Accessibility Standards (UFAS) and are not being altered, Title II entities are not required to make changes to those elements to bring them into compliance with the 2010 Standards.[158] Under the "program accessibility" standard, public entities are not necessarily required to make each of their existing facilities accessible if other methods are effective in achieving compliance with the regulations.[159] Instead, a public entity's services, programs, or activities, when viewed in their entirety, must be readily accessible to, and usable by, people with disabilities.[160]

Examples of alternative methods to ensure accessibility include relocating a service to an accessible floor or facility, or providing the service at home. There are limits to the program accessibility requirement; public entities are not required to take any action that they can demonstrate would result in an "undue financial

and administrative burden" or that would "fundamentally alter" the nature of the program, activity, or service.[161] However, they must take other necessary action to ensure that people with disabilities receive the benefits or services provided by the public entity.[162] Moreover, public entities may impose legitimate safety requirements necessary for the safe operation of services, programs, or activities.[163] However, the public entity must ensure that its safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about people with disabilities.[164] Similarly, public entities are not required to permit a person to participate in or benefit from its services, programs, or activities if that person poses a direct threat to the health or safety of others.[165] In determining whether a person poses a direct threat, a public entity must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk.[166]

Title III of the Americans with Disabilities Act

Title III of the ADA prohibits any public accommodation from discriminating against people with disabilities by denying them access to the full and equal enjoyment of goods, services, or facilities. Public accommodations include all areas open to the public, including restaurants, stores, banks, pharmacies, legal offices, doctors' offices, and hospitals. Pursuant to Title III, "private entities are considered public accommodations if the operations of such entities affect commerce and fall within one of the 12 categories set out in the statute."[167] Title III is relevant here because it unquestionably governs access to private adoptions, as it precisely includes "adoption agency" in the definition of public accommodations.[168] Similarly, assisted reproductive technology providers must comply with Title III because they provide services in a health care provider's office or hospital, which are included in the definition of public accommodations.

The purpose of Title III is to ensure that no person with a disability is denied goods or services offered to the public because of their disability. Under Title III,

- A public accommodation shall not impose or apply eligibility criteria that screen out or tend to screen out an individual with a disability from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of such goods, services, etc.[169]
- A public accommodation shall make reasonable modifications in policies, practices, or procedures when such modifications are necessary to ensure that people with disabilities have access to the goods, services, facilities, privileges, advantages, or accommodations, unless the public accommodation can demonstrate that making the modifications would fundamentally alter the nature of such goods, services, etc.[170]
- A public accommodation shall take those steps that may be necessary to ensure that

> no individual with a disability is excluded, denied services, segregated or otherwise treated differently because of the absence of auxiliary aids and services, unless the public accommodation can demonstrate that taking those steps would result in a fundamental alteration or undue burden.[171]

Public accommodations must also provide physical access for people with disabilities.[172] Generally, new construction and alterations must comply with the 2010 Standards if the start date for construction is on or after March 15, 2012. A public accommodation must remove architectural barriers where such removal is readily achievable; that is, easily accomplished without much difficulty or expense.[173] On or after March 15, 2012, elements in a facility that do not comply with the 1991 Standards requirements for those elements (e.g., where an existing restaurant has never undertaken readily achievable barrier removal) must be modified using the 2010 Standards to the extent readily achievable. The standards include revisions to the 1991 Standards as well as supplemental requirements for which there are no technical or scoping requirements in the 1991 Standards (such as swimming pools, play areas, marinas, and golf facilities). Public accommodations must comply with the 2010 Standards' supplemental requirements in existing facilities to the extent readily achievable.

Public accommodations may deny a person the opportunity to participate in or benefit from the goods, services, facilities, privileges, advantages, and accommodations if the person poses a direct threat to the health or safety of others.[174] In determining whether a person poses a direct threat, a public accommodation must make an individualized assessment based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence to ascertain the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk.[175] Moreover, public accommodations may impose legitimate safety requirements that are necessary for safe operation.[176] Safety requirements must be based on actual risks and not on mere speculation, stereotypes, or generalizations about people with disabilities.[177]

Ensuring Accessibility for the Whole Family

Despite the laudable requirements of the Rehabilitation Act and the ADA, parents with disabilities and their families continue to experience significant accessibility barriers. These barriers not only impede the abilities of these parents to fulfill their parenting responsibilities but also affect the entire family.

For example, parents with disabilities regularly experience accessibility barriers at their childrens' schools and daycare centers. In October 2006, TLG convened 55 representatives from the Bay Area to initiate the Bay Area Parents with Disabilities and Deaf Parents Task Force.[178] According to TLG:

> "Bay Area Task Force participants reiterated a frequent complaint of parents with disabilities nationally: they are excluded from active participation in their children's school life. Typically, because the majority of children of disabled parents are not disabled, center and/or school administrators and teachers are unaware of or insensitive to the needs of parents with

diverse disabilities. This can be [owing] to a number of factors: the physical inaccessibility of the center and/or school (e.g., inaccessible sites for a parent-teacher meeting or other school activities that other parents attend); inaccessible communication modes (e.g., no interpreters for deaf parents or inaccessible media for parents who are blind); assumptions about parents helping their children with homework if the materials are not in accessible formats. Further, because of a lack of education or familiarity with diverse disabilities, center and/or school officials may make inaccurate or negative assumptions about the capabilities of parents with disabilities."[179]

The task force cited the following specific accessibility problems parents with disabilities encounter:

- Parents with disabilities do not know what their rights are with regard to their children's centers and schools.
- Centers or school systems do not know what their legal obligations are with regard to parents with disabilities.
- Center or school administrators and teachers often do not know if any of their children's parents have disabilities or are deaf.
- Communication from center or school personnel—in person, by phone, or by written communication— may be inaccessible or inappropriate (e.g., no interpreters, inaccessible formats for written materials, linguistically difficult information for parents with intellectual disabilities).
- Information from the centers or schools is often not sent in a timely manner (e.g., a parent may need several days' notice to arrange transportation or get materials in braille).
- Even centers or schools that have classrooms/programs for children with disabilities may not consider the perspectives or needs of adults with disabilities or the fact that they can be parents.
- If there are multiple children in the family or if the child changes centers or schools, navigating different schools or different school districts can be challenging.
- Although most centers or schools include curricula on diverse ethnicities and languages, few address disabilities unless the focus is on children with disabilities.
- Deaf parents particularly noted that teachers inappropriately use their hearing children to interpret conversations between teachers and parents. Other parents with disabilities described center or school personnel who are visibly uncomfortable, paternalistic, or insensitive when talking with them.[180]

The parents with disabilities with whom NCD spoke reported encountering similar barriers. Christina,[181] a woman with significant physical and sensory (vision and hearing) disabilities and the single mother of three children, often encounters difficulties trying to get her children's schools to provide her with interpreters and materials in accessible formats. Christina also is frustrated that she cannot watch school football games with other parents because the stands are not wheelchair accessible. Danielle,[182] a deaf mother, describes her experiences with her children's schools as "hell," explaining that

Significant Accessibility Barriers Persist Despite Legal Requirements

Despite the requirements of the Rehabilitation Act and the ADA, parents with disabilities and their families continue to experience significant accessibility barriers:

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- Centers or school systems don't know what their legal obligations are with regard to parents with disabilities.
- Administrators and teachers of schools and centers often don't know if any of their children's parents have disabilities or are deaf.
- Communication from center or school personnel may be inaccessible or inappropriate (e.g., no interpreters, inaccessible formats for written materials, linguistically difficult information for parents with intellectual disabilities).
- Information from the centers or schools is often not sent in a timely manner (e.g., a parent may need several days' notice to arrange transportation or receive materials in braille).
- Even centers or schools that have classrooms/programs for children with disabilities may not consider the perspectives or needs of adults with disabilities or the fact that they can be parents.
- If there are multiple children in the family or if the child changes centers or schools, navigating different schools or different school districts can be challenging.
- Although most centers or schools include curricula on diverse ethnicities and languages, few address disabilities unless the center's or school's focus is on children with disabilities.
- Deaf parents particularly noted that teachers inappropriately use their hearing children to interpret conversations between teachers and parents.
- Other parents with disabilities described center or school personnel who are visibly uncomfortable, paternalistic, or insensitive when talking with them.

the school, especially the after-school program, refuses to provide interpreters even though she has sent several letters and threatened a lawsuit.

Kathryn,[183] a wheelchair user and mother of one child, experienced significant difficulties finding an accessible home daycare center. After contacting more than 10 providers, she eventually found one that was willing to provide her an accommodation: The house is not wheelchair-accessible, but the provider meets Kathryn at her car and takes her daughter in.

Jessica,[184] a wheelchair user and mother of twins, told NCD that in addition to the accessibility barriers at her children's school,

which she describes as "awful," the lack of accessibility in the community significantly affects her ability to care for her children. Community accessibility problems were identified in a 1997 national survey of parents with disabilities, conducted by Linda Barker and Vida Maralami under a contract from TLG: Sixty percent of parents reported barriers to accessing the community.[185] This survey also found significant barriers to employment (76 percent) and recreation (73 percent), presumably due, at least in part, to noncompliance with disability laws.[186]

The Rehabilitation Act and the ADA touch all aspects of the lives of parents with disabilities and their children. However, until these laws are fully complied with and enforced, countless families will continue to suffer. As Samantha,[187] a wheelchair user and mother, said, "Society must shift its focus from how do we accommodate people with disabilities to how do we accommodate people with disabilities and their children."

Conclusion

The proper application of federal disability rights laws for parents with disabilities is crucial to achieving and promoting the purposes and goals of the Rehabilitation Act and the ADA: namely, the full participation of people with disabilities in society and protection against discrimination that would limit such participation. Until these laws are properly applied and enforced, people with disabilities will continue to face barriers to exercising their fundamental right to create and maintain families.

Chapter 4. Pursuing Parenting Rights Through the Convention on the Rights of Persons with Disabilities

"Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities…."[188]

On December 13, 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD),[189] which entered into force on May 3, 2008. The United States signed the CRPD on July 30, 2009.[190] The CRPD will enter into force in the United States upon ratification. The purpose of the CRPD "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[191]

The CRPD is the first legally binding international human rights convention specifically applying human rights to people with disabilities. It marks a paradigm shift in attitudes and approaches to people with disabilities in international instruments[192] and has been celebrated as the "Declaration of Independence" for people with disabilities worldwide.[193] The CRPD reflects the principles and aims of American disability laws and marks a departure from the traditional medical or charitable models of disability that are still embedded in many national domestic law and policy frameworks.

The CRPD is critical for ensuring the rights of people with disabilities to create and maintain families around the globe.

The CRPD recognizes that people with disabilities have rights, thus adopting the social model perspective of disability "as an evolving concept…that…results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."[194] To eradicate these barriers, the CRPD uses the concept of universal design, which is defined as "the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."[195] The CRPD sets forth general principles that inform its overall

approach and apply across the treaty: (1) dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (2) nondiscrimination, participation, and inclusion in society; (3) respect for difference; (4) equality of opportunity; (5) accessibility; (6) equality between men and women; and (7) respect for the evolving capacities of children with disabilities.[196] The CRPD clearly makes nondiscrimination and equal access for people with disabilities a human rights issue, and, with its enforcement, it has the power to change the way people with disabilities are treated around the world.

The CRPD is critical for ensuring the rights of people with disabilities to create and maintain families around the globe.

Respect for Home and the Family

Article 23 of the CRPD, Respect for Home and the Family,[197] is the most relevant guarantee of the rights of people with disabilities to create and maintain families. Its provisions include the following:

- 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….
- 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.*
- States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. *In no case shall a child be separated from parents on the basis of disability of either the child or one or both of the parents.*[198]

As noted by Callow, Buckland, and Jones, "The allusion to adaptive equipment and the prevention of a child's loss of her parents is promising for children of parents with disabilities around the world."[199]

In addition to ensuring the rights of parents with disabilities and their children with regard to dependency and family law disputes as well as adoption, Article 23 addresses the reproductive rights of people with disabilities, which include access to assistive reproductive technologies. Specifically, Article 23 requires States Parties to ensure that:

- The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the *means necessary* to enable them to exercise these rights are provided; and
- Persons with disabilities, including children, retain their fertility on an equal basis with others.[200]

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD is critical for ensuring the rights of people with disabilities to create and maintain families around the globe:

Article 5

- Prohibits discrimination on the basis of disability;
- Guarantees legal protections for people with disabilities who experience discrimination; and
- Requires all appropriate steps be taken to ensure that reasonable accommodations are provided

Article 8

- Requires measures to raise awareness throughout society about people with disabilities to combat stereotypes, prejudices, and harmful practices relating to people with disabilities

Article 13

- Ensures effective access to justice for people with disabilities on an equal basis with others.

Article 23

- Ensures the rights of parents with disabilities and their children with regard to dependency and family law disputes;
- Ensures the rights of parents with disabilities and their children with regard to adoption; and
- Ensures the reproductive rights of people with disabilities, which include access to assistive reproductive technologies.

Article 25

- Ensures people with disabilities are provided the same range, quality, and standard of health care and programs, including in the area of sexual and reproductive health

Article 28

- Requires recognition of the right of people with disabilities to an adequate standard of living for themselves and their families.

Access to Reproductive Health

Proper health care, especially reproductive health care, is crucial for people who want to create and maintain families. In addition to Article 23's advancement of respect for family life, Article 25 ensures the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.[201] Specifically, States Parties shall provide people with disabilities the same range, quality, and standard of free or affordable health care and programs as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs. Article 25 also requires health care professionals to provide care of the *same quality* to people with disabilities as to others, including on the basis of raising awareness of the human rights, dignity, autonomy, and needs of people with disabilities through training and the promulgation of ethical standards for public and private health care. Article 25 also prohibits discrimination against people with disabilities in the provision of health insurance and prevents discriminatory denial of health care or health services on the basis of disability.

People with disabilities, particularly women, face significant barriers to receiving accessible, affordable, and appropriate health care, especially reproductive health care, including assisted reproductive technologies. Articles 25 is crucial, as people with disabilities receive lower standards of care and frequently encounter a lack of awareness among practitioners, despite seeking medical attention more regularly than people without disabilities. Moreover, Article 25 ensures that practitioners do not employ methods of discretionary access to reproductive health care, which currently occurs regularly, especially with regard to assisted reproductive technologies.

Additional Protections for Parents with Disabilities and Their Children

The CRPD provides extensive rights for parents with disabilities and their children. Parents with disabilities continue to face accessibility barriers that impede their ability to carry out certain parenting responsibilities. Article 5 addresses this problem by requiring States Parties to prohibit discrimination on the basis of disability, guarantee legal protections for people with disabilities who are discriminated against, and take all appropriate steps to ensure that reasonable accommodations are provided.[202]

Moreover, parents with disabilities and their children face significant discrimination based largely on ignorance, stereotypes, and misconceptions. Article 8 will combat this by requiring States Parties to adopt immediate, effective, and appropriate measures to raise awareness throughout society about people with disabilities; to combat stereotypes, prejudices, and harmful practices relating to people with disabilities, including those based on sex and age, in all areas of life; and to promote awareness of the capabilities and contributions of people with disabilities.[203] To do so, States Parties must initiate and maintain effective public awareness campaigns designed to nurture receptiveness to the rights of people with disabilities and promote positive perceptions and greater social awareness toward people with disabilities.[204] Further, States Parties must foster at all levels of the education system an attitude of respect for the rights of people with disabilities, encourage

the media to portray people with disabilities in a manner consistent with the purpose of the convention, and promote awareness training programs regarding people with disabilities and their rights.[205]

Article 13 addresses access to justice by requiring States Parties to ensure effective access to justice for people with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.[206] Moreover, to help to ensure effective access to justice for people with disabilities, States Parties shall promote appropriate training for those working in the field of the administration of justice. As this report demonstrates, parents with disabilities face significant barriers to meaningful participation in dependency and family law proceedings. Article 13 will ensure their rights in these areas.

Parents with disabilities and their children often live in poverty. Article 28 addresses this critical issue by requiring States Parties to recognize the right of people with disabilities to an adequate standard of living for themselves and their families—including adequate food, clothing, and housing, and to the continuous improvement of their living conditions. States Parties shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.[207] Further, States Parties must ensure access by people with disabilities and their families who live in poverty to assistance from the state with disability-related expenses, including adequate training, counseling, financial assistance, and respite care, as well as access to public housing programs.

Furthermore, the convention contains an array of provisions that emphasize the need for States Parties to develop and make available new technology as a critical component of equalizing the rights of persons with disabilities. These provisions are pertinent to adaptive baby care equipment.

Conclusion

The domestic disability rights legal framework in the United States, combined with the nation's ratification of the CRPD, would send a clear message to the international community that the United States is not only committed but remains the leader in the global effort to promote disability rights, nondiscrimination, and equality for parents with disabilities and their children.

Chapter 5. The Child Welfare System: Removal, Reunification, and Termination

Parents' Stories: Tiffany Callo

Tiffany Callo,[208] a wheelchair user with cerebral palsy, dreamed of being a mother. In 1987, Tiffany's dream came true when she gave birth to her son David. Immediately following David's delivery, the county's child welfare agency asserted that Tiffany and her boyfriend, who also had a physical disability, could only take their son home from the hospital if they had a nondisabled caregiver with him at all times. Shortly after David's birth, Tiffany's relationship with her boyfriend began to deteriorate, and domestic violence ensued. Unable to deal with the domestic turmoil, David's live-in caregiver moved out. David was immediately removed to foster care by child welfare workers. Meanwhile, Tiffany learned that she was again pregnant. Her second son, Jesse, was immediately removed to foster care by child welfare workers. Tiffany was granted limited supervised visits with David and Jesse while she fought with the county for custody of her children. Realizing that she would need some assistance to care for her sons, Tiffany requested attendant care to help her with parenting activities, which the county denied.

In June 1988, a custody hearing began. As evidence, the county presented a videotape of Tiffany slowly diapering David during a supervised home visit. The county asserted that the tape demonstrated Tiffany's inability to care for her child because it documented her slow movements as she changed David's diaper. This argument ignored Tiffany's adaptive care for her baby, encouraging him to be patient. Expert testimony supported the mother's behavior, stating that infants learn to hold still during long diapering sessions when parents support their patience.

Eventually, battling with the child welfare system wore her down. David and Jesse were ultimately adopted by two separate families, despite assurances that they would remain together. Tiffany was granted a supervised annual visit with each child.

Tiffany's tragic story highlights an all-too-familiar situation for many parents with disabilities. More than two decades since Tiffany lost her children, parents with disabilities still do not fit the norms and expectations of the American nuclear family, and often run

afoul of presumptions and myths when they have to deal with the child welfare system. Parents with disabilities and their families are frequently, and often unnecessarily, forced into the system and, once involved, lose their children at disproportionately high rates. This chapter examines the child welfare system's treatment of parents with disabilities and their families, including state dependency statutes, disparities caused by inadequacies in the ASFA, and the perceived limitations on the application of the ADA. The "unfit parent" standard regularly applied to parents with disabilities is one of the major threats to people with disabilities who choose to parent, and presumptions about "fitness to parent" carve out parents with disabilities as a key population that must prove its ability to parent in American society. Further barriers in representation and access within the child welfare system compound the discriminatory impact on parents with disabilities and the consequent breakup of loving families that can result.

The Child Welfare System: A Brief Overview

The child welfare system "is a group of services designed to promote the well-being of children by ensuring safety, achieving permanency, and strengthening families to care for their children successfully."[209] The system includes state child welfare agencies, the courts, private child welfare agencies, and other service systems (such as mental health, substance abuse, health care, education, and domestic violence).[210] The goal of the child welfare system is laudable: "To promote the safety, permanency, and well-being of children and families."[211] The primary responsibility for the child welfare system rests with the states; however, the Federal Government plays a significant role in supporting states in the delivery of services by funding programs and legislative initiatives.[212] The law in most states makes the child welfare system responsible for responding to and following up on allegations concerning the safety of and risk of harm to children in the community.[213]

The ACF at HHS is responsible for the administration and oversight of federal funding to states for child welfare services under Titles IV-B and IV-E of the Social Security Act.[214] Two titles under the Social Security Act provide federal funding targeted specifically at foster care and related child welfare services. Title IV-E provides an open-ended entitlement for foster care maintenance payments to cover a portion of the food, housing, and incidental expenses for all foster children who meet certain federal eligibility criteria.[215] Title IV-E also provides payments on behalf of eligible children with "special needs" who meet other federal eligibility criteria. Special needs are characteristics that can make it more difficult for a child to be adopted and may include disabilities, age, being a member of a sibling group, or being a member of a minority race.[216] Title IV-B provides funding for child welfare services to foster children, as well as children remaining in their homes.[217] Title IV-B also provides funding to states and eligible tribes to support family preservation services, community-based family support services, time-limited reunification services, and adoption promotion and support services.[218]

Families typically become involved with the child welfare system after an allegation of abuse or neglect (also referred to as child maltreatment) is made to child protective services (CPS). CPS is

a specialized part of the child welfare system.[219] State laws require CPS agencies to take reports from people who believe a child has been abused or neglected; determine whether abuse or neglect has taken place; ensure that there is a plan in place to keep children safe; and provide services to families to ensure their children's safety.[220] Anyone who suspects that a child is being abused or neglected can call the local CPS to report the suspicion.[221] Any member of the community, parents, or child victims themselves can initiate an allegation of suspected child abuse or neglect. Professionals who work with children or families—such as doctors, nurses, social workers, teachers, psychologists, and police officers—are "mandated reporters," legally required to report suspected abuse or neglect.[222]

Once they receive a report of child maltreatment, CPS workers screen the allegation for credibility.[223] A report is screened in when there is sufficient evidence to suggest that an investigation is warranted. Conversely, a report may be rejected for insufficient evidence or if the situation reported does not meet the state's legal definition of abuse or neglect.[224] These standards are in place to ensure that the state does not run afoul of the 14th Amendment right of parents to be free from state intrusion unless such intrusion is required to protect citizen children.

If CPS deems the allegation credible, workers conduct an investigation to determine whether the child is safe, whether abuse or neglect has occurred, and whether there is a risk of it occurring again.[225] At the end of an investigation, CPS workers typically conclude either that the allegations are substantiated and require further action or unsubstantiated and not worthy of continued investigation or action.[226]

The CPS agency will initiate a juvenile court action if it determines that a dependency proceeding is necessary to keep the child safe.[227] To protect the child, the court can issue temporary orders placing the child in shelter care during the investigation, ordering services, or ordering certain individuals to have no contact with the child. At an adjudicatory hearing, the court hears evidence and decides whether maltreatment occurred and whether the child should be under the continuing jurisdiction of the court. The court then enters a disposition, either at that hearing or at a separate hearing, which may result in the court ordering a parent to comply with services necessary to alleviate the abuse or neglect. Orders can also contain provisions regarding visitation between the parent and the child, agency obligations to provide the parent with services, and services needed by the child. If a child has been abused or neglected, the course of action depends on state policy, the severity of the maltreatment, an assessment of the child's immediate safety, the risk of continued or future maltreatment, the services available to address the family's needs, and whether the child was removed from the home and a court action to protect the child was initiated.[228]

For the state to succeed in termination proceedings, clear and convincing evidence must establish that statutory grounds for termination have been met and termination must be in the best interest of the child.[229] Termination of parental rights is devastating and final. Describing the severity and significance of termination of parental rights, Stephanie Gwillim, in her *St. Louis University Public Law Review* article, said, "Termination of Parental Rights (TPR) is the death penalty of civil cases. Once a

"**Termination of Parental Rights (TPR)** is the death penalty of civil cases. Once a parent's rights to his or her child are terminated, that parent's rights to care for, visit, or make decisions for the child are gone forever: the legal parent-child relationship has ended. The parent cannot seek a modification for the permanent custody order after his or her rights have been terminated. The child can immediately be put up for adoption and a biological parent may never see their child again."

Stephanie N. Gwillim, "The Death Penalty of Civil Cases: The Need for Individualized Assessment and Judicial Education When Terminating Parental Rights of Mentally Ill Individuals," *St. Louis University Public Law Review* 29 (2009): 344.

parent's rights to his or her child are terminated, that parent's rights to care for, visit, or make decisions for the child are gone forever: the legal parent-child relationship has ended. The parent cannot seek a modification for the permanent custody order after his or her rights have been terminated. The child can immediately be put up for adoption and a biological parent may never see their child again."[230]

Disability Law and the Child Welfare System

Both the ADA and Section 504 of the Rehabilitation Act (for agencies receiving federal funding) apply to the child welfare system. The ADA was passed with the intent of ensuring "full and equal opportunity" for Americans with disabilities. Undoubtedly, the ADA's breadth and national mandate of eliminating disability-based discrimination applies to the child welfare system and dependency courts. Indeed, the ADA's legislative history indicates a clear correlation. For example, during a congressional hearing, Justin Dart, Jr. (referred to as the "father of the ADA" by the disability community) testified, "We have clients whose children have been taken away from them and told to get parent information, but have no place to go because the services are not accessible. What chance do they ever have to get their children back?"[231] Another witness attested, "These discriminatory policies and practices affect people with disabilities in every aspect of their lives… [including] securing custody of their children."[232] Echoing the need to eliminate discrimination faced by parents with disabilities, another person testified that "being paralyzed has meant far more than being unable to walk—it has meant…being deemed an 'unfit parent'" in custody proceedings.[233] Thus, "The ADA's unequivocal rejection of prejudicial stereotypes and inflexible policies that harm people with disabilities could provide an important basis for rethinking child welfare policy toward families in which at least one or more parent has [a disability]."[234]

Because the child welfare system generally includes state and local agencies, Title II of the ADA applies.[235] Accordingly, the system must comply with Title II's mandate: "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."[236]

Pursuant to Title II, child welfare agencies must do the following:

- Provide parents with disabilities an equal opportunity to participate in programs, services, and activities.[237] (Agencies must make reasonable modifications in policies, practices, or procedures, unless such modifications would fundamentally alter the nature of the service, program, or activity.)[238]
- Administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified people with disabilities.[239]
- Not impose or apply eligibility criteria that screen out or tend to screen out any person with a disability from fully and equally enjoying any service, program, or activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.[240]
- Furnish auxiliary aids and services when necessary to ensure effective communication, unless an undue burden or fundamental alteration would result.[241]
- Provide, as needed, benefits, services, or advantages beyond those required by the regulation to people with disabilities.[242]
- Not impose surcharges on people with disabilities to cover the costs of measures to ensure nondiscriminatory treatment, such as making modifications required to provide program accessibility or providing qualified interpreters.[243]
- Not deny the benefits of programs, activities, and services to people with disabilities because entities' facilities are inaccessible.[244]
- Provide services, programs, and activities that, when viewed in their entirety, are readily accessible to and usable by people with disabilities.[245]

Moreover, the child or children at the heart of the TPR proceeding qualify as a party suffering discrimination in accordance with the ADA owing to their familial association. According to the ADA, "A state or local government may not discriminate against individuals or entities because of their known relationship or association with persons who have disabilities." This prohibition applies to cases where the public entity has knowledge of both the individual's disability and his or her relationship to another individual or entity.[246] Thus, the ADA protects the children of parents with disabilities involved in TPR proceedings.

The ADA applies to both TPR proceedings and reunification services. The Supreme Court has said, "The fact that the [ADA] can be 'applied in situations not expressly anticipated by Congress does not demonstrate ambiguity. It demonstrates breadth.'"[247] According to Dale Margolin, in her article "No Chance to Prove Themselves: The Rights of Mentally Disabled Parents Under the Americans with Disabilities Act and State Law," "TPR and the ADA are inherently related: The TPR

involves an examination of both a person's disability and the state's implementation of services. Furthermore, contrary to the fears of some state courts, allowing a parent to assert a violation of the ADA does not mean that that the child's rights will be compromised. The child is always the focus of a family court proceeding, even when the court is examining a potential violation of the ADA. In virtually every state, the 'best interest' of the child is considered during the TPR. Furthermore, a parent's evidentiary attack should not be viewed as necessarily contrary to the interests and rights of a child; if a parent has been discriminated against, and the parent-child relationship is severed, in part or in whole, because of this discriminatory treatment, the severance has drastic, and potentially harmful, consequences for the child."[248]

TPR proceedings are services, programs, and activities covered by the ADA, which requires that there be no discrimination in these proceedings and reasonable modifications in policies, practices, and procedures that affect custody determinations if such modifications are necessary to avoid discrimination on the basis of disability (unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity). In fact, DOJ considers court actions to be "state activity" for purposes of the ADA and thus prohibits discrimination in all state judicial systems.[249] Notably, the Ninth Circuit has applied Title II to parole proceedings, which, according to the court, exist to protect the public, just as TPRs exist to protect children.[250] Reunification and other family preservation services should also be recognized as services, programs, and activities. In fact, federal courts have interpreted Title II broadly and specifically held that it applies to social services.[251] In addition, appropriate reunification and preservation services to parents with disabilities should include relationship-based intervention that facilitates the development and experiences of infants and children. When parents are deprived of these services, their children suffer the same deprivation.

In sum, the child welfare system must comply with the ADA, as well as Section 504 of the Rehabilitation Act as long as it receives any federal funding. Agencies may not discriminate on the basis of disability and must provide reasonable accommodations to appropriately serve parents with disabilities.

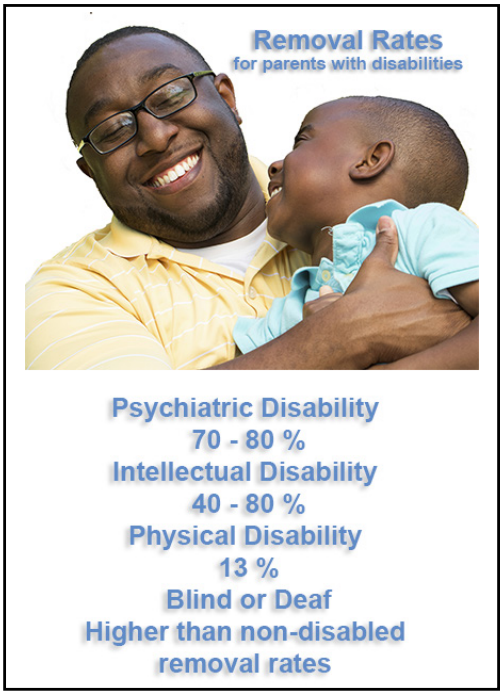
DOJ considers court actions to be "state activity" for purposes of the ADA and thus prohibits discrimination in all state judicial systems.

Disparate Impact of Child Welfare System on Parents with Disabilities and Their Families

Beginning with the investigation into a report of child maltreatment, bias pervades the child welfare system, and "at any step in the process, societal prejudices, myths, and misconceptions may rear their heads."[252] Systematic discrimination by state courts, child welfare agencies, and legislatures against parents with disabilities and their families has taken a toll. Statistics indicate that children of parents with disabilities are removed from their parents with alarming frequency.

Although no national study has identified the total number of parents with disabilities who have been involved in the child welfare system, TLG recently completed a research

study that identified the number of children in the child welfare system who have caregivers[253] with disabilities.[254] To complete this study, TLG analyzed data from 19 states[255] that met a 10 percent threshold for reporting to the National Child Abuse and Neglect Data System (NCANDS), a federally sponsored national data collection effort created to track the volume and nature of child maltreatment reporting each year in the United States. This study found that 29,986 victims (12.9 percent) had a caregiver with a reported disability: 21,543 victims (10.3 percent) had caregivers with a single disability and 5,443 victims (2.6 percent) had a caregiver with multiple disabilities. The race or ethnicity of children whose caregivers had a disability in the child welfare system of this study was as follows: white, 13,671 (50.7 percent); Latino/Hispanic, 4,922 (18.3 percent); African American, 4,255 (15.8 percent); American Indian/ Alaskan Native, 1,833 (6.8 percent); Asian/Pacific Islander, [179] (0.7 percent). The types of disability of caregivers with a single disability included emotional disturbance, 12,427 (6 percent); medical condition, 3,598 (2.2 percent); learning disability, 2,885 (1.9 percent); physical disability, 1,350 (0.8 percent); intellectual disability, 726 (0.5 percent); and visual or hearing disability, 419 (0.2 percent). No data were available on the distribution of disabilities among the 2.6 percent of caregivers with multiple disabilities. This research likely greatly underestimates the number of caregivers with a disability, as parents are not routinely assessed for disability at the beginning of cases; even so, it demonstrates that involvement in the child welfare system of caregivers with disabilities is affecting thousands of children.



Researchers at the Center for Advanced Studies in Child Welfare (CASCW) at the University of Minnesota recently completed a study to understand the prevalence of parental disability among cases of termination of parental rights and to assess disability disproportionality in TPR cases.[256] Using MinnLInK data, which includes Minnesota state administrative data from multiple agencies, cases of TPR were identified in the Social Service Information System (SSIS) database in 2000–2009. Parents whose parental rights were terminated were matched to their educational records in the Minnesota Department of Education database. A parent was determined to have a disability on the basis of his or her record of having a disability in the school system. This study found the risk ratio for TPR for a parent with a disability label in his or her education records to be 3.26. In other words, parents who had a disability label in their school records are more than three times more likely to have TPR than parents without a disability label. The risk ratio for child welfare involvement for a parent with a disability label in his or her educational records is 2.37. In other words,

parents who had a disability label are more than twice as likely to have child welfare involvement than their peers without such a label. Emotional or behavioral disorders (60.2 percent) were the most common disability labels for parents with TPR in this study. Parents who were labeled in the special education database with a specific learning disability made up 17.3 percent of the sample; those with a developmental or cognitive disability made up 9.3 percent of the sample; and 13.2 percent were labeled as having other types of disabilities. Although this study focused on a limited set of Minnesota parents with disabilities (parents who were involved in child welfare whose records could be located in the education database), it clearly demonstrates that disproportionality related to parental disability exists in child welfare.

Before these studies, little was known about what portion of child welfare populations comprised families with caregiver disability. Because child welfare agencies did not collect this kind of data, information at this level of detail was not available.[257]

Overall, involvement in the child welfare system results in increased numbers of families torn apart by removal of their children from their homes. Indeed, studies concerning the removal rates for parents with disabilities have long hinted at the significant over-involvement of these families with the child welfare system. Removal rates where parents have a psychiatric disability have been found to be as high as 70 percent to 80 percent;[258] where the parent has an intellectual disability, the rates range from 40 percent to 80 percent.[259] In families where the parental disability is physical, 13 percent have reported pathologically discriminatory treatment in custody cases.

Disability Disproportionality in Child Welfare Cases in Minnesota

- Parents who had a disability label in their school records are more than three times as likely to have termination of parental rights than parents without such a disability label.
- Parents who had a disability label in their school records are more than twice as likely to have child welfare involvement than their peers without a disability label.

Center for Advanced Studies in Child Welfare (CASCW) at the University of Minnesota

The deaf and blind communities also report extremely high rates of child removal and loss of parental rights.[260]

Overrepresentation is not a new phenomenon. A 1991 study examined more than 200 consecutive juvenile court cases in Boston and found that despite greater compliance with court orders, parents with intellectual disabilities had their children removed more often than parents without disabilities.[261] These initial removals often led to TPR. This is especially troublesome, as parents with disabilities who are involved with the child protection system are more likely to be facing allegations of neglect than of abuse or risk of abuse.[262]

Parents of color face even more risk of experiencing discrimination in the child welfare system. As stated in the NCD report *Meeting the Unique Needs of Minorities with Disabilities*, "Persons with disabilities who are also members

of minorities face double discrimination and a double disadvantage in our society."[263] The child welfare system is no exception. In 2009—according to Children's Rights, a national child welfare advocacy organization—more than half of the children entering foster care in the United States were children of color. African American and American Indian children are more likely than other children to be reported, investigated, substantiated, and placed in foster care. Thirty-one percent of the children in foster care are African American, double the percentage of African American children in the national population. Children of color, especially African American children and often American Indian children, are more likely to have longer placements in out-of-home care, are less likely to receive comprehensive services, and are less likely to reunify with their families than white children. The rates of child welfare involvement for African American and American Indian children are more than twice those of white children.[264] While no available data look specifically at the overrepresentation of parents of color with disabilities and their families, presumably the numbers are devastatingly high.

Researchers contend that parents with psychiatric disabilities are overrepresented in the child welfare system because of the common stereotype that people with psychiatric disabilities are dangerous. According to Loran B. Kundra and Leslie B. Alexander in their article "Termination of Parental Rights Proceedings: Legal Considerations and Practical Strategies for Parents with Psychiatric Disabilities and the Practitioners Who Serve Them," "As a result of this stereotype, it may be the case that judges and lawyers, upon hearing a diagnosis, will presume a level of dangerousness on the part of the parent involved in the termination of parental rights proceedings and will remove their children because of it."[265] Similarly, Diane T. Marsh found "that children of women with serious mental illness frequently enter the foster care system or, less commonly, are given up for adoption; that a majority of these parents have lost custody of their children; and that custody decisions are typically made with little communication between the mother's treatment team and child protective services."[266] In fact, Kundra and Alexander note that a recent study found that parents with psychiatric disabilities were almost three times as likely to have child welfare involvement or child custody loss.[267] The reasons for such targeting include the presence of psychiatric disability as a ground for termination of parental rights in many states, which triggers suspicion about these parents. In addition, many parents with psychiatric disabilities receive state services and are therefore under scrutiny.

Researchers contend that parents with psychiatric disabilities are overrepresented in the child welfare system because of the common stereotype that people with psychiatric disabilities are dangerous.

Similarly, parents with intellectual disabilities are overrepresented in the child welfare system and, once involved, face high rates of TPR. According to Chris Watkins, in his *California Law Review* article, "One result of the deinstitutionalization movement has been

in a dramatic increase in the number of parents with intellectual or developmental disabilities. Additionally, there has been a corresponding increase in the number of parental rights termination cases involving parents with intellectual or developmental disabilities."[268] Paul Preston of the National Center for Parents with Disabilities and Their Families contends that this "high rate of removal reflects greater discrimination and lack of appropriate services for parents with intellectual disabilities and their children. In discussing the political and social discrimination faced by parents with intellectual disabilities, experts assert that parents with intellectual disabilities are often held to a higher standard of parenting than non-disabled parents. Negative expectations and outmoded beliefs that children will eventually be maltreated and that parenting deficiencies are irremediable have contributed to children being removed from parents with intellectual disabilities despite lack of evidence for any abuse or neglect by the parent."[269] Like parents with psychiatric disabilities, parents with intellectual disabilities often have frequent contact with professionals, including those in the government, who often end up being the source of a CPS referral. Parents with intellectual disabilities are also likely to be living in poverty.

Bias pervades the child welfare system at every step. The disparities begin with the initial report of suspected abuse or neglect, usually to the police or CPS.[270] For most parents without disabilities, the initial report often comes anonymously from a neighbor, teacher, or physician.[271] However, because parents with disabilities frequently have regular contact with service providers, such as social workers and therapists, reports of suspected abuse or neglect may come from a state professional with whom the parents have had some previous contact.[272] Anecdotal evidence suggests that CPS is likely to take allegations from state professionals more seriously, regardless of whether they are actually more valid.

Poverty plays a significant role in bringing parents with disabilities into contact with service providers who end up being the source of a CPS referral, and poverty itself is the most consistent characteristic in families in which child neglect is found.[273] Unlike people with the financial resources to buy services privately, people who live in poverty are likely to come to the attention of the state by accessing public assistance.[274] Social scientists have often examined this phenomenon—which is referred to as "overexposure bias" or "visibility bias"—in the case of race.[275] For example, "Because children from African American and Native American families are more likely to be poor, they are more likely to be exposed to mandated reporters as they turn to the public social service system for support in times of need. Problems that other families could keep private become public as a family receives TANF, seeks medical care from a public clinic, or lives in public housing…. Research has shown that exposure bias is evident at each decision

Unlike people with the financial resources to buy services privately, people who live in poverty are likely to come to the attention of the state by accessing public assistance.

point in the child welfare system."[276] According to Ella Callow, legal program director at the National Center for Parents with Disabilities and Their Families, "While people with disabilities have been neglected by researchers examining this phenomenon, the…factors leading to overexposure bias in the African American and Native American communities are unquestionably present in the disability community. Poverty and reliance on public assistance are, unfortunately, the most common characteristic of the families with disabilities we see who are involved in the child welfare system and [are] quite often the reason they ended up there."[277]

According to Watkins, "These reports may be tainted by the same prejudices regarding parents with disabilities as are held by many members of society."[278] Further, once state involvement occurs, "Investigations are likely to be more probing, and investigating professionals are less likely to give these parents any benefit of the doubt."[279]

In 2003, Phillip Swain and Nadine Cameron of the School of Social Work at the University of Melbourne revealed findings from a study that examined the experiences of parents with disabilities with the court system.[280] Swain and Cameron's research concluded that parents with disabilities experience prejudicial or discriminatory treatment from CPS and the courts.[281] Commentators have characterized the court's approach to child protection involving parents with disabilities as one of "risk management."[282] A false dichotomy is established in which the children's rights are balanced against the rights of the parents.[283]

For example, Christina,[284] who has significant physical and sensory (vision and hearing) disabilities and is the mother of three children, has been inappropriately referred to CPS on various occasions. In one instance, her daughter's school reported maltreatment after her daughter injured herself doing summersaults. Although the CPS staff knew that Christina is hard of hearing and requires accessible relay services, they called her without the needed services, with the result that she could not effectively communicate. CPS alleged that she was being uncooperative and continued the investigation. The situation was ultimately resolved in Christina's favor, but it is doubtful that it would have ever progressed to this level if she did not have a disability.

Parents' Stories: Christina

Christina, who has significant physical and sensory (vision and hearing) disabilities and is the mother of three children, has been inappropriately referred to CPS on various occasions. In one instance, her daughter's school reported maltreatment after her daughter injured herself doing summersaults. Although the CPS staff knew that Christina is hard of hearing and requires accessible relay services, they called her without the needed services, with the result that she could not effectively communicate. CPS alleged that she was being uncooperative and continued the investigation. The situation was ultimately resolved in Christina's favor, but it is doubtful that it would have ever progressed to this level if she did not have a disability.

Parents' Stories: Cassandra

Cassandra, a wheelchair user and mother of one, was inappropriately referred to CPS by her daughter's pediatrician. During the investigation, Cassandra had difficulty securing an attorney who could effectively represent her. She eventually did find an attorney, and her daughter's medical records refuted the allegations of neglect.

In a similar instance of "risk management," Cassandra,[285] a wheelchair user and mother of one, was inappropriately referred to CPS by her daughter's pediatrician. CPS commenced an investigation. Cassandra had difficulty securing an attorney who could effectively represent her—a significant barrier for many parents, discussed later in this chapter. She eventually did find an attorney, and her daughter's medical records refuted the allegations of neglect.

The bias that permeates the child welfare system has many causes. According to law professor Robert L. Hayman, Jr., "Neither the training nor time constraints permit many social workers to transcend biased perceptions. Moreover, under most schemes, these perceptions are enough to justify state intervention."[286] Many states' child welfare statutes "generally require evidence of some connection between a parent's disability and her ability to parent; however, the level of proof required varies from state to state, and within many states, from case to case."[287] The consequences of this bias are devastating.

In fact, children have been removed from their families even when the evidence of neglect has been refuted and the court has acknowledged the parent's adequacy.[288] For example, in *In re G.C.P.*, the Court of Appeals of Missouri upheld a termination order even though it acknowledged that there was no indication of intentional abuse and the alleged neglect was supported only by reference to substandard housekeeping.[289]

Parents with disabilities and their families are frequently, and often unnecessarily, referred to the child welfare system. Connie Conley-Jung and Rhoda Olkin found in a study of blind mothers that "Mothers with disabilities feel vulnerable about their parental rights and the custodial rights of parents with disabilities are frequently questioned solely on the basis of the parents' disabilities."[290] In fact, nearly all the parents with whom NCD spoke reported living in constant fear that they would eventually be reported because of their disability. Kathryn,[291] a new mother who is a wheelchair user and little person, told NCD that she is "always worried that some random stranger could call [CPS]." Moreover, because of concern that their daughter's pediatrician will question their ability to parent, Kathryn and her husband, who has similar disabilities, always take a nondisabled person with them to appointments.

Jessica,[292] a wheelchair user and mother of twins, also lives in constant fear of being unnecessarily referred to the child welfare system. This fear leads her to always call her children's pediatrician before going to the emergency room. When her children were newborns she was constantly worried about scratching them with her wedding ring when changing their diapers, not because it would

Parents' Stories: Kathryn

Kathryn, a new mother who is a wheelchair user and little person, told NCD that she is "always worried that some random stranger could call [CPS]." Moreover, because of concern that their daughter's pediatrician will question their ability to parent, Kathryn and her husband, who has similar disabilities, always take a nondisabled person with them to appointments.

Parents' Stories: Danielle

Danielle, a deaf mother, feels fortunate that she has not yet been reported to CPS. However, she acknowledges that it could easily happen, which leaves her constantly in fear. Danielle has witnessed many instances in which deaf parents have been inappropriately referred to CPS; she told NCD that it is very common for the child welfare system to assert that the parents and child have no language if sign language is the primary language used in the home.

cause injury but because someone would see a scratch and call CPS.

Danielle,[293] a deaf mother, feels fortunate that she has not yet been reported to CPS. However, she acknowledges that it could easily happen, which leaves her constantly in fear. Dana has witnessed many instances in which deaf parents have been inappropriately referred to CPS; she told NCD that it is very common for the child welfare system to assert that the parents and child have no language if sign language is the primary language used in the home.

This pervasive fear unquestionably affects parenting. Susan,[294] a disability activist and mother with an immune system disorder, told NCD that she hides her disability when she is relating to people who are involved with her children, because she fears being judged on her ability to care for her children. Lindsay, a mother of two children, articulates the detrimental effects of fear on parenting:

> "Some of my fears now, as my disability status and identity have shifted to include recent psychological and cognitive impairments, are, or at least seem to me, more 'real.' I am afraid of disclosing the extent of my brain injury (TBI) and associated multiple cognitive impairment (MCI) to fellow parents, teachers, and service providers, and have even avoided some types of medical services for fear of stigmatizing my kids or giving their father ammunition to win full custody of them. For example, I grapple with intrusive symptoms of posttraumatic stress, as well as suicidal ideation, largely alone, with much minimizing and hiding. I expend a lot of energy trying to cover memory loss. I push myself way too hard, in ways that compromise my health by promoting seizures and other ill effects, so that I can process."[295]

This same fear leaves many parents afraid to ask for help. Jennifer,[296] a wheelchair user and mother of three children, told NCD that she is always afraid to ask for help as someone may

Parents' Stories: Jennifer

Jennifer, a wheelchair user and mother of three children, told NCD that she is always afraid to ask for help as someone may view that as being unable to adequately care for her children and may report her to CPS.

view that as being unable to adequately care for her children and may report her to CPS.

Fear that the state will take their children is common among parents with disabilities. According to Michael Stein, internationally recognized disability expert, "Even with the accomplishment of parental tasks through different techniques, mothers with disabilities fear that mainstream society will remove their children because of prevailing misconceptions. The result is the diminishment of parental joy for otherwise able and loving parents."[297] Overall, bias pervades the child welfare system and disparately affects parents with disabilities. As Ella Callow said, "This is the only class of children facing loss of family integrity due not to the behavior of their parents, but to their parent's disability status and how this is perceived and understood by child welfare professionals."[298]

Discriminatory State Statutes

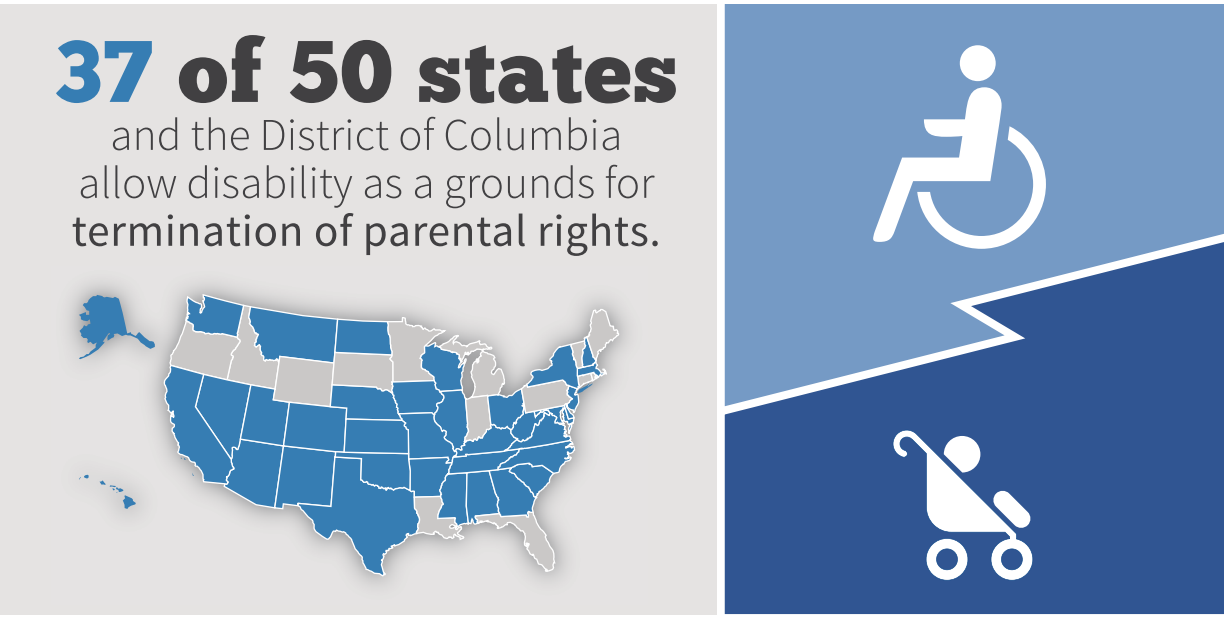
Child welfare allegations of unfitness are usually grounded in parental disability coupled with other factors, such as poverty, but the system also uses parental disability as a sole validating basis for presumed unfitness. In fact, 22 years since the passage of the ADA, states continue to include disability as grounds for TPR. Such statutes are examples of the oppression ADA proponents sought to eradicate, and they run entirely counter to the letter of the law, which prohibits state and local agencies, such as those in the child welfare system, from categorically discriminating on the basis of disability.[299]

In August 2005, a study revealed that 37 states still include disability as grounds for TPR.[300] Most of these state statutes use outdated and offensive terminology, have imprecise definitions of disability, and emphasize conditions rather than behaviors.[301] Parents with disabilities who are involved with the child protection system are more likely to be facing allegations of neglect than of abuse or risk of abuse.[302]

All the states that include disability in their grounds for termination specify explicit types of disabilities for courts to consider. Currently, 36 states list psychiatric disabilities, 32 list intellectual or developmental disability, 18 list "emotional illness," and 7 list physical disabilities as grounds for TPR.[303] Tennessee also uses the generic term "mental condition," which can imply a psychiatric disability or an intellectual or developmental disability.[304] North Carolina is the only state that also specifies organic brain syndrome as an explicit disability to consider in TPR.[305] Eleven states use a common combination of disability types—"emotional illness, mental illness and mental deficiency"—that came directly from the Neglected Children Committee of the National Council of Juvenile Court Judges of 1976.[306] For more information on state statutes and their inclusion of disability as grounds for TPR, see Appendix B.

Law professor Robert L. Hayman, Jr., said, "If the label is not used to help, it is inevitably used to hurt."[307] According to Elizabeth Lightfoot and Traci LaLiberte, a significant concern about the inclusion of disability in the grounds for TPR is that the mention of parental disability can shift

Legal Discrimination against Parents with Disabilities



the focus from a parent's behavior to a parent's condition or diagnosis.[308] No other parental conditions are listed in state statutes.[309] In fact, it is explicitly laid out in most state statutes that the condition of poverty, for instance, shall not in and of itself be considered grounds for TPR.[310] "However, old presumptions do not die easily, and presumptions of unfitness continue to subtly define the law's approach to parents [with disabilities]."[311] Thus, as Hayman says, "The formal classification should be abolished as a basis for state interference with the parent-child relationship. The classification has no empirical foundation, and its political roots are not ones to be proud of. The classification results, meanwhile, in a schematic processing of the labeled parent's claim to family, reducing individualized adjudications to formalities and foregone conclusions. In the end, the scheme makes us all a little less human."[312] Lightfoot and LaLiberte note, "When a parent's disability is explicitly included in legislation outlining the grounds for termination of parental rights, the disability can easily become the focus of a child protection case, even though the statutes do not say it can be the sole grounds for termination."[313]

[A] significant concern about the inclusion of disability in the grounds for TPR is that the mention of parental disability can shift the focus from a parent's behavior to a parent's condition or diagnosis.

TPR based solely on parental disability clearly violates the ADA's prohibition of decisions based on a person's disability status.[314] The full promise of the ADA will not be achieved until DOJ, in collaboration with HHS as appropriate, actively

enforces the ADA in child welfare matters and states stop denying parents with disabilities their fundamental right to create and maintain families.

Recurrent Barriers in Child Welfare Cases Involving Parents with Disabilities

This section examines barriers most often encountered by parents with disabilities when involved in the child welfare system, including barriers related to the Adoption and Safe Families Act; perceived limitations on the application of the ADA at the termination phase; bias, speculation and the "unfit parent" standard; and issues in meaningful participation and representation.

Adoption and Safe Families Act of 1997 and Its Impact on Parents with Disabilities

In November 1997, Congress passed and President Bill Clinton signed into law the Adoption and Safe Families Act (ASFA), significantly amending the Adoption Assistance and Child Welfare Act (AACWA) of 1980, which established the modern federal foster care program.[315] ASFA embodied an ideological shift from a statutory scheme that prioritized reunifying families in nearly all circumstances to one that unequivocally puts the health and safety of children first and aggressively seeks to move children through foster care to permanency in an expedited manner.[316]

While the goals of ASFA are laudable, the consequences can be devastating, especially for parents with disabilities and their children. A key provision of ASFA is the "15/22 rule," which requires states to file a petition for TPR if a child has been in foster care for 15 of the most recent 22 months (even shorter time frames, defined by state law, if the child is an infant).[317] While the goal of permanency is praiseworthy, research shows that many parents with disabilities find it difficult to comply within the strict timelines.

Pursuant to ASFA, states must make "reasonable efforts" to preserve a family before moving the child to an out-of-home placement and to reunify the family if a child has been removed.[318] "Reasonable efforts" are not defined in law or in federal regulations and have been interpreted in a wide variety of ways by states and the courts.[319] Unfortunately, the vagueness of this term, coupled with the unadapted services typically provided to parents with disabilities, means that the reasonable efforts requirement is not so reasonable when applied to parents with disabilities. Moreover, ASFA gives states flexibility in determining circumstances in which reasonable efforts are not required. In addition to defining specific instances, ASFA permits states to not provide reasonable efforts when "the state has determined that another reason exists that justifies not using reasonable efforts to reunify the family."[320] Research shows that states often include disability as one reason to deny families reasonable efforts.

ASFA also reduces an agency's focus on reunification by allowing workers to engage in concurrent two-track planning for children in out-of-home placement.[321] Although concurrent planning is not required, HHS has stated that it is "consistent with good practice."[322] Thus, even as a social worker makes efforts to reunify a family, he or she may also plan for the failure of those efforts by paving the way for TPR and for adoption.[323] A permanency hearing to develop a permanency plan must be held within 12 months of a child's entrance into foster care.[324] According to Theresa Glennon, law professor at

Temple University, because caseworkers have been shown to hold negative perceptions of people with disabilities, they may be more likely to focus on developing cases for termination than on helping parents with disabilities reunite with their children.[325]

Glennon says, "In sum, ASFA's emphasis on child safety, shorter placements in foster care, and permanency through adoptions places great pressure on parents with [disabilities] seeking reunification with their children and the advocates who represent them, particularly in a complex legal environment."[326]

The Race Against the Clock: The 15/22 Rule

ASFA requires state child welfare agencies to file a petition to terminate parental rights if (1) a child has been in foster care for 15 of the most recent 22 months; (2) the child is determined to be an abandoned infant, as defined by state law; or (3) a parent has committed or been involved in murder, voluntary manslaughter, or felonious assault of one of his or her children.[327] Exceptions are allowed on a case-by-case basis if (1) a child is being cared for by a relative; (2) the state shows a compelling reason why TPR is not in the best interest of the child; or (3) the state agency has not provided the services required by the case plan to return the child to a safe home if reasonable efforts were required.[328]

In response to ASFA, all states have adopted limits to the maximum time a child can spend in foster care before termination proceedings can be initiated.[329] Typically, states have adopted the ASFA standard of 15 of the most recent 22 months in care. Some states specify shorter time limits, particularly for very young children.[330]

These austere timelines are detrimental for parents with disabilities and their families. For parents, the time lines are often challenging—if not impossible—to comply with. Alexander and Kundra found that "these timelines are often difficult to adhere to for parents who must secure adaptive equipment, secure services that are more involved than those for non-disabled parents, and, in the case of parents with psychiatric disabilities, may be impossible because of the need to seek psychiatric inpatient care and treatment at some point in the dependency process."[331] Kundra and Alexander further articulate, "Parents with psychiatric disabilities are at a particular disadvantage with respect to the time requirement for family reunification efforts as treatment for mental health issues can sometimes require more than a year to be effective."[332] At the same time, evaluation of specialized services to parents with intellectual disabilities and their children documents steady but slow progress.[333] Furthermore, although filing of the mandatory termination petition does not take place until the child has been in the foster care system for 15 of the previous 22 months, the decision to terminate parental rights often comes at the 12-month hearing if it is believed that sufficient progress has not been made.[334] In fact, according to Barbara J. Friesen and colleagues, there have been "cases in which, even with the court's recognition of ongoing progress, parents with mental illnesses had their rights terminated because they were unable to meet reunification goals within the requisite timeframe."[335]

In 2006, researchers Lenore M. McWey, Tammy L. Henderson, and Susan Tice released findings from a study that sought to (1) identify

how ASFA influences foster care outcomes of cases involving parents with psychiatric disabilities; (2) examine trends in TPR decisions of parents with psychiatric disabilities; (3) explore the court's account of how parental behaviors influenced decisions to terminate parental rights; and (4) provide implications for family therapists.[336] This study found that therapists either were not aware of the time concerns associated with ASFA or could not sufficiently treat clients within the time period.[337] The finding was demonstrated, in part, by therapists' own recommendations to the courts, such as that the parent "needs 6–8 months of treatment before change can even begin to occur"; mother needs "at least 2 years of therapy"; "family needs at least 1 year of family therapy before returning children to the home"; and parents will need "several years of treatment."[338]

McWey, Henderson, and Tice also found that some parents with psychiatric disabilities had their parental rights terminated because they were unable to demonstrate within the time limit mandated by ASFA that they had successfully remedied the situation that led to the child being placed in foster care.[339]

A 2002 report from the U.S. Government Accountability Office (GAO) said that child welfare agencies found it difficult to work within ASFA's strict timelines.[340] These timelines often result in TPR for parents with disabilities. According to Joshua B. Kay, law professor at the University of Michigan, "Often, it is the timeframe of a service, rather than the nature or method of a service, that is a barrier for parents with disabilities."[341] Statutory time periods need to be extended to reflect the needs of parents with disabilities and their children. Specifically, ASFA must be amended to fully accommodate parents with disabilities. Likewise, the child welfare system must modify policies to comply with the ADA. Although these timelines were enacted out of concern for children, how are hasty timelines, which do not take into account the needs of a subset of parents, in the best interest of children?

The Reasonableness of "Reasonable Efforts"

Pursuant to ASFA, states must make reasonable efforts to preserve families before moving a child to an out-of-home placement and to reunify the family if the child has been removed.[342] This means that child welfare agencies should provide services such as family counseling, respite care, and substance abuse treatment.

At first reading, the provision seems particularly helpful for parents, especially those with disabilities. One of the exceptions to the 15/22 rule is if the state agency has not made reasonable efforts to provide the services required by the case plan to return the child to a safe home.[343] However, a 1999 GAO report said, "According to child welfare officials in the three states visited, their agencies have so far 'exempted few, if any, children—and are unlikely to exempt children—for this reason.'"[344]

Laws in all states, the District of Columbia, Guam, and Puerto Rico require the provision of services that will help families remedy the conditions that brought the family into the child welfare system.[345] However, the statutes in most states use a broad definition of what constitutes reasonable efforts.[346] According to Esme Noelle DeVault, "The 'reasonable efforts' standard is ill-defined and inconsistently applied."[347] In fact, a 1999 GAO report notes that the term is not defined in law or in federal regulations and

has been interpreted in a wide variety of ways by states and the courts.[348] This vagueness has devastating implications for parents with disabilities.

For example, DeVault says, "As applied to developmentally disabled parents…, the 'reasonable efforts' offered are often inadequate reunification services that fail in any meaningful way to rehabilitate the parent's fitness. These efforts would be improved if the state were to enact formal guidelines that define with greater specificity what constitutes 'reasonable efforts.'"[349] She goes on to say, "In many cases, reunification services are offered pro forma with the one size fits all concept. Under these circumstances, failure is projected and expected, not from the parents with the mental disability, but from the judges, social workers and service providers. Despite their efforts, parents are usually found unable to improve."[350]

Researchers at the UPenn Collaborative on Community Inclusion reached a similar conclusion: "Although our society has afforded parents with psychiatric disabilities legal rights to receive accommodations, these rights are routinely given short shrift in the child welfare system. Courts typically determine that reasonable efforts have been made when a parent has been offered a one-size-fits-all set of parenting services. This approach does not work well for families in general, and it is especially inappropriate for parents with disabilities, whose special needs are rarely addressed."[351] Thus, "many parents with psychiatric disabilities lose their children because they never receive meaningful help to safely care for their children. Many others lose their children based on unfounded assumptions that their disabilities make them unfit parents or on past episodes before the parent began receiving effective mental health treatment."[352]

Neither ASFA nor most state child welfare statutes specifically require that the reasonable efforts be designed to meet the needs of parents with disabilities, despite the fact that the ADA requires child welfare agencies to provide reasonable modifications for parents with disabilities.[353] Reunification efforts are not reasonable if they do not take into account a parent's disability—failure to do so means that the services will have little chance of success.[354] Unfortunately, the majority of case law concludes that the efforts made by states to provide individualized services to prevent people with disabilities from losing parental rights constitute reasonable efforts, even when they appear to be inadequate.[355] This is true even when the ADA requirements for modifications are raised.

Reunification efforts are not reasonable if they do not take into account a parent's disability—failure to do so means that the services will have little chance of success.

Furthermore, a statutory mandate is not a guarantee that parents with disabilities will receive such services. For example, in *B.S. v. Cullman*, two psychologists opined that rehabilitative services might not enable the mother to successfully parent on her own.[356] Therefore, the court determined that providing services "would place an undue burden on an agency, [which was] already struggling

with its duty to rehabilitate those parents and reunite those families who [could] be aided by its assistance."[357] Thus, even in states with statutory obligations to provide services, parents with disabilities "face barriers based on what may be ambiguous or discriminatory criteria."[358]

So ASFA's reasonable efforts provision is not so reasonable when it is applied to parents with disabilities; in fact, it has potentially devastating consequences for them. The provision is incredibly vague and has led to child welfare agencies providing generic, one-size-fits-all services, which violates the ADA reasonable accommodation mandate. (See Chapter 9 for a discussion of appropriate adapted services.)

Fast Track: Bypassing Parents with Disabilities

In an attempt to clarify AACWA's reasonable efforts requirement, Congress singled out a handful of circumstances in which efforts to reunite were *not* required.[359] This significant provision of ASFA, commonly referred to as "fast track," allows states to bypass reasonable efforts if a parent has committed murder or voluntary manslaughter of another of his or her children; been complicit in such a murder or manslaughter, or an attempted murder or manslaughter; committed a felony assault resulting in serious bodily injury to the child or another child; or when the parent's rights to a sibling of the child have been terminated involuntarily.[360] Additionally, under ASFA, reasonable efforts to reunite children with their parents are not required if "the parent has subjected the child to aggravated circumstances (as defined in state law, which definition may include but need not be limited to abandonment, torture, chronic abuse, and sexual abuse)."[361] In such cases, states are required to hold a permanency hearing within 30 days and to make reasonable efforts to place the child for adoption, with a legal guardian, or in another acceptable permanent place.[362]

According to Kathleen S. Bean, law professor at Brandeis School of Law, University of Louisville, "The impact on the health and safety of children when reunification efforts are not required can be tremendous. It ends the state's responsibility to provide services; it ends the duty to facilitate and encourage visitation; and it almost inevitably places the parent just steps away from termination of parental rights. Without reasonable efforts, the opportunity to address the problems that contributed to the child's removal and to work toward reunification to avoid the damage from disrupting the parent-child relationship is remote."[363]

The fast-track provision has many detrimental consequences for parents with disabilities and their children. For example, states are not required to provide reasonable efforts if the parent's right to a sibling of the child have been terminated involuntarily.[364] Anecdotal evidence suggests that this ground for bypass may disparately affect parents with disabilities because the previous loss of a child might have been caused by the state's failure to provide proper services.

Equally detrimental is the "aggravated circumstances" portion of the fast-track provision. Bean says, "The vagueness of the aggravated circumstances exception contributes to the likelihood that life-altering decisions will be arbitrary, capricious, and discriminatory. The phrase invites inconsistent, unpredictable

decisions about when a state should expend efforts to reunite a child with his or her parents."[365] This vagueness unquestionably affects parents with disabilities, particularly because some states have expressly included parental disability as an "aggravated circumstance." That is, some state statutes explicitly state that when a parent has a disability—intellectual or psychiatric—a court may dispense with reunification services if it finds that the parent is not likely to benefit from them.[366] Such bypass provisions exist in six states (Alabama, Alaska, Arizona, California, North Dakota, and Utah) as well as Puerto Rico.[367] In these states, the child welfare system is not required to provide services if the court finds by clear and convincing evidence that the parent has a psychiatric or intellectual disability "that renders him or her incapable of utilizing services."[368] Watkins says, "Thus, a parent's disability often serves as a dual liability: Her disability leads to the initial intervention and then precludes her from an opportunity to regain custody of her child."[369]

Parents' Stories: Lorena

Lorena's story demonstrates just how devastating bypass statutes are for parents with disabilities and their children.[370] Lorena, an older Latina mother in California who has autism, has raised one daughter to adulthood. Her daughters Sasha and Marie—ages 12 and 14, respectively—still live with her. Lorena was unable to work for several years, and between her autism and Sasha's autism, the cost of treatment and transportation for medical, educational, and therapeutic care resulted in their becoming homeless.

Lorena contacted social services for help. They convinced her to place Marie and Sasha in foster care temporarily. Because of Sasha's disability, she was placed separately from her big sister in a special needs foster care home. Lorena was very upset that her children were separated. Her case moved from voluntary to involuntary, and a public defender was appointed. Lorena became alarmed when she saw Sasha's deteriorating emotional state and lack of personal hygiene: long, jagged, dirty nails; unwashed hair; inflamed and infected gums. Child welfare workers reprimanded her for taking pictures of her daughter's condition and sending them to county counsel representing social services. When Lorena became overwhelmed and upset during a visit with Sasha because Marie was not brought, as had been promised, the police were called to intervene. They found no safety issue.

Child welfare then required Lorena to submit to two psychological evaluations. If these evaluations were interpreted to show that Lorena was unlikely to benefit from parenting services, she could be bypassed (denied the due process rights that a nondisabled parent receives). Lorena "failed" the tests and was deemed bypassed, ending her limited services and visitation. Throughout this process, Lorena felt that her public defender was unmotivated

to help. The attorney never raised the ADA, even to argue against bypass; was not willing to accommodate Lorena's communication needs; was dismissive of motherly concerns about her vulnerable daughter's care; and refused to work with TLG. Ultimately, however, the children's attorney became interested in working with TLG's legal program. Together, they located a psychiatrist affiliated with a local university disability program who had research and clinical familiarity with the subject. Despite the bypass, the local child welfare agency agreed to fund a proper assessment. The matter is ongoing.

ASFA's fast-track provision is incredibly disconcerting and has led to states denying many parents the due process guaranteed to nondisabled parents before they lose their constitutionally protected parenting rights. Congress must amend ASFA to protect the rights of parents with disabilities and their families. Further, this provision undoubtedly conflicts with Title II of the ADA, which prohibits public entities, such as those in the child welfare system, from denying people with disabilities access to services and programs on the sole basis of disability.[371] DOJ, in collaboration with HHS as appropriate, must actively enforce these mandates.

Concurrent Planning: Just How Concurrent Is It?

Concurrent planning is another significant component of ASFA. Although it is optional, HHS states that it is "consistent with good practice."[372] Concurrent planning involves considering all reasonable options for permanency at the earliest possible point following a child's entry into foster care and concurrently pursuing those that will best serve the child's needs. While the primary plan should typically be reunification, in concurrent planning, an alternative permanency goal is pursued *at the same time*.[373]

Some critics have asserted that the early development of an alternative permanency plan conflicts with agencies' pursuit of family reunification.[374] Others have raised concerns that concurrent planning practices may undermine family reunification efforts.[375] Fred Wulczyn of the University of Chicago notes that concurrent planning may lead caseworkers to work less vigorously toward family reunification.[376] Another concern is that birth parents may have difficulty working with caseworkers when they know that alternative permanency options are being actively pursued.[377] In fact, findings from a recent survey (posted on the Child Welfare Information Gateway Web site, a service of HHS Children's Bureau) reveal that CPS workers themselves believe that concurrent planning "can cause anxiety for birth and/or foster adoptive parents and impede reunification efforts."[378]

It is not clear how many states have formal concurrent planning policies, but the Child Welfare Information Gateway indicates that some states mandate concurrent planning in cases with "poor prognosis indicators."[379] The most commonly used poor progress indicator is this one: "Parent has significant, protracted, and untreated mental health issues and parent's

rights to another child have been involuntarily terminated."[380]

Concurrent planning can negatively affect parents with disabilities and their children. Jude T. Pannell, in his *Drake Law Review* article, says, "Some caseworkers fail to make the necessary efforts to preserve and reunite families because sanism leads them to believe any efforts they make are futile and mentally disabled parents cannot become capable of parenting. The taint of such prejudice may color the caseworker's efforts in the concurrent planning phase, making TPR inevitable instead of merely possible. A caseworker is less likely to recommend helpful services if he or she is convinced the parent will remain unstable, dangerous, and violent regardless of those services."[381] He also says, "The tight timeframes and concurrent planning called for by the ASFA make it essential for parents to quickly rehabilitate themselves. Parents facing TPR rely on their state caseworkers to guide them through the process, but the same parents understand the caseworker is also evaluating them for fitness as parents."[382] As a result of this situation, parents with psychiatric disabilities "may be fearful of alienating their caseworkers by being too demanding; may fear being stigmatized by their caseworker if they are seen as mentally ill; or may not be ready to acknowledge the presence of mental illness."[383]

According to the Adoption and Foster Care Analysis and Reporting System (AFCARS), reunification was the stated permanency planning goal for only 49 percent of children in foster care between 2006 and 2009.[384] It would be interesting to know how many of those children have parents with disabilities.

Perceived Limits on Application of the Americans with Disabilities Act at Termination Phase

Despite the ADA's obvious application to the child welfare system, state courts have resisted ADA defenses in TPR cases. The case law concerning the ADA and parental rights has overwhelmingly favored states and rejected the claims of parents with disabilities. Many courts have held that the ADA may not be raised as a defense to TPR proceedings for a variety of reasons.[385] Some courts have refused to apply the ADA because TPR proceedings are not a "service, program or activity" within the meaning of the ADA.[386] Others have held that the ADA does not apply to TPR proceedings because the court's jurisdiction is limited to interpreting the state child welfare law (i.e., determining the best interest of the child or reasonable efforts) rather than conducting "an open-ended inquiry into how the parents might respond to alternative services and why those services have not been provided."[387] Finally, some courts have concluded that the ADA provides no defense to TPR proceedings because Title II contemplates only affirmative action on the part of the injured party rather than defenses against a legal action by a public entity.[388]

Despite the ADA's obvious application to the child welfare system, state courts have resisted ADA defenses in TPR cases.

Not all courts have held that the ADA is inapplicable to TPR proceedings. Some courts have held that the law does provide a defense in such proceedings,[389] and others have applied

the ADA in TPR proceedings without specifically ruling on its applicability.[390] Overwhelmingly, however, those courts have failed to appropriately apply the ADA, concluding that sufficient reasonable modifications in services were made to accommodate parents' disabilities and, therefore, no ADA violations occurred.[391]

The Supreme Court has not ruled on whether state court proceedings such as TPR proceedings constitute "state activity" or "service."[392] In October 2006, a certiorari petition was filed in the Supreme Court seeking review of a Rhode Island court's decision that a TPR proceeding "does not constitute the sort of service, program or activity that would be governed by the dictates of the ADA."[393] The question presented was "whether Title II applies to termination of parental rights proceedings initiated by state agencies and prosecuted in state courts."[394] The petition noted that the Rhode Island decision is inconsistent with the plain language of the ADA and with the Supreme Court's ruling in *Pennsylvania Dep't of Corrections v. Yeskey*,[395] which made clear that the ADA makes no exceptions for activities that implicate particularly strong state interests.[396] This petition was denied, and conflict still exists on these issues among state courts.

The ADA was enacted to ensure the rights of all people with disabilities, including parents with disabilities. DOJ, and HHS as appropriate, must hold state courts and the entire child welfare system accountable. Furthermore, given the patchwork of decisions concerning the ADA and the child welfare system, the Supreme Court should address this issue, holding that the ADA does in fact apply. Until the mandates of the ADA are fully recognized and complied with, parents with disabilities and their children will continue to be torn apart unnecessarily.

Bias, Speculation, and the "Unfit Parent" Standard

Beginning with the investigation into a report of child maltreatment, bias pervades the child welfare system at every step. TPR generally hinges on "unfitness."[397] Most termination statutes identify various factors that the courts should consider when determining parental unfitness.[398] Although the factors are inexact, states typically focus on neglect and abuse.[399] Moreover, these statutes almost unvaryingly include disability, often psychiatric and intellectual, as factors for courts to consider.[400] Watkins says, "Although the statutes generally require evidence of some connection between a parent's disability and her ability to parent, the level of proof required varies from state to state and, within many states, from case to case."[401] Even in states that do not list disability as a ground for termination, courts have largely included it as a factor to consider in termination proceedings, usually under the rubric of "unfitness" or "incapacity."[402] While all parents are presumed "fit" until the state proves otherwise,[403] "the presumption that children's best interests are in remaining with their natural parents who wish to raise them" is frequently reversed in practice for parents with disabilities. Instead, "they must prove their competence in the face of myriad presumptions of inadequacy."[404]

Presumptions of unfitness are most obvious in cases where the parent has never actually had custody of the child. Intervention in these cases often takes place before or shortly after birth, even though the parents have done nothing to harm their child.[405] Such cases are quite common, and "parents in these cases often do not contest removal or termination,

perhaps because no strong bond has formed between parent and child, or perhaps because of pressure from the social service system."[406]

Also, the oppression most people with disabilities experience in their lifetimes can affect their ability to self-advocate.

Parents' Stories: Erika Johnson and Blake Sinnett

In 2010, a Missouri couple experienced the tragic consequences of the presumption of unfitness when their two-day-old daughter was taken into custody by the state because the both parents were blind.[407] This removal was not based on allegations of abuse, just a fear that the parents would be unable to care for their daughter. Because the couple was presumed unfit, for nearly two months they were permitted to visit their daughter only two to three times a week, for just an hour at a time, with a foster parent monitoring.[408] Questions arose within hours of their daughter's birth, after awkward first attempts at breast-feeding—something many new mothers experience.[409] Following this incident, a nurse wrote on a chart, "The child is without proper custody, support or care due to both of parents being blind and they do not have specialized training to assist them."[410] "Her words set into motion the state mechanisms intended to protect children from physical or sexual abuse, unsanitary conditions, neglect, or absence of basic needs being met."[411] A social worker from the state came by the mother's hospital room and asked her a variety of questions about how they would care for their daughter.[412] The social worker then told the parents they would need 24-hour care for their daughter, which the parents replied they could not afford and did not need.[413] Nonetheless, their daughter was taken into foster care, and a 57-day battle ensued before they were finally reunited with her.[414] This family's story shows the devastation that can occur when there is a presumption of unfitness; the parents were presumed to be unfit and had to fight to prove their fitness to be parents.

Parents' Stories: Tyler and Brandy

Tyler and Brandy also faced the consequences of the presumption of unfitness.[415] A young Native American couple with psychosocial (Tyler) and intellectual (Brandy) disabilities, had a new baby daughter, Pia. Brandy has a caseworker and receives services for her disability through the Department of Rehabilitation. Brandy and Tyler's capacity to parent was not questioned until Pia came home from the hospital, at which point Brandy's caseworker and a social worker from child welfare explained to her that a case would be opened based on parental disability. After two weeks of child welfare visits, Brandy became upset during a

(continued)

visit and left the house to take a break. She was accused of leaving the nonmobile Pia lying "unattended," although Tyler and the workers were in the living room. This incident and the parents' disabilities were considered grounds for removal. Brandy and Tyler were provided with neither evaluation nor parenting services.

The family contacted TLG's legal program, which contacted the child welfare agency, attorneys on both sides, and the family's tribe, notifying them of the need to consider the ADA and provide accommodated services. CPS argued that the lack of such services excused compliance. The director of TLG's legal program cold-called universities and located a psychologist with the proper qualifications to provide an accommodated parenting assessment, which CPS then refused to fund. The psychologist herself found funding for and completed the assessment, making formal recommendations to child welfare and the court. The recommendations included the following accommodated reunification services: "increased opportunity for parenting time with Pia in the natural setting of their home, starting with two hours at a time several times per week with a support person who is trained to teach parenting skills and is sensitive to accommodations necessary when working with developmentally disabled parents." The psychologist also said, "A professional provider independent of the state should evaluate Brandy and Tyler's progress or lack thereof on parenting weaknesses periodically. This provider should be one source of input to the court and child welfare regarding expanding or limiting parenting time." The child welfare agency refused to implement or fund any services.

The family filed a civil rights complaint with DOJ, which transferred it to HHS. The HHS investigation found no discrimination and did not discuss the post evaluation recommendations. After the issuance of the ADA Amendments Act (ADAAA) regulations, the family refiled with DOJ, hoping for a new investigation. This has not occurred. When notified of the complaint, the judge said, "No one around here is afraid of a civil rights investigation." The family members who supported Brandy and Tyler in filing the complaint were excluded from all future courtroom proceedings. Pia's tribe (unfamiliar with the ADA's application in child welfare) formulaically endorsed the child welfare department's reunification efforts as sufficient and has provided no support to the parents' efforts to secure proper services. The family recently participated in a jury trial (their state is one of the few that uses jury trials in child welfare matters). The jury found that child welfare had not provided proper services and that termination of parental rights was not appropriate. The child welfare agency has been ordered to work with the family to provide proper services. After the trial, some members of the jury cried and hugged the father, whose own traumatic childhood as a disabled foster child had been presented on direct examination. This matter is still ongoing. Pia has been out of her family's care for several years; whatever the ultimate resolution of this case, someone will lose.

The child welfare system is fraught with bias and speculation concerning the parenting abilities of people with disabilities. The impact of this situation on the best interests of children is rarely addressed but has devastating consequences, as Jeanne's story illustrates.[416]

Parents' Stories: Jeanne

Jeanne, a young Native American mother with intellectual disabilities, lives in a supported living facility in Florida with her five-year-old daughter, Leya. On the basis of Jeanne's disability, she and Leya have had assigned social workers and an open child welfare case since Leya's birth and have received parent-child intervention services.

With Leya starting kindergarten, social workers began questioning how an intellectually disabled mother could promote the child's well-being. Jeanne was assessed with IQ testing, interviewing, and limited observation. On the basis of the results, it was speculated that by middle school, Jeanne would be unable to help Leya with homework and would possibly have trouble retaining parental authority. Social workers, therefore, decided to establish for Leya a relationship with her estranged father. She had never lived with him, and her mother had no relationship with him, but he did not have a disability. The goal: to eventually switch custody to the father.

Jeanne was opposed and anxious but acquiesced. However, after a number of visits, Jeanne told the social workers that she did not want them to send Leya to see her father any longer. She told them that Leya was scared to go there—she was regressing, fearful of sleeping, wetting herself after having been potty-trained for years, and she came home from visits upset. The social workers dismissed her concerns and continued to insist that Leya spend time with her father. Finally, after Leya's return from a visit, Jeanne was giving her a bath and observed evidence of sexual abuse. She contacted the police and the social workers. Leya was given medical treatment, the police opened an investigation, and the father was eventually convicted of, and jailed for, child sexual abuse.

And yet local child welfare remained convinced that Jeanne could not parent Leya. A personal attendant helped Jeanne contact TLG's legal program, which referred her to the local Indian legal services. There, a devoted attorney persuaded child welfare to close the case. Jeanne fled the area with her child, fearing the Leya might again be harmed by arbitrary actions. She has not contacted anyone involved in the case.

Presumption of unfitness is a common problem for parents with psychiatric disabilities. Indeed, according to Susan Stefan, a highly recognized disability law attorney, there are "a number of false stereotypes reflected in lower court decisions and termination filings that also permeate the attitudes of child protective services workers and the agencies where they

operate: psychiatric disability and symptoms are permanent and unchanging; requiring assistance means the person is unfit to parent; being disrespectful to the social worker means unfitness to parent; and attempting suicide means unfitness to parent."[417] In essence, "the social stigma of being a parent with a mental disability, generalized statistical data, age-old stereotypes, and horrific news stories may affect court determinations about a parent's ability to raise a child based on their condition instead of their conduct."[418]

Lightfoot, Hill, and LaLiberte note, "Parents with disabilities face social stereotypes and prejudicial presumptions that they will inevitably maltreat their children or put them at risk from others, or that they have irremediable parenting deficiencies that put their children at risk and risk their developmental outcomes."[419] In fact, many child welfare practices specify that parental disability is a high risk for abuse, so parents with disabilities often experience more scrutiny from child protective services.[420] For example, NCANDS, a federally sponsored data collection effort that tracks the volume and nature of child maltreatment reporting each year in the United States, considers parental disability a risk factor. Presumption of unfitness of parents with disabilities applies equally to the courts. "When courts allow presumptions of inadequacy to replace individual inquiry, they erect insurmountable hurdles for parents [with disabilities]."[421] Undoubtedly, this unfortunate presumption is a result of attitudinal bias, which is still prevalent. "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 involvement and often leading to termination of parental rights."[422]

The child welfare system must make significant changes in the way it serves, and even views, parents with disabilities and their children. Parental disability must not be considered a "risk factor." Moreover, the ADA forbids the child welfare system from presuming that parents with disabilities are unfit.

"When courts allow presumptions of inadequacy to replace individual inquiry, they erect insurmountable hurdles for parents [with disabilities]."

Issues in Meaningful Participation and Representation

Once involved with child welfare services and facing TPR, parents with disabilities face numerous and significant obstacles to meaningful participation and representation.

Pursuant to Title II of the ADA, child welfare agencies, including the courts, must accommodate parents with disabilities and ensure that they are guaranteed meaningful participation. Nonetheless, Callow, Buckland, and Jones note, "Because of inaccessible, inappropriate or non-existent services, parents with disabilities are often prevented from meaningful participation in evaluations, mediations, case plan services and court hearings."[423] A variety of accommodations and modifications, as required by the ADA, can ensure that parents with disabilities have

meaningful participation in the process. Examples of accommodations for parents at hearings and meetings include phone contact, email, or brailled notices of hearings and meetings to blind parents; meeting or hearing rooms that parents with a physical disability can access and use with their equipment; computer-assisted real-time translation (CART) or sign language interpreters so deaf and hard of hearing parents can follow proceedings; meetings held at a time of day when a parent with psychiatric disabilities is least impaired by psychotropic medications; allowing an advocate to accompany a parent with intellectual disabilities to help him or her meaningfully participate in the proceedings.[424]

Obtaining legal representation is a significant barrier for many parents facing TPR. In *Lassiter v. Department of Social Services*,[425] the Supreme Court held that the due process clause of the 14th Amendment does not automatically provide the right to counsel to indigent parents facing TPR. Instead, the Court held that courts had the responsibility to determine, on a case-by-case basis, whether the facts of the particular case created a federal constitutional right to counsel. However, the Court did note that "a wise public policy . . . may require that higher standards be adopted than those minimally tolerable under the Constitution" and that "informed opinion has clearly come to hold that an indigent parent is entitled to the assistance of appointed counsel not only in parental termination proceedings, but in dependency and neglect proceedings as well." Since the *Lassiter* decision, states have responded in various ways to the mandate to provide legal counsel to indigent parents.[426] A national survey revealed that in at least 12 states, parents do not have an absolute statutory right to counsel after the initiation of child protection proceedings against them.[427] In at least six states, parents do not have an absolute statutory right to counsel in TPR hearings.[428] And in many

Examples of Accommodations for Parents at Child Welfare Hearings

1. Phone contact, email, or brailled notices of hearings and meetings to blind parents;
2. Meeting or hearing rooms that parents with a physical disability can access and use with their equipment;
3. Computer-assisted real-time translation (CART) or sign language interpreters so deaf and hard of hearing parents can follow proceedings;
4. Meetings held at a time of day when a parent with psychiatric disabilities is least impaired by psychotropic medications; and
5. Allowing an advocate to accompany a parent with intellectual disabilities to help him or her meaningfully participate in the proceedings.

states, the right is governed by statute and not protected by constitutional principles.[429]

In August 2006, recognizing the importance of representation in dependency cases, the American Bar Association (ABA) House of Delegates unanimously passed a resolution endorsing a civil right to counsel in cases related to basic human needs.[430] The basic human needs identified in this resolution as most critical for low-income persons and families include shelter, sustenance, safety, health, and child custody.[431] Moreover, "This resolution focuses the right on low-income persons but gives each jurisdiction the flexibility to determine who should be considered to fit into that category."[432] In fact, according to the ABA, the association's "long history of examining this issue has led it to conclude that the risk of error when indigent parent-defendants are not represented in such matters is so great that fair and equal access to justice requires the appointment of counsel."[433] The ABA states that "despite the relaxed evidentiary standards in abuse and neglect proceedings, most unrepresented parents cannot perform the advocacy functions—including investigating facts, making an orderly factual presentation, and cross-examining witnesses—that are required. Cases throughout the country demonstrate that the need for and manner in which evidence must be presented remains beyond the understanding of many indigent parent-defendants."[434] Further, "not only are indigent parent-defendants ill-equipped to defend their fundamental right to parent, but there is a high probability that whether they are represented by counsel will be outcome-determinative."[435]

Despite the significance of having representation during dependency matters, indigent parents often experience barriers to securing affordable and effective representation. For parents with disabilities, securing representation is even more challenging. Many attorneys lack the skills and experience to meet the needs of parents with disabilities. Parents with disabilities are often represented by court-appointed legal representatives who typically have excessive caseloads and little if any training in disability.[436] The parents "may not receive adequate explanations of proceedings or the help they need in order to be able to articulate their wishes and respond to the evidence filed in court. Such legal representatives may not appreciate the need for explanations to be couched in language that parents can understand. Moreover, legal representatives may be unable—if not unwilling—to appreciate the parents' commitment to caring for their children."[437] In fact, McConnell and Llewellyn "found that among the thirty lawyers they interviewed there was substantial agreement that these parents require more time in such cases—time that is rarely available and for which there is no extra remuneration. The lawyers explained that it is very difficult to determine whether parents with intellectual disability adequately understand the nature of court proceedings, the evidence and the legal strategy proposed. It was therefore thought very difficult to not only obtain reliable instructions—that is,

Parents with disabilities are often represented by court-appointed legal representatives who typically have excessive caseloads and little if any training in disability.

to know what the parent really wants his or her legal representative to do—but also to thoroughly scrutinize the evidence, given that many parents have poor literacy skills."[438]

Callow, Buckland, and Jones have found a "failure of the bar to rise to the occasion and zealously work to win on evidence in these cases involving parents with diverse disabilities. Evidence is not created to defend parents, such as adapted baby care evaluation reports. Evidence is not presented, such as failure to present the court with evidence of adaptive equipment that will enable a parent to care for a child or tackle emergency situations (such as bed-shaking smoke alarms for parents who are deaf). Finally, evidence is not challenged, as in counsel failing to challenge a biased/unadapted parenting evaluation that recommends termination of rights or a switch in custody from a parent with a disability."[439]

Hayman says, "The parents' advocate is not immune to the biases that affect legislators, administrators, and judges."[440]

In sum, parents with disabilities regularly encounter a dearth of accessible, appropriate services. This prevents them from meaningful participation in evaluations, mediations, case plan services, and court hearings. Furthermore, a parent's right to an attorney (in some states), the right to cross-examine witnesses, and the right to present expert testimony to contradict or clarify testimony from the state's expert is unattainable for many parents with disabilities. Instead, they are appointed attorneys who may have no knowledge of disability and often fail to understand the impact of disability on parenting capacity.

Teri L. Mosier, a deaf attorney, said "Each day in courtrooms across the United States, a recurring drama unfolds. Parents who want to maintain a relationship with their child will be told they cannot because, in the state's view, they are unfit beyond redemption. They will be told that the companionship, custody and care of their child will be forever denied to them. They will no longer have the right to participate in their child's upbringing, or even to visit the child. The child will permanently lose the connection to his or her natural family. If the child is not subsequently adopted, that child will forever remain a judicially mandated orphan."[441] For parents with disabilities, this nightmare is compounded by significant barriers to meaningful participation and representation.

Given their expertise in representing people with disabilities, the P&A system must make parenting rights a priority. Similarly, child welfare agencies, including the courts, must fully comply with the ADA. DOJ, in collaboration with HHS as appropriate, must ensure that parents with disabilities are treated fairly and lawfully.

The Impact on Children

> "No matter where they live in the world, no matter what they eat for dinner, no matter where they go to school, there is one common thread you can find in every child; they expect to go to bed and wake up with the same family. In almost every situation, children thrive most with their natural families.[442] 'When family integrity is broken or weakened by state intrusion, [the child's] needs are thwarted and . . . [t]he effect on the child's developmental progress is invariably detrimental.'[443] Children placed in foster care are at risk for more behavioral, psychological, developmental and academic problems."[444]

Children are removed from parents with disabilities with startling frequency. TPR is undoubtedly traumatic for parents with disabilities, but what is its impact on children? Is removing children from their home always truly in their best interest?

Nearly every child who is removed from a parent with a disability experiences some trauma over the separation. In their article in the *Texas Journal of Civil Liberties and Civil Rights*, Callow, Buckland, and Jones said, "Psychology and 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. In fact, arguably the most significant issue for a child's development is now known to be a secure attachment to a sensitive, responsive, and reliable caregiver."[445]

When children are removed from their parents, their experiences go through specific phases. Callow, Buckland, and Jones articulate: "The child will first express *protest* and do everything it can to get back to the mother or other caregiver. The next phase is *despair* as the child begins to fear it will not be reunited with the mother or other caregiver. Finally, the child will experience *detachment*, when it gives up hope. The pain may be so great that it loses hope of ever having that security and love again."[446]

This process has significant detrimental effects. The children often experience "pathological attachments to the old caregiver if reunited or toward new caregivers during separations. *Insecure attachment*; the more severe *disorganized attachment*, in which a child wants but cannot bring itself to seek the soothing and comfort of a caregiver; and reactive attachment disorder, which is mentally and emotionally disabling, are all in the spectrum of predictable outcomes from traumatic and/or repeated separations."[447] The long-term results are even more devastating: "Traumatic and/or repeated separations from caregivers place children at an increased risk of conduct disturbances, disruptive behavioral problems, attention disorders, and mood disorders. 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 formulate positive self-esteem and self-reliance."[448]

"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 formulate positive self-esteem and self-reliance."

Social science research demonstrates the harm of taking children out of their families and placing them in foster care. A matched study of drug-exposed babies, which compared newborns placed in foster care with newborns allowed to stay with their parents, showed that "at six months of age, the infants left in foster care were significantly less likely to reach, roll over, or sit up than those left with their mothers."[449] Many child development theorists and practitioners argue that despite the need for permanence, children are harmed by TPR, and "severing the relationship with a biological parent is deeply

traumatic, even when that parent has been neglectful."[450] Substantial evidence demonstrates children in foster care benefit from contact with their parent "in terms of greater emotional security and self-esteem and improved ability to form relationships."[451]

Despite extensive evidence regarding the danger of removal and multiple placements for young children, such procedures are still the standard for children involved in the dependency process. For parents with disabilities, removal and reunification is more common than maintenance and services with the children in the home.[452] After the removal, foster care brings its own set of problems. To begin, removal of a child most often means *many* foster care placements for the child. For example, in Los Angeles, which has the nation's largest dependency system, 24.3 percent of foster children less than one year old, 33.5 percent of children aged one through two, and 38.8 percent of children aged three through five experience three or more caretakers in a 13- to 23-month stay in foster care.[453] Throughout the country, most children remain in foster care for a substantial length of time after TPR, while an adoptive home is sought and finalized. Recent data reveal that "there are currently half a million children in foster care, with twenty percent of these children having remained there for five years or longer."[454] The Congressional Coalition on Adoption Institute reports that more than 65,000 children in foster care in the United States are placed in institutions or group homes, not in traditional foster homes.[455]

The current economic condition is significantly affecting the child welfare system and most important, the children involved. Poverty is a factor in the increase in the number of children placed in foster care. According to Deborah Paruch, law professor at the University of Detroit, "The United States has approximately fourteen million children living at or below the poverty level, which is the highest child poverty rate among all industrialized nations."[456] As the number of children in poverty and, in turn, in the foster care system increases, so do the caseloads of social workers, which limits "their ability to visit children, assess safety, and respond appropriately to the needs of the children and their families," and in turn contributes to longer stays in foster care.[457] Moreover, states continue to face significant budget deficits and are slashing child welfare funding.[458] Paruch says, "Such a sequence of Catch-22s is clearly not in the best interest of children, their families, or the professionals charged with their oversight."[459]

Children raised in foster care end up with more mental health issues, lower employment rates, less insurance coverage, and a higher rate of homelessness than the rest of the population.

Being placed in foster care significantly affects children. Children raised in foster care end up with more mental health issues, lower employment rates, less insurance coverage, and a higher rate of homelessness than the rest of the population.[460] Attorney Alexis Collentine says, "The foster care system is meant to

offer security to children, but it often does the opposite. While there are many excellent foster parents, there is also abuse of children in care by both foster parents and other foster children. A national report on child fatalities found that a child in foster care is twice as likely to die from abuse as is a child in the general population of children. New Jersey parents whose children were removed due to inadequate housing sued because their children returned from foster care with clear signs of physical abuse. Long stints in foster care often involve moving between multiple foster homes, with children experiencing disruptions in schooling and relationships. These constant changes make it difficult to develop and maintain connections that are crucial to a child's growth."[461] Children in foster care are twice as likely to be killed, two to four times more likely to be sexually abused, and three times more likely to be physically abused.[462] In fact, according to a recent study conducted by Joseph Doyle, an economics professor at MIT who studies social policy, "Children on the margin of foster care placement have better employment, delinquency, and teen motherhood outcomes when they remain at home."[463] According to Gary Stangler, executive director of the Jim Casey Youth Opportunities Initiative, a foundation for foster teens, this study "confirms what experience and observation tell us: Kids who can remain in their homes do better than in foster care."[464]

Despite such significant problems, foster care remains a reality for many children. Reunifications have declined, dropping steadily from 60 percent in 1998 to 53 percent in 2006.[465] Furthermore, while adoptions of youth in foster care increased between 1998 and 2006, more youth aged out of care unadopted between 1998 and 2006.[466]

Children's Stories: Bobby

Bobby's story illustrates the trauma endured by children when a family is wrongfully separated.[467] In Kentucky, Louise, a grandmother in her early 60s, has arthritis and uses a walker. She has had custody of her two-year-old grandson, Bobby, since his birth. When Bobby's mother was arrested, she was asked if she had any children. She explained that her son lived with her mother. Social workers came to Louise's house and explained that they were removing Bobby but he could stay three more weeks, until his third birthday, since there was no immediate need for removal. The social worker added that it is "textbook" that Bobby would be better off with a young, healthy family than a grandmother who is "old and handicapped."

Louise did her best to explain the unexplainable to Bobby—that child welfare was taking him and she didn't know for sure when he could come home. Bobby was removed just after he turned three, and he engaged in developmentally appropriate protest for an extended period. The social worker viewed this as pathological; she repeatedly physically dragged Bobby away from Louise at the end of visitations, threatening to end contact if he did not "behave." Eventually, she acted on her threat: Citing how "upsetting" visitations were and Louise's

poor choice in feeding him candy on a visitation (she brought a marshmallow "Peep" to an Easter visitation) the social worker severely curtailed the visits.

At that point, Bobby became despairing and detached quite quickly. He refused to eat, and when he did eat, he vomited. Child welfare sent him for barium treatments to see if he was physically sick; he wasn't. He was then hospitalized for an injury sustained in foster care. Louise was not allowed to visit, and his foster parents chose not to. Bobby spent his hospitalization alone in a crib with a top to prevent him from getting out, surrounded by IVs and other invasive equipment. Bobby was then labeled as "willful" and considered a "high-needs, difficult child." This label was used as another reason not to return him to Louise. Bobby was eventually adopted; thankfully, the adoptive parents kept some contact with Louise. Her knowledge of his foster care history helps Bobby's adoptive parents understand the psychiatric work he requires to deal with his reactive attachment disorder, claustrophobia, and ongoing nightmares.

Efforts to move the court to acknowledge the discrimination and its effects met with complete truculence. The trial judge stated from the bench, "For the record, disability has nothing to do with this case."

The detrimental effects of spending long periods in foster care have been well documented. Watkins says, "Less is known about how children are affected by the termination of their relationship with their parents. Parental rights termination in large numbers is a relatively new phenomenon, and little research has been done with the children affected. However, one study indicates that adopted children cut off completely from their biological parents often experience a sense of profound deprivation."[468] Another study found that the children of parents with intellectual disabilities whose rights were terminated "experienced a deep sense of loss. Often the bond between the parent and child is especially strong. There is also the potential for a negative impact on the child's self-esteem and identity. Where parental rights are involuntarily terminated due to some 'defect' in the parent, the child must either disconnect from the parent and lose part of his identity or maintain identification with the family and the concomitant identification with the defect, resulting in injury to his self-esteem. In addition, leading to less permanency rather than more, parental rights may be terminated without having an adoptive family ready to take the child. Children in this situation have been termed 'legal orphans' because they have no connection to a family, neither adoptive nor biological."[469]

Such a child may continue to live with various foster parents even though he or she is legally free and available for a permanent placement. This is of special concern when the children themselves have disabilities. Children with disabilities have lower rates of adoption and,

once adopted, have higher rates of disruption (the termination of an adoption proceeding before it is legally finalized).[470] This is noteworthy because parents with intellectual disabilities are more likely to have children with intellectual disabilities.[471] Thus, high rates of termination for parents with intellectual disabilities lead to more children with disabilities entering the adoption pool, where they have a strong likelihood of remaining orphans.

Thus, research shows that children experience countless detrimental consequences when they are removed from their home, whether temporarily or permanently. Watkins says, "Of course, each situation is unique; thus, there will be times when children are better off having no relationship with their biological parents. As a result, each child's case should be individually scrutinized, avoiding presumption and stereotype based upon the parent's status if the child's best interest is to be served."[472]

Conclusion

Parents with disabilities face multiple layers of discrimination from the moment they enter the child welfare system. Parents with disabilities, particularly intellectual or psychiatric disabilities, face statutes that allow the state to presume unfitness solely on the basis of their disability and to use the disability to justify intervention into the family and TPR. Moreover, while some state termination statutes require evidence of a link between disability and detriment to the child before TPR, the courts rarely enforce this requirement. Biased beliefs about the pathology of people with disabilities are assumed to hold true for all parents with disabilities. Additionally, parents with disabilities encounter significant barriers to meaningful participation and representation in their own legal cases. "Intervention from state social service agencies and dissolution of the family is often the final blow to parents already struggling under the accumulating impact of stressful and disempowered lives with few choices and fewer opportunities."[473]

While parents with disabilities are especially affected by issues discussed here—historic oppression, current bias, denial of ADA-protected rights to accommodation and inclusion, and discriminatory statutes—they are not alone. Indeed, in *no* community is "the welfare of children…served by breaking up families based on fear and stereotype. If we are truly concerned about the welfare of children, we should invest more money and energy in preventive services for families rather than in parental rights termination and foster care. Our conception of the parent or parents as individuals, standing alone, without help from the broader community, does children no service."[474]

Accordingly, several steps must be immediately taken to eradicate the pervasive discrimination that parents with disabilities and their children regularly encounter. States must eliminate from their statutes disability as grounds for TPR and must enact legislation that protects the rights of parents with disabilities. Congress should address the disparate treatment experienced by parents with disabilities by adding specific protections for parents with disabilities in the Adoption and Safe Families Act. Further, Congress should shift funding priorities at the federal level so that states have a greater incentive to provide services to families while the children are maintained in the home, as research has shown that in-home services are most effective,

particularly for people with disabilities. DOJ should issue guidance to states—namely child welfare agencies and dependency courts—on their legal obligations pursuant to the ADA. HHS and DOJ should gather data on parents with disabilities and their interactions with child welfare and dependency court systems. In addition, DOJ, in collaboration with HHS, must investigate all reported allegations of child welfare agencies or dependency courts that violate the ADA and must enforce the law as appropriate.

Chapter 6. Parental Disability and Child Welfare in the Native American Community

A Winnebago mother who has intellectual disabilities faces termination of parental rights to her six-year-old son on the basis of speculation about her capacity to help her child with homework and provide discipline in the future. A Cherokee father is told that his mild and controlled psychiatric disability is grounds for his infant daughter's removal to a non-Indian foster home with no finding of neglect or abuse. A Pomo mother and Blackfoot father, both with physical disabilities, are denied services for 18 months to reunify with their child, who was removed from them at birth. An Alaskan Native mother and grandmother are informed that they are "unfit" to retain custody of the family toddler because of the grandmother's physical disability and the mother's intellectual disabilities. At stake in these cases are more than just the breaking hearts of children and parents. These cases tear at the dignity of people with disabilities, the welfare of Native American families, and the very fabric and future of sovereign Native American nations.

The Tribal Context: A Brief Overview

There are 565 federally recognized Indian tribes, living in 326 reservations, *rancherias*, villages, and urban Indian communities nationwide.[475] Indian tribes are sovereign entities that have a nation-to-nation relationship with the federal government. That relationship and their relationships to state and local governments are highly circumscribed by statutory and case law. Most of these tribes have some form of executive, legislative, and (in 150 tribes) judicial systems, in the form of tribal courts.[476] They also have independent social and health services funded through a complex web of federal, tribal, and state monies. Although underfunded, many tribal courts are developed enough to provide a child welfare court. However, many others are not. Moreover, even when the court exists, 61 percent of Native American (NA) people live outside of the jurisdictional boundaries of their tribe.[477] This means that child welfare cases involving NA families frequently occur in state child welfare courts and rely on state and local social services in the child welfare process.

The History of Native Americans and Child Welfare

A Native American family that includes a parent with a disability combines two of the most historically oppressed populations in American history. Between 1978 and 1990, sweeping federal laws were enacted—the ADA and the Indian Child Welfare Act—that recognized the need of both populations for protection after many decades of relentless, systemic violation of their human and civil rights. The Indian Child Welfare Act of 1978 (ICWA) was passed

in response to the fact that 25 percent to 35 percent of all Native American children were being systematically removed from their homes and adopted into European American homes.[478] In passing ICWA, Congress declared "that there is no resource that is more vital to the continued existence and integrity of Indian tribes than their children and… that an alarmingly high percentage of Indian families are broken up by the removal, often unwarranted, of their children from them by nontribal public and private agencies."[479]

The Statistics

In a 17-state survey conducted by TLG, there was a 26.5 percent rate of disability among Native American caregivers from whom the child welfare system removed children. The number is shockingly high, yet it makes sense. The disability rate among Native Americans between the ages of 16 and 64 is 27 percent, compared with 18 percent in the general U.S. population.[480] As discussed in Chapter 5, child welfare removal rates are disproportionately high for parents with disabilities. Similarly, Native American children are overrepresented in child welfare systems wherever they reside.[481] While Native Americans are only 0.8 percent of the total U.S. population,[482] they constitute 1.7 percent of the child welfare caseload nationally, a vast overrepresentation.[483] Native Americans and African Americans are more likely than all other U.S. groups to be investigated by child welfare, to have allegations of abuse or neglect substantiated, and to have their children removed and placed in foster care.[484]

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Summary of the Indian Child Welfare Act

ICWA applies whenever a parent is legally restricted from accessing his or her child if the child is enrolled or eligible for enrollment with a federally recognized Indian tribe.[485] The most significant class of cases to which ICWA applies are child welfare cases. Theoretically, ICWA should protect children of parents with disabilities and their families. Caseworkers in ICWA-governed cases must take the following actions:[486]

- Provide active efforts to the family.
- Identify a placement that fits under the ICWA preference provisions.
- Notify the child's tribe and the child's parents of the child custody proceeding.
- Actively involve the child's tribe and the child's parents in the proceedings.

Unfortunately, the reverse tends to occur when the ADA and ICWA intersect. Instead of ICWA strengthening the protections for parents with disabilities, the parent's disability appears to undermine the protection ICWA is designed to provide.

The Intersection of the ADA and ICWA

These two laws and populations are increasingly intersecting in child welfare cases in state courts. In a recently concluded study entitled *The Perspective and Demographics of Parents Contacting Through the Looking Glass Regarding Custody Issues*, Native Americans made up 5 percent of all participants.[487] This is six times

the percentage of Native Americans in the U.S. population.[488] This result prompted the primary investigator to conduct an informal survey of 100 child welfare appeals cases in which the child claimed to be Indian within the meaning of the ICWA and the child or a parent had a disability. She found that in 19 percent of the cases, the child was in fact Indian and the parent's disability was a factor in the case.

In tribal courts, neither the ADA nor ICWA applies automatically to the activities of tribal governments, because these are sovereign nations.[489] However, many tribes incorporate ICWA into their own legislation and attempt to enforce its provisions in state court, where tribes have standing in child welfare cases involving their citizen children. Understandably, they are no more sophisticated than the general population of professionals in their understanding of how the ADA applies to cases involving parental disability. As a result, they may endorse as "active" efforts that fail even to reach the level of "reasonable": services not accommodated for the disability of the parent. Moreover, they are vulnerable to the same assumptions regarding lack of capacity as other professionals who do not understand the types of services, equipment, and techniques that can support good parenting with this population.

In tribal courts, neither the ADA nor ICWA applies automatically to the activities of tribal governments, because these are sovereign nations.

Lack of Services

We could not find a disability or Native American organization that provides any services specific to parents with disabilities, culturally relevant or otherwise. Lack of services has been identified as a factor in decisions to substantiate allegations of abuse or neglect.[490] It is known that a serious barrier to success in child welfare is the lack of service providers, especially in rural areas,[491] and that overinvolvement in child welfare is a significant indicator of insufficient services for parents with and without disabilities.[492] This is of special concern in the context of Native American communities because, in the words of researchers Harris and Hackett, "Racial inequity in service availability and service delivery has been found to be the strongest contributing factor in disproportionate numbers of children of color in placement with child welfare."[493]

Need for Culturally Relevant Services and Training

Because of the complex funding scheme for Native American services, delivery systems look different in Indian country than they do in non-Native counties or municipalities. Differences also exist between service delivery systems on different reservations and between reservation and urban settings. Five basic service systems should "touch" child welfare cases in which parental/caregiver disability is involved: (1) tribal lawyers, judges, law enforcement, ICWA specialists, social workers, and foster care system staff working in the context of child welfare cases; (2) mental health and independent living/skills training staff; (3) occupational therapists and rehabilitation staff; (4) medical staff who work with expectant mothers or in delivery settings; and (5) early intervention, Early Head Start/Head Start, and family wellness program staff who serve families in education, child care, or abuse/neglect prevention.

Services and training capacity must be developed with an eye toward cultural relevance and practical utility in the community. For example, although each tribe is unique, many Native American cultures share a concept of family very different from that of mainstream society. In Native American culture, the extended family, clan, and larger community have various levels of rights and responsibilities for tribal children. Similarly, traditional Native American views of disability—its causes and implications—are generally dissimilar to views in non-Native communities. In fact, most tribal languages have no term for disability, and the idea has no direct parallel in Native cultures.[494]

[M]ost tribal languages have no term for disability, and the idea has no direct parallel in Native cultures.

Regarding successful child welfare projects in Indian country, a substantive examination by the National Indian Child Welfare Association stated:

> "What can be brought to a community is help with problem-solving skills and strategies, facilitation of a community development process, and sharing of technical information or knowledge to show people how to achieve their own goals."[495]

Emerging organizations such as the Bay Area Collaborative on American Indian Resources and the National Urban Indian Family Coalition, along with existing Native American disability services, are starting to provide technical information and knowledge about parents with disabilities and how to support them in their own communities. Long-standing organizations such as the Native American Independent Living Services (which serves American Indian/Alaskan Native people in New Mexico) and the Native American Disability Law Center (which works with the Pueblo communities in the Southwest) are the kinds of partners from whom advocates in the field of disability/parenting could benefit.

Need for Data Collection

Tribal courts are often left out of data collection on child welfare matters. In fact, the National Child Abuse and Neglect Data Set—a significant national database that collects information on the causes and demographics of child welfare system consumers—does not include any tribal court information.

Conclusion

It is imperative for the future of sovereign Native American nations that their families be preserved. Addressing the intersection of disability in ICWA cases with training and support services developed for both reservation and urban Indian communities could play a significant preservative role. It is not necessary that the ADA be legislated into tribal law, although tribal law acknowledging the need to retain nonpathological views of people with disabilities would be useful. Instead, tribes need to be supported in (1) developing culturally relevant supportive services to prevent the entry of their families into child welfare systems or increase the likelihood of good outcomes when they do have to deal with these systems; (2) having policies and guidelines to inform their course of action when they recognize that attitudinal bias is influencing the state child welfare process; and (3) recognizing when the ADA should be, but is not being, implemented appropriately in these cases.

Chapter 7. The Family Law System: Custody and Visitation

Parents' Stories: Kaney O'Neill

In September 2009, Kaney O'Neill, a veteran and quadriplegic mother, faced an unexpected battle when her former boyfriend filed for custody of their 10-week-old son, alleging that Kaney was "not a fit and proper person" to care for their son and that her disability "greatly limits her ability to care for the minor, or even wake up if the minor is distressed."[496]

Refuting this allegation, Kaney demonstrated her ability to care for their son. Indeed, she had prepared for motherhood by working with an occupational therapy program for expectant mothers and parents, adapting her house for parenting, securing adapted baby care equipment, and using personal assistants to help her as needed.[497]

Illustrating the bias that pervades the family law system, an attorney who was not affiliated with the case remarked, "Certainly, I sympathize with the mom, but assuming both parties are equal (in other respects), isn't the child obviously better off with the father?"[498] This attorney, who has specialized in divorce and custody cases for more than 40 years, said that Kaney "would likely not be able to teach her son to write, paint or play ball."[499] The attorney asked a news reporter, "What's the effect on the child—feeling sorry for the mother and becoming the parent?"[500]

Parents with disabilities often face such sentiments. Kaney's battle endured for a year-and-a-half before both parties came to an agreement that gives the father visitation rights.[501] Although she was elated with the outcome, Kaney told reporters that she was "…disappointed that the courts allow for someone to question your ability to have custody based on your disability."[502]

This chapter explores the family law system's treatment of parents with disabilities and their families involved in custody and visitation disputes. It begins with a brief overview of the family law system, as it relates to custody and visitation disputes, followed by an examination of the discriminatory practices in the system. Next, the chapter analyzes the

patchwork quilt of state laws, many of which overtly discriminate against parents with disabilities. This chapter then discusses the family law system's bias, speculation, and the arbitrary "best interest of the child" standard. It concludes with a discussion of the significant barriers parents with disabilities and their families face in securing legal representation and meaningful participation in their cases, as well as the impact of the family law system on children.

The Family Law System: A Brief Overview

The family law system deals with a variety of domestic relation matters, such as marriage, divorce, domestic abuse, prenuptial agreements, child support, and child custody and visitation. This chapter focuses on the family law system's involvement in 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 TPR by the state in child welfare. However, when parents are unable to reach a custody or visitation agreement between themselves, the family law courts are left to decide child custody without the constitutional mandates, based on the best interest of the child standard. Family law cases are governed by individual state statutes. Most states have developed their own factors to determine which custody arrangement is in the best interest of the child. In making child custody and visitation decisions, family courts typically try to determine which parent is more likely to fulfill the child's physical, emotional, intellectual and basic health and safety needs.

Disability Law and the Family Law System

Section 504 of the Rehabilitation Act and Title II of the ADA mandates access to family law courts. Indeed, DOJ considers court actions to be "state activity" for purposes of the ADA. In addition, entities that receive federal financial assistance from DOJ, including state judicial systems, are prohibited from discrimination on the basis of disability under Section 504 of the Rehabilitation Act.[503] The Supreme Court has held that providing people with disabilities with access to courts is a mandate of Title II. According to the Court, "Unequal treatment of disabled persons in the administration of judicial services has a long history," which the ADA has sought to redress.[504]

Family law courts:

- Must provide parents with disabilities with an equal opportunity to participate in programs, services, and activities.[505] To implement this mandate, the courts must make reasonable modifications in policies, practices, or procedures unless such modifications would fundamentally alter the nature of the service, program, or activity.[506]
- Should administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified people with disabilities.[507]
- May not impose or apply eligibility criteria that screen out or tend to screen out any person with a disability from fully and equally enjoying any service, program, or

activity, unless such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.[508]

- Must furnish auxiliary aids and services when necessary to ensure effective communication, unless an undue burden or fundamental alteration would result.[509]
- May provide benefits, services, or advantages beyond those required by the regulation to people with disabilities.[510]
- May not impose surcharges on people with disabilities to cover the costs of measures to ensure nondiscriminatory treatment, such as making necessary modifications required to provide program accessibility or providing qualified interpreters.[511]
- May not deny the benefits of programs, activities, and services to people with disabilities because entities' facilities are inaccessible.[512]

In addition, programs and activities, viewed in their entirety, must be readily accessible to and usable by people with disabilities.[513]

Family Law System

- Marriage
- Divorce
- Domestic abuse
- Prenuptial agreements
- Child support
- Child custody and visitation

Title III of the ADA is also relevant, as it governs private attorneys and most court evaluators. Private attorneys and mostevaluators:

- Shall not impose or apply eligibility criteria that screen out or tend to screen out a person with a disability from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of such goods, services, and so on.[514]
- Make reasonable modifications in policies, practices, or procedures when such modifications are necessary to ensure that people with disabilities have access to the goods, services, facilities, privileges, advantages, or accommodations, unless they can demonstrate that making the modifications would fundamentally alter the nature of such goods, services, and so on.[515]
- Shall take the necessary steps to ensure that no person with a disability is excluded, denied services, segregated, or otherwise treated differently because of the absence of auxiliary aids and services, unless they can demonstrate that taking those steps would result in a fundamental alteration or undue burden.[516]

The System Parents with Disabilities and Their Families Are Likely to Experience

More than half of American families will experience legal separation or divorce.[517] Parents

with disabilities who become involved in the family law system for adjudication of custody or visitation disputes do not expect a pleasant experience; however, they are often shocked at the bias they encounter in the system.

Such bias was apparent in the 1979 case *In re Marriage of Carney*,[518] which is among the most widely recognized decisions to address the custody rights of parents with disabilities. In this case, the mother of two children petitioned the courts to have a previous custody order changed because the father had sustained a spinal cord injury and had quadriplegia. The lower court granted the mother's motion to change custody, having determined that because of the father's disability, his relationship with his children would no longer be "normal." The father appealed the decision, and the case was heard by the California Supreme Court. The California Supreme Court reversed the trial court's decision, stating that the father's disability did not suggest a lesser ability to be a good parent to his children. The court felt strongly that the parent-child bond was not merely the ability to engage in physical interaction, and thus the father should not have his parental rights severed or reduced simply because of his disability. In reaching this landmark decision, the court stated:

> "On a deeper level…the stereotype [about parents with disabilities] is false because it fails to reach the heart of the parent-child relationship. Contemporary psychology confirms what wise families have perhaps always known—that the essence of parenting is not to be found in the harried rounds of daily carpooling endemic to modern suburban life, or even in the doggedly dutiful acts of 'togetherness' committed every weekend by well-meaning fathers and mothers across America. Rather, its essence lies in the ethical, emotional, and intellectual guidance the parent gives to the child throughout his formative years, and often beyond. The source of this guidance is the adult's own experience of life; its motive power is parental love and concern for the child's well-being; and its teachings deal with such fundamental matters as the child's feelings about himself, his relationships with others, his system of values, his standards of conduct, and his goals and priorities in life."[519]

Of the *Carney* decision, Dave Shade says, "Although it was overturned, the trial court's decision paints an all-too-familiar picture of the parent with a disability: unable to provide care, unable to provide love, unable to be a parent."[520]

Although the higher court in *Carney* held that a parent's disability should not be a factor in determining custody, this view has not been consistently enforced. Many parents continue to experience discrimination in child custody and visitation cases, and published court opinions reflect an ambivalent approach to deciding custody and visitation disputes in which a parent has a disability. The frequency and significance of family law issues was demonstrated in 2008, when the TLG legal program completed a study of 200 cases concerning a parent with a disability involved in child custody litigation and found that that largest number of calls (44 percent) came from parents who were involved with the family law system.[521]

Parents with disabilities encounter pervasive discrimination in child custody and visitation disputes. For example, in the summer of 2011, a custody dispute concerning a mother with stage IV breast cancer made headlines. In this case, which reached the Supreme Court of North

Phoebe Ball, NCD Legislative Affairs Specialist, hugs her daughter, Sophia, in a candy store.

Carolina, a judge ruled that the children must live with their father, in part because of their mother's breast cancer diagnosis.[522] A psychologist who evaluated the couple as part of the custody proceedings sided with the father. Nonetheless, she said she had reservations about the decision because "she did not know for sure whether it would be better for the children to be with [the mother] in the last year or years of her sickness."[523] In response to this case, a family attorney told a news reporter, "Medical conditions and their potential consequences on parents often are factors in custody and divorce proceedings. Weighing the possibility of a parent's deteriorating condition or premature death might sound terrible to parents, but they are valid questions the court must consider."[524] The issue of "normal" reared its ugly head in this case, when the judge cited a psychologist's testimony: "The more contact [the children] have with the non-ill parent, the better they do.[525] They divide their world into the cancer world and a free-of-cancer world. Children want a normal childhood, and it is not normal with an ill parent." Further, according to Courtney Hutchison, ABC News Medical Unit, "In accordance with the Uniform Marriage and Divorce Act, it is not uncommon for family court to take into account the health, both physical and mental, of a parent in making custody decisions."[526]

In another example of how the family law system treats parents with disabilities, "A judge maintained that a mother with a physical disability could not parent despite findings of psychological and occupational therapy evaluations documenting her capability. He assumed that the children would function as her attendants, though the mother was independent, there was personal assistance to meet her needs, the home was modified with adaptations, and her children had only the usual household chores. There were concerns about how quickly she could get upstairs in an emergency. When her ability to get upstairs was demonstrated, the next demand [by the judge] was to test her speed with a stopwatch."[527]

As recent cases illustrate, despite the 1979 *Carney* decision, parents with disabilities often face disparate treatment in the family law system. Certainly, *Carney* "articulated a standard vis-à-vis parents with physical disabilities to which a number of other states have hewn. Even in the context of stigmatized illnesses, such as infection

with human immunodeficiency virus (HIV), courts generally have been inclined to rule in favor of custody or visitation, absent proof of some direct risk to the child's well-being."[528] Appellate cases that involve parents with sensory disabilities, such as blindness and deafness, indicate an approach similar to the *Carney* line of cases.[529] However, recent cases demonstrate that parents' disabilities are still often raised as an issue.

In custody and visitation cases involving parents with intellectual or developmental disabilities, the family law system demonstrates an ambivalent approach. A North Dakota case reveals a disturbing lack of basis for limiting a parent with an intellectual disability custody and access to her child. In *Holtz v. Holtz*,[530] the trial court heard evidence and argument regarding the need for changing custody from a custodial mother with a developmental disability, dyslexia, and a learning disability. The father sought primary physical custody, despite admitting that he had had almost no contact with his 7-year-old child prior to the lawsuit. The trial court's stated basis for granting the father custody was that the mother had a "mental incapacity to develop as [the child] grows….Therefore, [she] would not be capable or competent to raise the minor child…." Using a "clearly erroneous" standard of review, the state Supreme Court found that there was no reversible error. The decision was affirmed despite the court's acknowledgment that no expert evidence established the parameters of the mother's disabilities at the time of the divorce (though the parenting aide and guardian ad litem gave evidence). That is, the trial court did not make an explicit connection between the child's best interest and the mother's parenting skills, but the North Dakota Supreme Court upheld the trial court's determination.[531]

Parents' Stories: Abbie Dorn

Recently, in a highly publicized case, the courts addressed the visitation rights of a mother with a disability. Abbie Dorn acquired a severe brain injury in 2006, after delivering triplets.[532] In March 2011, after a lengthy battle, Abbie was granted five-day visits annually with her children, as well as monthly 30-minute Skype sessions to maintain a parental relationship.[533] In the ruling, the judge noted that when the children were granted a visit with their mother the previous December, they immediately established a bond with her.[534] As evidence, the judge noted that the children would physically hold on to photographs of their mother that they were given after the visit for long periods of time.[535] According to the ruling, "The court finds that even though Abbie cannot interact with the children, the children can interact with Abbie—and that the interaction is beneficial for the children. They can touch her, see her, bond with her, and can carry these memories with them."[536]

While the family court in Abbie's case ultimately ruled in her favor, many parents with cognitive disabilities are not as fortunate. Lindsay,[537] a mother of two children, was astonished when she learned how the family law system viewed her disability. Like Abbie, Lindsay has an acquired brain injury. Although Lindsay had had custody for a while, the father of her children wanted to establish a more formal agreement. During the mediation, she was astounded by the focus on her disability, especially given that she

had had custody without any problems. Lindsay's physicians and friends were deposed about her disability. Beaten down by her experiences with the family law system, Lindsay ended up relinquishing her custody rights and now has only visitation with her children.

The attitudinal bias that is obvious in cases involving parents with intellectual and developmental disabilities or cognitive disabilities is even more striking in custody and visitation cases involving parents with psychiatric disabilities. According to Kirshbaum, Taube, and Baer:

> "Parents with current psychiatric disabilities—whether minor or major—are more likely, however, to have such disabilities considered and used, at least in part, to decide custody in favor of the nondisabled parent…[I]n a recent case involving an allegation of a change in circumstances, the Supreme Court of North Dakota upheld the trial court's determination that a mother experiencing depression secondary to fibromyalgia and migraine headaches should lose physical custody of her three children to their father. The court so held on the basis of an expert mental health professional's testimony that the oldest child was 'becoming destructively parentified' (that is, 'assuming adult responsibilities and acting as a care provider for younger siblings') because of the mother's disabilities. This change of custody is unusual, given the typical reticence shown by appellate courts to disturb ongoing custody arrangements absent significant effects on children, and the fact that 'parentification' is a theoretical concept for which little, if any, empirical verification exists."[538]

Another example of the use of persistent social stereotypes and prejudicial assumptions can be found in discussions regarding parents on the autism spectrum. These parents are subject to many of the same unfounded stereotypes, claiming incapability to parent or risk of violence, which parents with intellectual and psychiatric disabilities encounter. Additionally, parents on the autism spectrum are often presented as uncaring or lacking empathy toward their children or spouses.[539] Despite research showing these claims to be inaccurate, they persist in guidance provided to family law professionals regarding autism and Asperger's syndrome (a type of autism).[540] For example, a 2003 article by a family law professional made the case that in high-conflict divorces in which one party has a diagnosis of Asperger's, the fault should be presumed to lie predominantly with the autistic parent, even if evidence suggests otherwise.[541] The long-term consequences of these stereotypes are significant—some parents who are on the autism spectrum have said that fear of discrimination in child custody proceedings keeps them from leaving relationships with abusive partners.[542]

As these cases demonstrate, even 33 years after *Carney*, parents with disabilities continue to face discriminatory practices, reflecting attitudinal bias on the part of the family courts. As noted by Jennifer Spreng, professor at Phoenix School of Law, a "'well' father or husband can have an advantage in obtaining custody even if he is an inferior caregiver or has maltreated the children himself."[543]

Bias, Speculation, and the "Best Interest of the Child" Standard

As previously mentioned, family courts use the best interest of the child standard to decide custody matters. Most states have developed their own list of factors to determine which

custody arrangement would be in the best interest of the child.[544] Typical factors include which parent best meets the physical, emotional, intellectual and basic health and safety needs of the child; what does the child want (if the age and maturity of the child render an expressed desire reliable); 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; whether either placement involves a significant other with history of violence or dependency issues. The best interest analysis always allows for a parent's own 'health' to be considered.[545]

Kirshbaum, Taube, and Baer note, "Despite the disability civil rights movement, attitudinal bias regarding disability is still prevalent."[546] Unfortunately, "legal, medical, and mental health professionals are not immune to these biases. Negativity and a lack of cultural competence about disability are reflected in language appearing in unpublished court documents and evaluations, such as 'afflicted with dwarfism,' 'wheelchair bound,' 'suffers from physical disability.'"[547]

The best interest of the child standard has been criticized for giving too much discretion to trial courts and for allowing judicial bias to affect custody and visitation decisions, which often has significant and detrimental consequences for parents with disabilities and their children.[548] Breeden, Olkin, and Taube believe that the best interest of the child standard is too vague and offers little guidance to courts and evaluators.[549] According to Kirshbaum, Taube, and Baer:

Negativity and a lack of cultural competence about disability are reflected in language appearing in unpublished court documents and evaluations, such as 'afflicted with dwarfism,' 'wheelchair bound,' 'suffers from physical disability.'"

"The near absence of explicit rules addressing bias in the assessment of parents with

Factors Used to Determine Best Interest of the Child

1. Which parent best meets the physical, emotional, intellectual and basic health and safety needs of the child;
2. What does the child want (if the age and maturity of the child render an expressed desire reliable);
3. Length of the current custody arrangement and whether it is positive;
4. Whether the alternative arrangement is suitable and stable;
5. Primary caretaking history;
6. Evidence of domestic violence or substance abuse;
7. Evidence of lying to the court about domestic violence or other matters;
8. Whether either placement involves a significant other with history of violence or dependency issues;
9. Parent's own 'health'

disabilities in statutes, rules of court, and professional standards gives few grounds upon which appellate courts can address common problems of bias against parents with disabilities at the pretrial and trial court level. In addition, appellate court cases themselves show signs of bias against parents with disabilities, although they are subtle. Further, one can observe increasingly biased assumptions as the appellate courts move from cases involving obvious physical disabilities (e.g., a person with paraplegia who uses a wheelchair) to those with more subtle or stigmatized disabilities, such as cognitive or psychiatric disabilities. That is, custody cases involving physical disabilities tend to give the impression that appellate courts are giving careful consideration to parenting capacities and the best-interest standard. On the other hand, custody cases involving cognitive or mental disabilities are more suggestive of biased assumptions about the effects of such disabilities on parenting capacities."[550]

Cases frequently reflect underlying presumptions that it is not in a child's best interest to live with—or in some cases even visit—a parent with a disability.[551] Custody and visitation decisions also reflect patterns of increased attitudinal bias regarding certain disabilities.[552] Kirshbaum, Taube, and Baer found that "negative speculations about the future are common and often seem to be based on stereotypes rather than on evidence."[553] Furthermore, courts often assume that children will be forced to provide care to their parents with physical disabilities, which is in stark contrast to what researchers have consistently found.[554]

Parents' Stories: Paul

Paul's story demonstrates the gravity of the situation faced by many parents with disabilities who are involved in the family law system.[555] Paul was a father with quadriplegia and a stay-at-home parent for his three-year-old son Leo. He had spent 20 years as a police officer and became quadriplegic when he was shot on the job. Although Paul used walking canes, his active son was safe in his care. He had door alarms on the doors and bookcases in case Leo tried to climb or leave the house. An ingeniously installed alarm system triggered if Leo tried to leave the yard. Leo had never been hurt or gotten away as a result of Paul's disability. Then Leo's mother filed for divorce, moved out, and filed for full physical custody. She asserted that quadriplegia rendered Paul unable to care for Leo.

Despite uncontested testimony that Paul had always been the primary parent, the Georgia family law court awarded temporary custody to the mother, with severely limited visitation to Paul. Twenty-four-hour supervision was required during the visitation periods, and Paul was ordered to hire a professional nanny to supervise visitations. Over the next two years of litigation, Paul went through a significant portion of his disability retirement fund paying for attorneys, private nannies, interim child support, and assessments.

(continued)

He and his attorney concluded that the only way to show parental capacity was with an Adapted Baby Care Assessment. No occupational therapist was able to do the assessment in their area, so a therapist from TLG flew to Georgia, conducted the assessment, completed and submitted a court report, and appeared in court to defend it at trial. Paul won half custody of Leo with no requirement of supervision. While grateful, he was sad that he had missed a great deal of his son's life. Both he and Leo experienced tremendous grief during the long periods of court-ordered separation.

Parents with intellectual disabilities are not immune to the negative effects of bias and the best interest of the child standard used in the family law system. In fact, several researchers, including attorney Duffy Dillon, contend that parents with intellectual disabilities are in an even more vulnerable position at these proceedings than during dependency cases.[556] Fewer procedural protections are afforded to parents with intellectual disabilities in the context of divorce.[557] Because the best interest standard governs from the beginning, parents with intellectual disabilities "are explicitly denied both an initial fitness analysis and the opportunity to rehabilitate their parenting skills before a final decision is made. Moreover, unlike termination proceedings, divorces involve additional (presumably 'fitter') parties who also vie for the child's custody. Since the best interest standard requires as little disruption in the child's life as possible, pressure exists to make a decision sooner rather than later. Consequently, although divorce courts unquestionably give serious consideration to their custody decisions, decision-makers might gloss over the grave issues that arise in termination proceedings when they arise in divorce."[558]

Parents' Stories: Andrew

Parents with psychiatric disabilities often encounter similar bias, as demonstrated by Andrew's experiences.[559] Andrew is a Korean-American father in New York who has bipolar disorder. He relied on his wife and extended family to help him parent his two young children, Clayton, seven, and Katie, four. His wife decided to move out, taking Clayton and Katie. Her pleadings began by discussing Andrew's mental health history. Although Andrew was stable, this biased the court. Then he became overstimulated by the emotional intensity of the courtroom—flustered, inarticulate, and loud, and unable to make eye contact. The court granted him very limited, supervised visitation.

After the first visit, the mother filed a police report stating that Andrew was "crazy" and abused the children. Her attorney filed to suspend visits pending investigation and won. The judge noted concern regarding the allegation of abuse in combination with Andrew's diagnosis. This became the pattern, repeating over months. Andrew's therapist contacted TLG's legal program, which supported her in filing a motion to have one of its therapists supervise visits and provide intervention services with Andrew and the children. The therapist had expertise in family systems and psychosocial disability and parenting. She met regularly with Andrew and his children for weeks in their home and in the community. She believed that Andrew was not abusive and did not require supervision.

Her report submission coincided with the final allegation of abuse. The mother alleged that Andrew sexually abused Clayton in a mall bathroom during an afternoon visit. Fortunately, surveillance camera footage was available, and the police determined that Andrew never took Clayton into a mall bathroom. With proof that this allegation was false and a positive report from the therapist, the court granted unsupervised visits.

Andrew's family was unable to absorb the financial and emotional strain and believed that it was all too much for Andrew; that he would decompensate over time from the stress. They refused to allow visits or overnights at their home. Andrew does not feel able to live independently, so he has lost contact with his children.

Thus, even in cases where the parent with a disability eventually wins, he or she may lose. These parents face an arduous and expensive task to prove their ability to care for their children, even when they have been doing so before the proceedings without any problems. Duffy Dillon notes, "Although the best interest standard necessarily requires a comparison of two parents, a presumption cannot exist that a disabled parent is per se the weaker parent."[560] As discussed next, the family law system—as well as parents with disabilities and, more important, their children—would greatly benefit from the development of protections for parents with disabilities that counter the current bias, speculation, and discriminatory application of the best interest of the child standard.

The Patchwork Quilt of State Laws

From state to state, statutory criteria for the award of custody vary considerably, but all states use the best interest of the child standard.[561] In an effort to clarify the meaning of this standard, most states have adopted, at least in part, the model custody language proposed by the Uniform Marriage and Divorce Act.[562] Several states have expanded the best interest standard and the model statute to include a wide range of factors for the courts to consider in making custody determinations.[563] Some states leave it to the courts to determine the factors that constitute a child's best interest.[564] All states allow—and a number mandate—consideration of a parent's physical and mental health.[565]

Many states remain silent on the issue of whether a parent's disability should affect child custody and visitation matters. Further, many states do not have adequate laws to protect parents with disabilities in child custody proceedings. Omission or inadequacy of protections for parents with disabilities coupled with an amorphous judicial standard leave parents with disabilities in family court exposed to unnecessary, often expensive, litigation. This is true even when the person with the disability has successfully parented for many years.

Fortunately, there has been moderate progress in child custody laws for parents with disabilities. For example, in August 2010, California Governor Arnold Schwarzenegger signed SB 1188; the law, which went into effect on January 1, 2011, codifies *Carney*, shifting the burden of proof onto the parent who raises the disability as an issue and states that disability cannot form the basis of custody or visitation orders "unless that party establishes by clear and convincing evidence that a grant of custody or visitation to the disabled parent would be detrimental to the health, safety, and welfare of the child."

Similarly, Minnesota Statute 518.17 addresses the issue of disabilities of a proposed child custodian. This statute states that the court can consider and evaluate the mental and physical health of all persons involved, "except that a disability…of a proposed custodian or the child shall not be determinative of the custody of the child, unless the proposed custody arrangement is not in the best interest of the child."

Idaho has passed the most extensive and thorough protections for parents with disabilities, including in family law cases. Idaho Statute 32-717 states:

> "If the parent has a disability as defined in this section, the parent shall have the right to provide evidence and information regarding the manner in which the use of adaptive equipment or supportive services will enable the parent to carry out the responsibilities of parenting the child. The court shall advise the parent of such right. Evaluations of parental fitness shall take into account the use of adaptive equipment and supportive services for parents with disabilities and shall be conducted by, or with the assistance of, a person who has expertise concerning such equipment and services. Nothing in this section shall be construed to create any new or additional obligations on state or local governments to purchase or provide adaptive equipment or supportive services for parents with disabilities…. [N]othing in this chapter shall be construed to allow discrimination on the basis of disability. In any case where the disability of a parent is found by the court to be relevant to an award of custody of a child, the court shall make specific findings concerning the disability and what effect, if any, the court finds the disability has on the best interests of the child."

While states such as California, Minnesota, and Idaho have moved in the right direction in protecting parents with disabilities in family court, many states have not. Capricious legislation coupled with the ambiguous best interest of the child standard leaves parents with disabilities open to discriminatory treatment and their children at a disadvantage. Until state laws are harmonized, with clearer allocation of evidentiary burdens and enforcement of nexus provisions, parents with disabilities will continue to face discriminatory treatment, and their children will suffer.

Issues in Meaningful Participation and the Total Lack of Guaranteed Representation

Compounding an already arduous situation in the family law system, parents with disabilities face a complete lack of guaranteed legal representation and a plethora of barriers to meaningful participation. While parents have a right to representation in dependency cases in the majority of states, "there is no corps of family law specialists comparable to the public defender system that is educationally, administratively, and financially prepared to represent the rights of the indigent parent."[566] Indeed, obtaining appropriate and effective legal representation is often the first obstacle a parent with a disability faces in a child custody case. Whereas in dependency cases parents with disabilities generally have a right to counsel, no such right exists in custody and visitation matters—litigants must fund their own legal representation. Parents with disabilities often have limited incomes and more expenses than parents without disabilities.[567] They are less likely to have the financial resources to retain private attorneys.[568] Similarly, court costs and filing fees present significant barriers for parents with disabilities.[569]

Parents with disabilities often seek representation from legal service agencies and other advocacy organizations.[570] However, Kirshbaum, Taube, and Baer found that "many parents with disabilities are surprised to discover that, throughout the United States, it is rare for disability legal advocacy organizations to become involved in marital custody cases…. P]arents with disabilities are often unable to obtain assistance from local, non-disability-specific legal service agencies [; these…] agencies are restricted in the types of cases for which they can provide representation."[571] Additionally, "Even where low-cost representation is offered by legal service agencies, it may be effectively unavailable. In many states, legal service agencies will represent only one spouse in dissolution or child custody dispute due to conflict of interest issues."[572] Moreover, legal service agencies have experienced significant funding cuts, further hampering their ability to represent parents with disabilities.[573] In 2012, legal service agencies anticipate laying off nearly 400 employees; the reductions continue a staff downturn that began a few years ago.[574] Limited financial resources also make it difficult—if not impossible—for many parents with disabilities to obtain expert witnesses, who are extremely important and often determinative in these cases.[575]

Limited financial resources also make it difficult—if not impossible—for many parents with disabilities to obtain expert witnesses, who are extremely important and often determinative in these cases.

Even when parents can retain private legal representation, finding an attorney with disability-relevant experience and knowledge is challenging.[576] Parents with disabilities face significant barriers within the family law system, largely because of bias and speculation; attorneys, like judges, are not immune to prejudice. Parents with disabilities must retain counsel that understands the barriers they

face and how to overcome them. Counsel must not only have expertise in family law but must understand disability or be willing to work with experts and advocates. Unfortunately, such legal representation does not exist in large numbers.

Parents with disabilities are also likely to encounter difficulty retaining a private attorney who will adequately accommodate their disability. Title III of the ADA mandates private attorneys to provide clients with disabilities reasonable accommodations, such as interpreter services.[577] Because private attorneys are generally required to absorb the costs of accommodations, they may decline this kind of case, although they will likely justify declining the case on other grounds.

Because obtaining affordable and effective representation is a significant barrier for many parents with disabilities, Kirshbaum, Taube, and Baer have found that those "who do not have legal representation often will simply not show up for a court appearance, unaware of the consequences of a failure to appear. They often think that their absence will merely postpone the issue, not that their legal rights may be lost, and [they] do not know that they can appear in court and ask the judge for a continuance while they find an attorney."[578] Such actions have enormous implications in these cases.

Parents with disabilities encounter a variety of other obstacles to meaningful participation in the family law system. Despite the mandates of the Rehabilitation Act and the ADA, physical access to courts is still a challenge in many communities, particularly in smaller towns and rural regions.[579] Similarly, it is very common for parents with disabilities to face limited programmatic access, such as effective communication, during or regarding family court proceedings.[580] Even when they request accommodations in advance, parents with intellectual disabilities often are not provided with advocates or translators so they can understand the family court process.[581] Moreover, attorneys are often hesitant to request accommodations because they think calling attention to the parent's disability might affect the custody outcome.[582] Such barriers to physical and programmatic access greatly impede parents with disabilities from meaningful participation.

[A]ttorneys are often hesitant to request accommodations because they think calling attention to the parent's disability might affect the custody outcome.

Thus, parents with disabilities all too frequently face significant barriers to retaining effective and affordable legal representation as well as meaningful participation in the family law system. At the same time, because of discrimination, their participation and involvement are crucial to securing a reasoned and nonbiased outcome in their child custody case. Professionals—including judges, attorneys, and evaluation personnel—need to be trained regularly on parents with disabilities and their children. This training should be a mandatory component of continuing education requirements for such professionals. Moreover, DOJ must issue guidance to family courts and attorneys,

reinforcing their legal obligations pursuant to the ADA. Such guidance must address (1) the applicability of the ADA to custody and visitation proceedings; (2) the courts' duty to provide reasonable accommodations to parents with disabilities; and (3) the fact that presumptions of parental incompetence based on disability violate the ADA.

The Impact on Children

Children are at the center of all custody and visitation disputes, and are the most deeply affected by the outcomes of these cases. Children who are removed from their parents because of parental disability experience the same trauma from separation and loss of the primary caregiver that they face in dependency cases.[583] Moreover, Callow, Buckland, and Jones believe that "these children also have a greatly increased risk for postremoval maltreatment. As a biased response to the parent's disability, court officers, evaluators, and mediators are frequently in a rush to justify a move from the parent with a disability to a typical or able-bodied caregiver. This brings the courts to accept alternatives that would be unacceptable were the disability not a factor. Unlike Callow's experiences with the general population in family court cases, [she] finds that children with a parent who has a disability are more frequently placed with the other (nondisabled parent) or an extended family member who has a history of abuse, addiction, poor decision making or parenting; has had little or no contact with the child; or will not be a 'friendly parent'; that is, one who will facilitate an ongoing relationship between the child and the parent with a disability."[584]

> "For many, many children, the trauma of losing their families—one of the greatest traumas a child can endure—is heightened when they are abused or neglected…by co-parents or extended family members who have histories of violence, substance abuse, or neglect and would never have won custody from an able-bodied parent. Such suffering has repercussions not only for the children, but for society."[585]

Conclusion

Each year the destiny of millions of children are decided in divorce, custody, and visitation proceedings throughout the United States.[586] Custody and visitation disputes should be based on the best interest of the child; a parent's status as disabled should be irrelevant to the analysis without an evidentiary showing of nexus between the parental disability and a detrimental impact on the child.

Parents with disabilities are likely to encounter disparate treatment in the family law system entirely on the basis of other people's perception of their disability and its impact on parenting. This discrimination is compounded by the patchwork quilt of state laws, attitudinal bias regarding the child-rearing abilities of parents with disabilities, and the effect of this bias on the already amorphous best interest of the child standard. Parents with disabilities have their child-rearing abilities evaluated with inappropriate and unadapted assessments as well as a lack of adaptive services and equipment. They often face significant barriers to retaining legal representation and participating in a meaningful way in the proceedings. These barriers are not just problematic in theory;

they have practical ramifications right now. A national study conducted by Margaret A. Nosek and colleagues revealed that women with disabilities are significantly more likely than those without disabilities to stay in a bad marriage out of fear of losing their children.[587] Thus, the unnecessary obstacles and stereotypes plaguing the family law system for parents with disabilities have profound consequences for people with disabilities and their children.

Chapter 8. Inappropriate and Unadapted Parenting Assessments in Child Welfare and Family Court

Assessments to evaluate a parent's ability to care for his or her child are often crucial to the outcomes of custody proceedings in child welfare and family court. These assessments are generally sought or court-ordered; they are conducted by mental health professionals, primarily psychologists, who then frequently function as expert witnesses in court. This chapter considers the quality, the appropriateness, and the role of bias in parenting assessments of parents with disabilities.

The Role of Assessments in Determining Outcomes

Some scholars link an overly heavy reliance on expert testimony by mental health professionals in decisions in child custody matters to the vagueness of the best interest of the child standard.[588] Guidelines from the American Psychological Association (APA) reflect controversy in the field regarding the appropriateness of such evaluators making "ultimate opinion" testimony recommendations about child custody or termination of parental rights determinations. The acknowledged influence of these evaluators on outcomes leads the APA to caution them against "relying on personal biases or unsupported beliefs."589 Psychologists who conduct child protection evaluations are urged to be aware that in TPR there is "a finality prompting both due process protections and higher standards of proof."590 The reliance on parenting assessments, conducted with questionable evaluation methods, has raised concerns about invalid and biased recommendations and decisions in general custody evaluation practice.[591]

Using a systematic examination of foster care court cases, Lenore M. McWey, Tammy L. Henderson, and Susan N. Tice found that family therapists are often asked to provide expertise even though they lack knowledge of current foster care policy.[592] In all the cases examined, only two (6 percent) mentioned a therapist seeing the parent and child together before testifying about parental fitness.[593] In one of those cases, a therapist did conduct a family assessment before testifying in court, but the therapist only saw the family together twice for a total of two hours. In the other case, the therapist saw the family once, completed a "parent–child interaction assessment," conducted family play therapy, then testified about parental fitness. In the rest of the cases, therapists testified that although they had not seen the parent and the children together, they could make decisions about parental rights solely on the basis of the parent's mental health status. In one case, a parent appealed the lower court's decision explicitly because the therapist had never seen

the family interact together before testifying that parental rights should be terminated. However, the court did not uphold the appeal and asserted that although the therapist "had never seen the children, or seen [the client] interact with them, the therapist had seen [the client]…and admitted that the parent did not qualify as an exceptional parent, not for lack of trying, but for the issues she was still struggling within herself to resolve in therapy." In another instance, a therapist who worked with a mother at an inpatient facility testified that "based on her interview and testing of the mother . . . the mother lacked the emotional ability to parent effectively." Again, parent-child assessments were not conducted.[594]

Bias in Assessment

APA guidelines for psychologists regarding child custody evaluations in family law, evaluations in child protection matters, and assessment and intervention with people with disabilities all emphasize the importance of culturally informed and nondiscriminatory practices.[595] According to the APA, "Biases and an attendant lack of culturally competent insight are likely to interfere with data collection and interpretation and thus with the development of valid opinions and recommendations."[596]

Recent APA guidelines for evaluations in child protection matters incorporate additional language highlighting potential bias concerning parental disability:

> "Unrecognized personal biases may compromise the ethical integrity and legal reliability of evaluation conclusions and recommendations. Such biases include those related to age, gender, gender identity, gender expression, race, ethnicity, national origin, religion, sexual orientation, disability, language, culture and socioeconomic status and immigration status…. Societal prejudices, just as perniciously, may lead to discriminatory, unfair use of evaluation methods and reasoning that disrespect examinee's rights and dignity and undermine the scientific and professional bases of the child protection evaluation…. Psychologists also seek to remain aware of the stigma associated with disabilities often found in child protection cases, such as intellectual disabilities and psychiatric disabilities…and they ensure that they have sufficient professional competencies to provide an objective and accurate evaluation of persons with these disabilities…. In addition, psychologists seek to address aspects of the disability that are relevant to parenting, and remain mindful of the potential impact of stigma or bias in their own professional work and that of others involved in the case."[597]

APA's new guidelines for assessment and intervention with persons with disabilities emphasize that "particular care needs to be exercised by psychologists performing assessments in high-stakes, potentially contentious contexts," including parenting.[598] This exercise of care must include the management of potential bias.

Unfortunately, as attorney Joshua B. Kay notes, mental health professionals conducting parenting assessments "may harbor their own stereotypes about people with disabilities. These stereotypes may reinforce those that judges and agency workers bring to the table, thereby replacing meaningful individualized inquiry with class-based declarations."[599]

Bias can ripple through the system, beginning with the referral to the evaluator. Analysis of evaluations in the child welfare system suggests that in cases involving parents with disabilities, the referral questions that the courts ask the evaluator to address often reflect bias.[600] Negative assumptions about outcome may be included in the referral and may affect the objectivity of the evaluation. Referral questions are often structured like this:

> "If Ms. X. suffers from a mental disability that renders her unable to care for and control the child adequately and if the disability renders her incapable of using reunification services, does the disability nevertheless make it unlikely that she will be capable of adequately caring for and controlling the child if reunification services were provided for six months?"

This question contains a problematic premise from the point of view of disability rights: It assumes that the disability status of the person being tested is in itself sufficient to determine whether the person can access services. In questions like these, no onus is put on services funded by the court to adapt to the needs of the parent with the disability.[601]

Testing of People with Disabilities in General

The Rehabilitation Act of 1973 requires "appropriate adjustment or modification of examinations" and "reasonable accommodations" to avoid discrimination against people with disabilities.[602] Similarly, Title III of the ADA governs psychological practice and requires "reasonable accommodation and the inclusion of modified examinations as a form of accommodation."[603]

For many years, evidence has indicated that testing people with diverse disabilities may require extensive specialized knowledge and skills; that a measure's appropriateness for particular individuals with disabilities requires reviewing its validating efforts; that standardized instruments may lack appropriate norms or accommodations; that the meaning of test scores may be significantly altered in the presence of disability; and that erroneous and misleading results can be produced without attention to these issues.[604] According to Rhoda Olkin, distinguished professor and director of the Institute on Disability and Health Psychology, Alliant International University, "Disability can affect testing in a variety of ways: if tests contain items that measure disability instead of the intended construct, if the process of taking a test is appreciably altered, and if the interpretations of results misapplies able-bodied norms to the client with a disability. A hallmark of testing is standardization, and the essence of disability is individualization."[605]

Although the Rehabilitation Act and the ADA require modification of examinations as a reasonable accommodation, parents with disabilities are often not afforded these protections when it comes to parenting assessments.

Assessment of Parents with Disabilities in Both Systems

Although the Rehabilitation Act and the ADA require modification of examinations

as a reasonable accommodation, parents with disabilities are often not afforded these protections when it comes to parenting assessments. Instead, and to their detriment, parents are often evaluated using inappropriate and unadapted assessments.

Evaluators in child custody situations in child welfare and family courts typically use generic standardized tests as well as tests designed to assess parenting. Critics have questioned the validity and reliability of standardized assessment procedures applied to assessment of the capability and functioning of parents in general, as well as instruments specifically designed to assess general parenting.[606]

Concerns about appropriate test selection fall broadly into two categories: ecological validity of the tests and appropriateness of the normative samples for assessment of this population. Ecological validity is the question of whether or not the test measures a construct that relates to the ability in question; for example, whether a test of IQ or performance on the Rorschach accurately relates to parenting capacity. The question of an appropriate normative base relates to whether people in the population being tested were included in the population sample on which the test was normed. APA guidelines urge that psychologists use, whenever available, tests and norms based on populations similar to those being evaluated.[607]

People with disabilities have not been included in the sample populations on which many psychological tests and measures are normed.[608] This increases the likelihood that their test performance will look deficient in comparison with that of the general population. It also makes it impossible to derive population-specific norms that would indicate an expected range of performance on a given test or measure for people with specific disabilities.

In-process research on tests and measures being used in child welfare and family court evaluations of parents with diverse disabilities suggests that it is rare for people with disabilities to have been included in the normative bases of the tests and measures.[609] This is particularly concerning because of the disproportionate role of testing in parenting evaluations of people with disabilities compared with observation of parent-child interaction.

A number of studies have shown that the "parental-child relationship dictates parental fitness and not IQ levels." Nonetheless, children are often removed primarily on the basis of their parent's IQ.

Evaluators' reliance on psychometric testing has included IQ tests and assumptions about what people with various IQ scores can and cannot do. This is particularly detrimental for parents with intellectual disabilities. According to researchers David McConnell and Gwynnyth Llewellyn, "These tests continue to be administered despite the research evidence demonstrating that parental IQ is a poor predictor of parenting competence. When norm-referenced assessments are used, (sub)normal may be equated with (in)adequate so that the parenting practices and behaviors of parents with intellectual disability are judged subnormal and inadequate rather than simply different."[610]

In her *Whittier Journal of Child and Family Advocacy* article, Jennifer A. Culhane said, "Parenting ability is a complex set of variables that cannot be reduced to a simple intelligence test. It is imperative that evaluators asked to determine the parenting capabilities of an individual observe the parent and child together over extended periods of time."[611] A number of studies have shown that the "parental-child relationship dictates parental fitness and not IQ levels."[612] Nonetheless, children are often removed primarily on the basis of their parent's IQ.[613]

Sole reliance on the IQ, resulting in diagnosis of intellectual disability, leads to states having "bypass" statutes. For example, many removals occur simply on a categorical or diagnostic basis, without any individualized assessment or observation of parenting. Such categorical removals also occur when parents have psychiatric disabilities, although specialists urge individualized assessment and extensive observation of the parent-child relationship when assessing the capability of such parents.[614] International researchers Alexander Tymchuk and Maurice Feldman warn, "Psychologists must avoid the trap of making assumptions of parental competency primarily on the basis of IQ scores."[615]

In addition to problematic interpretation of IQ tests, Benjamin E. Fife examined the quality of psychological assessments received by parents with disabilities involved in TPR cases and found that projective tests tended to be overused on parents with intellectual disability.[616] He points out that forensic psychologists have urged caution regarding the use of projective measures such as the Thematic Apperception Test and the Rorschach with people with cognitive disabilities.[617] These tests generally are used to help assessors describe personality functioning and the relationship of personality traits to other aspects of psychological functioning. Responses that adults with intellectual disabilities make on projective tests run a high risk of being misinterpreted as showing other pathology and should be interpreted with caution.

In a study conducted by Breeden, Olkin, and Taube of 206 family court custody evaluators,

Study of Family Court Custody Evaluators

In a study of 206 family court custody evaluators, although 68% had conducted at least one custody evaluation with a parent with a physical disability:

- 67% reported they would not modify the process of testing or interpretation of results despite a physical disability of a parent being evaluated
- 85%+ had no specific training regarding custody evaluation of parents with disabilities
- 49% had no training in the psychology of disability, disability culture, or disability studies
- 63% had no training in testing accommodations for people with physical disabilities

Christine Breeden, Rhoda Olkin, and Daniel Taube, "Child Custody Evaluations When One Divorcing Parent has a Physical Disability," Rehabilitation Psychology 53(4) (2008): 445.

two-thirds reported that despite the physical disability of a parent being evaluated, they would use the same tests, in the same way, and with no modifications to the process of testing or interpretation of results. More than 85 percent of the participants had absolutely no specific training regarding conducting custody evaluation with parents with such disabilities; 49 percent had no training in the psychology of disability, disability culture, or disability studies; and almost 63 percent had no training in testing accommodations for people with disabilities. Nevertheless, more than 68 percent of the evaluators had conducted at least one custody evaluation with a parent with a physical disability.[618]

Few psychologists receive adequate specialized education or training regarding disability issues.[619] "Few graduate psychology training programs offer disability coursework.[620] This paucity of training is a major barrier to providing effective services to clients with disabilities.[621] Limited training and experience may leave many psychologists unprepared to provide clients with disabilities with professionally and ethically sound services, including provision of assessments and interventions."[622]

When evaluators have no disability training, the need for consultation with disability specialists is heightened. APA guidelines emphasize this point: "When an examinee possesses a cultural, racial, or other background with which psychologists are unfamiliar, psychologists prepare for and conduct the evaluation with the appropriate degree of informed peer consultation and focal literature review."[623]

According to the APA's guidelines for psychological evaluations in child protection matters, "Particular competencies and knowledge are necessary to perform psychological evaluations in child protection matters so that adequate and appropriate psychological services can be provided to the court, state agencies or other parties…. For example, in cases involving physical disability, such as hearing impairments, orthopedic handicaps, etc., psychologists strive to seek consultation from experts in these areas…."[624]

Despite the heightened need for input from disability specialists, in the aforementioned study of 206 child custody evaluators for family court, only 2 said they would seek consultation when evaluating parents with physical disability, even though most lacked relevant disability training.[625]

"Few graduate psychology training programs offer disability coursework. This paucity of training is a major barrier to providing effective services to clients with disabilities."

In producing such high-stakes, life-transforming reports for child welfare or family court, the APA urges that "psychologists strive to communicate any relevant limitations upon the use, findings, or interpretations of psychological assessment procedures, tools, and/or tests to persons who rely upon their reports or professional opinions/recommendations for guidance or decision-making…."[626]

However, Fife's analysis of child welfare evaluations regarding TPR of parents with diverse disabilities documents that a significant number of evaluations failed to note the limitations of the reliability or validity of their findings.[627]

Megan Kirshbaum, an internationally recognized expert, describes an evaluation she critiqued for court:

"In one child welfare case the mother had significant cerebral palsy with speech involvement. The father, her partner and attendant, had a history of abuse and severe neglect of the mother. The psychologist evaluating the mother's capability as a parent did not observe her with her baby as part of the evaluation; rather, he relied on interviews in his office. Since he couldn't understand the speech of the mother he had the father always present to translate her responses. His evaluation did not cite this as a limitation regarding his conclusions."[628]

In general, it appears that a lack of familiarity with disability issues and resources has resulted in evaluators underestimating both the limitations of their assessments and the importance of adaptations and input from disability specialists in supporting appropriate practice.

Analysis of evaluations of parents with diverse disabilities for child welfare and family court systems has raised a number of issues that compromise quality, in addition to those previously cited:[629]

- Informed consent or parental understanding of the evaluation and its meaning tend not to be documented, despite the heightened attention to informed consent required when a parent has an intellectual or psychiatric disability.[630]
- The parent's disability is often not identified with the accuracy or specificity required to determine appropriate adaptations in practice.[631] For instance, a mother who was hard of hearing was incorrectly diagnosed as having a cognitive disability when tests were used that did not take into consideration that American Sign Language was her primary language.[632]
- Inappropriate and stigma-laden language regarding disability, signaling lack of familiarity with disability culture ("afflicted with multiple sclerosis," "wheelchair bound"), may be used in the evaluation report.[633]
- When the parenting appears adequate at present, pathological speculations may be included regarding problems that might develop in the future. These speculations often reflect a lack of familiarity with disability adaptations and research regarding parents with disabilities and their children.[634]
- Poor-quality evaluations are reported to be common, including substandard writing, use of boilerplate analyses by the same evaluator (even forgetting to change the name from a previous evaluation), and verbatim computer-generated interpretations of tests and measures.[635]

One problem in the evaluations for child welfare and family court is particularly critical. Many of these evaluations do follow the APA guidelines regarding multiple methods of data gathering, including clinical interviews, observations, and psychological assessments. However, observation, if it is included, is often minimal, done in clinical offices, or only during interviews. Studies of child custody evaluation practices with parents in general rank clinical observation of parent and child ahead of psychological testing.[636]

Bias and lack of familiarity with disability and relationships between parents with disabilities and their children increase the importance of observation of actual parent-child interaction. It is encouraging that custody evaluations have become more relational in recent years. There is

more recognition of the parent-child relationship as important to the functioning of both the parent and the child, and more measures are being used that seek to assess parent-child interaction and attachment.[637]

However, Fife's analysis of evaluations for child welfare found that parent-child observation and home visits were underutilized as assessment tools in working with parents with disabilities. And when evaluators did observe parents and children together, they tended to describe parental disability in pathologizing terms, often interpreting as pathological aspects of the parent's functioning with the child that were normal for disability culture and have been found in studies of parent-child interactions not to be detrimental to child development. For example, when a father with cerebral palsy (and no adaptations) needed to take longer to complete a structured play routine with his son compared with nondisabled foster parents, this was identified as evidence of reduced parenting capacity.[638]

Observation of parents with disabilities and their infants or children requires specialized knowledge about disability. Breeden, Olkin, and Taube note, "For example, in evaluation of the emotional attachment of the parent and child, some of the characteristics observed and considered as evidence of poor bonding include a parent's rigid posture, awkward physical touch, stiffness, blank expression, failure to maintain eye contact with the child, and keeping physical distance.[639] Each of these characteristics could be explained by various physical disabilities. For example, rigid posture, awkward physical touch, stiffness, and blank expression could all describe Parkinson's disease. Failure to maintain eye contact is the norm for a parent with visual impairment, and keeping physical distance is self-preservation when arthritic joints are painfully inflamed."[640]

Recent APA guidelines emphasize that it is "essential to consider the interaction between the individual with a disability and his or her environment…the central role of contexts in assessing a person's psychological functioning."[641]

Observation in the home setting is crucial during evaluation of parents with disabilities, because the functioning of the parent and the parent-child dyad can be profoundly affected by being in an unfamiliar environment, without the adaptations and home modifications that are normally used. Analysis of evaluations of diverse parents with disabilities documents the rarity of home visiting.[642] In the study mentioned earlier of 206 family court evaluators, only 3 percent said they would do a home visit for a parent with a physical disability.[643]

An important trend that can enhance practice with parents with disabilities is a shift from describing clients as having or not having deficiencies toward using assessments to inform treatment and intervention strategies, discharge planning, and the development of a sense of what might help.[644] However, this approach requires expertise with disability issues and solutions, including the natural adaptive process between parents and children and any adaptations that are used or introduced. All too often, current practice with parents with disabilities and their children is not informed by this expertise.

Conclusion

Parents with disabilities who are involved in dependency or family law proceedings regularly face evidence regarding their parental

fitness that is developed using inappropriate and unadapted parenting assessments. To address this issue, state statutes, rules of court, and professional standards must require evaluators to thoroughly investigate whether they are in compliance with the 2012 American Psychological Association Guidelines for Assessment of and Intervention With Persons With Disabilities, and whether they need to modify the evaluation process or incorporate parenting adaptations to provide a more valid, reliable assessment of a parent's capacities in the context of child welfare and child custody cases. Such standards must require adapted naturalistic observations—for instance, in the parent's modified home setting rather than an unfamiliar setting—instead of leaving the venue for observation open to the evaluator's discretion. They must require explicit evidentiary support for statements about a parent's capacity and prohibit the use of speculation and global diagnostic or disability labels as a ground for limiting custody or visitation. Professional standards must address the problem of using appropriate standardized testing to assess parenting capacity in parents with disabilities. Finally, state legislatures must mandate training for current custody evaluators in the skills necessary to conduct competent disability-related custody evaluations. Such training must include valid methods that directly evaluate parenting knowledge and skills, and must consider the role of ecological factors that may impede or support positive outcomes.

Chapter 9. Lack of Adapted Services, Adapted Equipment, and Parenting Techniques in Child Welfare and Family Court

The previous chapter discussed the crucial need for disability expertise and observation of parent-child interaction in appropriate settings. This chapter focuses on some of the complex adaptation issues that affect overall involvement with child welfare and family court and assessment in these systems.

Amy Nichols, NCD Attorney Advisor, and her daughter, Shelby, enjoy leisure time in the pool.

Adaptations and adapted services are integral to the lives of parents with diverse disabilities and to appropriate assessment and appropriate intervention in custody situations. The time-limited opportunity to document a parent's potential and progress increases the need for specialized practice that is knowledgeable about adaptation issues. Disability accommodation and adaptation needs should be clarified from the outset of involvement with child welfare and family court systems, so that adaptation is appropriate throughout the process—in communication, settings for meetings, visitation and assessment, case plans, parenting evaluations, and services.

Many parents with disabilities who are involved in custody disputes have not previously benefited from the adaptive resources and supports of disability and deaf cultures and specialized programs owing to a worsened or new disability, not identifying as having a disability, multiple disability, isolation, poverty, dependence on nondisabled partners or family members, or even abuse or domestic violence. Numerous issues may have to be addressed to level the playing field during involvement with child welfare or family courts.

Communication Adaptation Issues

Communication must be adapted for some parents with disabilities. Communication access is often a barrier for parents who are deaf or hard of hearing. For instance, deaf parents may be reluctant to request a sign language interpreter, fearing that this will undermine their credibility and militate against gaining or retaining custody of their child. Some professionals may assume that the deaf parent can read lips, but most deaf people are not proficient at lip reading. It is estimated that even the best lip readers catch only 25 percent to 30 percent of what is spoken, and this percentage can be affected by context and environment as well as the extent of the person's hearing loss and the age at which he or she became deaf.[645] Many deaf people are not proficient at written English, and this too can undermine effective communication with those who do not use sign language.[646]

Parents who are blind and those who have intellectual or other cognitive disabilities (e.g., traumatic brain injury, stroke, or dementia) that limit their ability to read are often sent crucial printed material in custody situations, such as notices of required meetings or hearings. Parents with cognitive or intellectual disabilities often require "translators" to facilitate their comprehension of crucial processes, to ensure that their consent to assessment is informed, and to make their participation in court meaningful.

To be effective, communication during reunification services must be individualized and adapted to the parent's processing abilities. For instance, to absorb information, a parent with auditory processing disabilities might need a reduction of background noise and face-to-face communication, without glare from a window behind the speaker. Many examples are available of adaptations for parents with intellectual disabilities from specialized programs with positive long-term outcomes.[647] They include using multiple modalities to convey important information (e.g., talk, video, charts, photos, demonstration, and teamwork between parent and provider during practice of tasks or behaviors), and practicing during parent-child interaction in varied settings (home, community) to support integration and generalization of information. Neuropsychologists and cognitive rehabilitation specialists are other sources of cognitive adaptations. Their assessments can identify strengths and difficulties, thus reducing trial-and-error attempts to clarify the most effective modes of intervention.

At the outset of involvement with the child protection system, a parent with a head injury received an assessment from a speech and language therapist specializing in cognitive rehabilitation, which contained many practical communication suggestions to compensate for her significant auditory processing problems. These suggestions were ignored throughout the reunification services, undermining the effectiveness of the services. She was described as unable to benefit from services, and termination of her parental rights was sought.[648]

Adaptations and Assessments

Appropriate adaptations are integral to parenting assessment, not only in the choice of assessments and the manner of conducting formal assessments but also to level the playing field before and after assessments. It is crucial that evaluators cite the limitations of their assessments with regard to adaptive issues. Evaluators need to understand the adaptive resources used by parents with disabilities and

the appropriate practice with such parents and their children to determine whether the parent could have been expected to benefit from services previously provided. Evaluators should review records and interview providers with this in mind, and their reports should reflect an assessment of the disability-appropriate incorporation of adaptations during previous practice. Any recommendations must be informed by disability and adaptation expertise.[649]

Expert witness analysis of child welfare and family court records of custody cases involving parents with disabilities has found a pattern of inappropriate disability practice; in particular, a lack of adaptations and failure to identify this problem in the parenting evaluations in the records.[650] A study of child welfare evaluations found that evaluators were largely unable to identify appropriate or adapted interventions for supporting or strengthening the parenting capacities of people with disabilities.[651]

Appropriate adaptations are integral to parenting assessment... to level the playing field before and after assessments.

However, new APA guidelines regarding practice with people with disabilities reflect increased awareness of the role of adaptations and accommodations:

> "When conducting psychological assessments in clinical settings, it is essential to consider the interaction between the individual with a disability and his or her environment.... When the client uses assistive technology and accommodations, it is advisable to incorporate them into the behavioral observation to avoid capturing unaccommodated disability rather than the target behavior.[652] …This [functional] assessment focuses on social behavior, activities of daily living, family... communication, motor skills…and ensures disability accommodations in an assessment setting. For example, for restrictions to be functionally assessed, the home environment needs to be appropriately adapted."[653]

Studies of adaptations for parents with physical disabilities document the effect of such equipment on parental functioning and infant-parent interaction. These demonstration projects designed, provided, and evaluated the effect of baby care adaptations to ease obstacles at the outset of parenting.[654] Adaptations included adapted cribs, baby care trays on wheelchairs, walkers with baby seats, wheelchair-accessible diapering tables and highchairs, lifting harnesses, and accessible childproofing. Pre-and post-videotaping analysis showed that such adaptations increased parents' functional care abilities and involvement, decreased pain and fatigue, and enhanced infant-parent interaction. An overarching conclusion from these studies and subsequent clinical intervention and evaluation is that "one cannot assess the potential of a parent with a significant physical disability and an infant without first providing whatever adaptive techniques and equipment make it possible for interaction to occur and the infant-parent relationship to develop."[655]

A parallel process that developed adaptations for parents with intellectual disabilities[656] concluded that "one cannot discern the full

potential in parents with cognitive disabilities without providing adaptations that are individualized with the parent's functioning."[657] Obstacles and adaptive solutions used by mothers with vision disabilities were also documented in research and in a resource guide compiled from parents' suggestion.[658] These adaptations have been found to be particularly useful for parents who are newly blind.

Lack of Adaptation Expertise Linked to Exaggeration of Needs

The lack of disability expertise and provision of adapted and appropriate services leads to assumptions that parents with disabilities cannot benefit from services or will require long-term, 24-hour supervision. When such supervision is not available, unjust removals or custody arrangements may result. It is particularly common in child welfare custody cases involving parents with intellectual disabilities that generic services are offered that are claimed to be ineffective in producing improvements in parental functioning. It is then argued that the parent is unable to benefit from services, and TPR is sought. However, specialists on parents with intellectual disabilities have emphasized that appropriate adapted services can result in progress and positive outcomes.[659] All too often, parents with intellectual disabilities have experienced inappropriate services—they are sent to standard parenting classes without home-based parent-child intervention or have numerous short-term, uncoordinated providers who lack expertise about their specialized needs.[660]

Child welfare and family courts might assume that 24-hour supervision or assistance will be required over the long term, even for parents whose physical disability (e.g., paraplegia) is quite manageable during parenting, without an understanding of the adaptations and modifications that support independence in the home. Twenty-four-hour supervision might also be assumed to be a long-term requirement for parents with psychiatric disability, based on diagnosis rather than individualized assessment and observation of parent-child interaction. Negative assumptions about prognosis might not take into account the effectiveness of infant mental health services or other community supports adapted to the needs of parents with psychiatric disabilities.[661]

Avoiding Bias Regarding Adaptive Supports

Lack of familiarity with disability supports and adaptations can lead to bias in practice. Parents with physical disabilities in both family court and child welfare cases have been negatively evaluated regarding their capability because they use personal assistants to compensate for functional limitations.[662] It would be more appropriate to assess how the parent maintains connection to the child and authority in the eyes of the child during assisted physical care.[663] Similarly, parents with intellectual disabilities have received negative evaluations because they use independent living services or reside in supported living residences.

Assessment Setting Issues

Parenting evaluations and observations are frequently conducted in psychologists' offices, without adaptations to the settings.[664] A parent who is blind is at a profound disadvantage in an unfamiliar environment as opposed to the

home, where organization and adaptations can support parenting. Similarly, the functioning of parents with physical disabilities can be dramatically enhanced by their home modifications as well as by parenting and general disability adaptations. The absence of accustomed environmental adaptations creates a distorted picture of their parenting. The functioning of parents with intellectual or other cognitive disabilities also can be compromised in an unfamiliar setting owing to memory and organization issues.

For example, in one custody case, distraction problems of a parent with an intellectual disability were intensified during an in-home observation that involved numerous professionals. In another observational assessment, a social worker was present who had been consistently negative about the potential of a mother with a psychiatric disability. Her presence was stressful and preoccupying for the mother; as a result, the mother's usual sensitivity toward her baby was reduced during the session.[665]

Parenting evaluations… are frequently conducted in psychologists' offices, without adaptations to the settings... The absence of accustomed environmental adaptations creates a distorted picture of [one's] parenting.

Piloting Adaptations During Assessments

Knowledge of adaptive options is necessary so they can be introduced and their potential impact observed during assessment. Piloting adaptive strategies with a parent who has an intellectual disability can provide information about the parent's processing issues and acceptance of intervention. For instance, child welfare involvement owing to an infant's "failure to thrive" is not uncommon when parents have intellectual disabilities, owing to their problems with reading infant cues, understanding time, and measuring and mixing formula. Given the urgency of this situation, assessment would include adapted intervention to establish appropriate feeding while clarifying what led to the difficulty.

Parents with intellectual or psychiatric disabilities often live in households with other adults who co-parent. It can be difficult to discern the potential functioning of the parent with the disability when the co-parent is present, as the natural adaptation in the family is to fill in the gaps, sometimes more than is necessary or helpful for the role of the disabled parent with the child. During assessment, a crucial strategy can be observing the parent with the disability and child without the presence of the co-parent.

Providing baby care adaptations for a parent with a physical disability can produce rapid change in parental functioning and infant-parent interaction. Even piloting limited adaptations can be informative about potential. For example, in a child welfare case involving a mother with significant cerebral palsy, the psychologist conducting the evaluation speculated that the lack of mutual gaze between mother and baby was likely due to the intrapsychic pathology of the mother. However, no one had set up a physical situation in which the mother and baby were comfortably located face-to-face at an appropriate distance from one another to allow mutual gaze to develop. The disability specialist simply attached a laptop tray to the

mother's motorized wheelchair and positioned the baby on a pillow on the tray (with pillow and baby secured by a wide Velcro strap); mutual gaze between mother and baby began immediately.[666]

Addressing disability obstacles can clarify underlying psychological or relational issues that can be targeted in services. For instance, after baby care adaptations made it feasible for a mother with a significant physical disability to provide care for her baby, the mother's problem with understanding her baby's experience was revealed and addressed in infant mental health services.[667]

Providing baby care adaptations for a parent with a physical disability can produce rapid change in parental functioning and infant-parent interaction.

Impact of Separation on the Natural Mutual Adaptation Process

Separation as a result of foster care or custody arrangements is recognized as a stress, particularly for infant-parent relationships. However, there are additional issues when a parent has a disability or deafness. Insufficient contact between the parent and infant can compromise their mutual adaptive process. Research videotaping care from birth through toddlerhood documented a natural mutual adaptation process between mothers with physical disabilities and their babies over time. Infants as young as one month began adapting to their mother's disabilities; for example, by holding still and curling up like a kitten during lifts.[668] In later clinical services, it was found that out-of-home placement interfered with the natural adaptation process. For instance, a baby developed an aversion to the sound of his mother's motorized wheelchair after he was removed from the home, although it is typical for babies to enjoy and be drawn to the sound of their parents' wheelchairs.[669]

Temporarily removing a child from his or her deaf parent(s) interrupts natural adaptations between parent and child, as well as effective communication within the family. Hearing children of deaf parents may be discouraged from or even denigrated for using sign language by people outside the home, including hearing neighbors and relatives. Prolonged lapses in developing bilingual skills can significantly undermine the child's ability to effectively communicate with their deaf parent(s), which can have lifelong consequences.[670]

Adaptations During Reunification Services

Because of the lack of expertise regarding disability and adaptations, reunification services provided by the child welfare system are often inappropriate and ineffective. A disability specialist describes working with a mother with very high quadriplegia (she could control movements only above her shoulders). The specialist was engaged by child welfare after the child was six months old. Up to this point, the mother had had no services that were knowledgeable about or appropriate to her disability, and she had no links to the disability community. She had been sent for urine testing to a site that would not deal with her catheter and had been expected to use buses to get

there. She lived in a housing project where her motorized wheelchair had been stolen—when the disability specialist arrived, the woman was sitting on a sofa.[671]

Parents' Stories: The Power of Adaptations

"A young African-American mother with quadriplegia had had her baby removed at birth after testing had shown prenatal substance abuse. The social worker described the mother as forming no relationship to her baby despite weekly visitation. She thought the mother was psychologically incapable of forming a relationship with her child. In the six months since the baby had been born the mother had been provided no assistance in order to make it possible for her to hold or care for her baby in any way. Everyone, including the mother, just assumed this was impossible. The able-bodied grandmother did the care or left the baby in a playpen during the visits. During the first visit I saw a depressed mother who indeed appeared estranged from and disinterested in her baby. But when I showed her videotapes of parents with disabilities and their babies—images of possibilities—she asked if I could help her hold and feed her baby. So in the second visit, with a variety of frontpacks and pillows, she was able to hold her baby for the first time. She tenderly nuzzled and murmured to her, caressing with her lips, greeting her baby for the first time as mothers do immediately after giving birth."[672]

Adaptations to Inform Visitation

Adaptations are often necessary to inform visitation decisions. For instance, a disability specialist's input was sought by family court to clarify the appropriateness of visitation:

> "In one case a nondisabled mother did not allow a preschool boy contact with his father during the father's long hospitalization after spinal cord injury. The child had developed a fear of his father (associating him with monsters), so the mother argued that visitation was not in the child's best interest. The father had extremely high-level quadriplegia and was receiving oxygen through a tracheal tube, so he could not speak with his child. A clinician specializing in disability introduced adaptations so the child and father could begin communicating nonverbally through play, first playing a computer game together, using switch-operated toys, and then painting pictures together (the father holding the brush in his mouth). The boy's fear of his father's disability equipment was addressed by allowing him to play in a motorized wheelchair. In a few sessions the child's fears had subsided and he had begun to rediscover his father."[673]

The Role of Interdisciplinary Expertise

Researchers have suggested that evaluators receive specific training on parenting with a disability and on the impact of disability-appropriate interventions and parenting adaptations on the parent child relationship.[674] Experts on disability and parenting have suggested a reexamination of the assumption

that psychologists provide the highest quality assessments in these cases and have suggested the possibility of broadening the field of parental assessment to involve more interdisciplinary practice.[675]

According to the APA, "Psychologists are encouraged to consider a multidisciplinary perspective in assessing clients with disabilities."[676] To address the limitations in the appropriateness of psychometric assessment tools for use with parents with disabilities—as well as the limited disability training, education, and experience among many evaluators—a multidisciplinary approach to assessment is encouraged. For example, a psychologist or neuropsychologist might work with an occupational therapist, speech and language therapist, or other disability and rehabilitation specialists. Assessments by occupational therapists have been found to be very helpful in custody situations involving questions about parental physical functioning and the potential of parenting adaptations. *The Baby Care Assessment for Parents with Physical Limitations or Disabilities*, an occupational therapy tool for evaluating baby care functioning, has been used both in child welfare and family court cases.[677]

Collaboration among practitioners from different disciplines can be especially important when parents have multiple disability issues. Specialists with varied disability expertise are needed to address adaptive obstacles and solutions for parents who have more than one category of disability; for example, blindness and physical disability or intellectual and psychiatric disability.

Implications for Adoption and Assisted Reproductive Technologies

Many of the concerns about practice with parents with disabilities in the child welfare and family law systems should be considered in the context of adoption and assisted reproductive technologies, which are examined in Chapters 10 and 11, respectively. Evaluation of the capability and health of parents with disabilities occurs in ART practice as well as in home studies in adoption. The disability expertise of practitioners making these determinations is questionable, as is their awareness of potential adaptive solutions. Occupational therapy evaluations using *The Baby Care Assessment for Parents with Physical Limitations or Disabilities* have been employed effectively in adoption. For instance, a woman with a physical disability experienced difficulty during the home study required for adoption. The social worker said she had serious reservations about the woman's ability to parent, especially that she might drop a baby or be unable to catch a toddler who ran off. The woman—a leader in the independent living community—assumed that it would not be wise to express her dismay about the social worker's speculations. Rather, she contacted a national center that provides technical assistance regarding custody issues of parents with disabilities. The center conducted a baby care adaptation assessment, using weighted dolls and adaptations that have proved helpful to other parents with disabilities. The mother provided the adoption agency with the assessment report, documenting capabilities and solutions to potential difficulties, as well as the center's video and publication illustrating

such adaptations in use by other parents. She successfully adopted a baby.[678]

Conclusion

Parents with disabilities who are involved in child welfare or family law proceedings regularly encounter a national dearth of resources to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques. Even when such resources exist, dependency and family courts do not often use them. Adaptations and adapted services are integral to the lives of parents with diverse disabilities and to appropriate assessment and appropriate intervention in custody situations. Many parents with disabilities who are involved in custody disputes have not previously benefited from the adaptive resources and supports of disability and deaf cultures and specialized programs. They may have a new or worsened disability, may not identify as having a disability, may have multiple disabilities, may be poor or isolated, and may be dependent on nondisabled partners or family members. Abuse or domestic violence may also be factors in their failure to access resources and supports. Thus, a lot can be done during involvement with child welfare or family court to level the playing field. Many of the concerns about adapting practice with parents with disabilities in the child welfare and family law systems should also be considered in assisted reproductive technologies and adoption systems.

Chapter 10. The Adoption Law System

Adoption horror stories are all too common for prospective parents with disabilities. The adoption system is riddled with de facto and de jure discrimination that prevents countless prospective parents with disabilities from adopting. Examination of domestic and international adoption practices reveals that reforms are urgently needed across the broad spectrum of adoption practices and procedures.

Parents' Stories: Rachel

In 1995, when Rachel[679] and her partner (both wheelchair users) decided to adopt, they had no idea they were embarking on a 15-year journey to become parents. They contacted the local child welfare agency to express interest in becoming foster or adoptive parents. They were immediately told that because of their disabilities they were not qualified. After they worked their way "up the chain" and threatened a lawsuit, the agency finally allowed them to apply. The couple met all the requirements and completed the necessary training. Soon after that, a brother and sister were placed with them. After only three months, the agency removed the foster children because their birth mother did not want them placed with a disabled couple. The agency offered another child, who proved to be an inappropriate match. Nearly five years later, with no communication from the agency, Rachel and her partner went through the training process again. Despite successful completion of training a second time, they never heard from the agency.

In 2004, after Rachel's partner started a new job that paid well, the couple decided to apply for private adoption, hoping a private agency would better engage and assist prospective parents with disabilities. But the private adoption process was also riddled with discrimination. In 2006, the couple applied to adopt a young girl. After a home study and nearly two years of silence, they inquired again. Finally, in early 2009, Rachel and her partner were allowed to meet a child. In March 2009, the agency contacted the couple and told them that the girl's foster parents were relinquishing her (which Rachel and her partner assumed was owing to her significant intellectual and psychiatric disabilities) and asked if they would like to become her foster parents. They agreed and she moved into their home in April 2009. In June 2010, 15 years after beginning their journey to become parents, Rachel and her partner adopted their daughter. Tragically, Rachel's partner passed away five months later.

The Adoption Law System: A Brief Overview

Adoption law (both domestic and international) creates and governs the legal relationship of parent and child and bestows on the adoptive parents all the rights and responsibilities of that role.[680] Once adoption is finalized, adoptive parents play the same role as biological parents in the life of their child.[681] There is no inherent right to adopt a child or become a foster parent. Parenting by adoption is not guaranteed by the United States or any state constitution.[682] Accordingly, many people with disabilities encounter discrimination when engaging in the adoption process.

The goal of adoption is to "provide a permanent home that is suitable for the child and that is in his or her best interests."[683] The uncertainties posed by the best interest standard, well documented in legal commentary on issues involving rights and protection of minors, also contribute to bias in adoption cases. Reaffirming this issue, researchers from Northwestern University note:

> "The vagueness of the 'best interests of the child' standard is compounded in practice by the administrative structure of adoptions agencies in the US. The vast majority of non-family adoptions in the US are arranged by private, independent agencies that usually operate on a commercial or for-profit basis. These independent agencies are generally lightly regulated and characterized by wide variability in terms of policies, practices, and procedures. Consequently, adoption remains a complicated construct within the legal system of the United States. In fact, there is no national legal framework governing the adoption process, with matters of law and policy determined separately by each of the 50 states and the District of Columbia. A few umbrella pieces of legislation along with related judicial decisions bring a degree of national foundation for adoption in the legal realm, but statute law, policy, and practice in relation to adoption are largely determined at the state level."[684]

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During the adoption process, courts and agencies consider a list of criteria to determine whether an individual or couple will be suitable parents. 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 non-marital parenthood, the attitude of significant others, total personality, emotional maturity, and feelings about children."[685] In deciding among prospective adoptive families, agencies may also consider where the couple lives and whether they have other children.[686] For international adoption, each country defines its own criteria.

Types of U.S. Domestic Adoption

1. Public agency adoptions
2. Licensed private agency adoptions
3. Independent adoptions
4. Adoption through a facilitator (allowed in some states)
5. Unlicensed private agency adoptions

Domestic Adoption

Domestic adoption is largely governed by state law, with federal laws providing overarching standards with which state adoption laws must comply.[687] Massachusetts passed the first adoption statute in the United States.[688] 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 each must be approved by a presiding judge.[689] 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), adoption through a facilitator (allowed in some states), and unlicensed private agency adoptions.[690] Public and licensed private agencies are required to meet state standards and operate under more oversight to ensure quality services.[691] Unlicensed agencies and facilitators often are not subject to the same state oversight; consequently, there may be more financial, emotional, and legal risk for adoptive and birth families who use these services.[692]

Public agencies generally oversee the adoption of children in the state child welfare system.[693] Children in foster care have been removed from their families for a variety of reasons, including abuse or neglect, and range in age from infants to teens.[694] In public agency adoptions, matches are generally arranged by the agency—through a meeting of several social workers and supervisors or by a placement committee—and are based on the needs of the child and the ability of the family to meet those needs.[695]

In licensed private agency adoptions, the birth parents relinquish their parental rights to the agency and the adoptive parents then work with the agency to adopt.[696] Many agencies allow birth parents to choose a prospective adoptive family for their child on the basis of profiles prospective families create to share information about themselves.[697] "Prospective parents may have an opportunity to meet the birth parents face to face; however, social workers may make decisions about which families' profiles are shared with expectant parents considering adoption, or agency staff may make the match of a child and prospective adoptive parent. In addition, agencies may give preference to certain types of individuals or couples (e.g., due to religious affiliation or marital status)."[698]

In independent adoptions, private attorneys assist prospective parents with the adoption process, which usually involves the adoption of an infant.[699] Families that adopt independently identify the expectant parents without an agency's assistance, and[700] infants usually are placed with the adoptive parents directly from the hospital after birth.[701] While state laws differ about the timing of the birth parents' consent and the conditions and timing of the birth parents' right to revoke that consent, there is always

Members of the Lucas family pose outside at the edge of a bridge.

the possibility that birth parents will change their minds when the baby is born; because of the inherent parenting rights of the biological parents, their rights are stringently protected.[702] The birth parents are the child's legal parents until they consent to the surrender of their parental rights.[703] Birth parents typically provide written consent for the adoption, which must be approved by the court.[704] Independent adoptions are permitted in 46 states; Colorado, Connecticut, Delaware, and Massachusetts prohibit them.[705]

Adoptive placements by facilitators and unlicensed private agencies offer the least amount of supervision and oversight.[706] A facilitator is a person who links prospective adoptive parents with expectant birth mothers for a fee.[707] Facilitators may or may not be regulated in their state and may have varying degrees of expertise in adoption practice.[708] Two states (Delaware and Kansas) strictly prohibit the use of facilitators.[709]

Adoptions often take place across state lines; these are regulated by federal legislation.[710] Interstate adoptions are affected by two agreements between the sending and receiving states: the Interstate Compact on Adoption and Medical Assistance (ICAMA) and the Interstate Compact on the Placement of Children (ICPC). These agreements carry the force of law.[711] Currently, 42 states participate in the ICAMA, which regulates and coordinates the payment of benefits to children with special needs, adopted pursuant to an adoption assistance agreement, when they are adopted from one state by a family in another state, or when the 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. The compact applies to placements of minor children made from one state to another by public and private agencies, the courts, independent placers (i.e., physicians and attorneys), and individuals.

There is a growing need for adoptive families; but although the number of children in foster care is on the rise, adoptions have dramatically decreased since the 1970s.[712] Nearly 127,000 children are adopted every year in the United States, but this is "a sharp drop since the century-long high point of 175,000 adoptions in 1970."[713]

International Adoption

International adoption (also referred to as intercountry adoption) differs from domestic adoption in several significant ways.[714] 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.[715] In some cases, children adopted through intercountry adoption come from orphanages or institutional settings.[716] 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.[717] The convention is "designed to protect the best interests of children and prevent the abduction, sale, and trafficking of children."[718] In the United States, the Department of State has overall responsibility for implementing the Hague Convention, although the U.S. Citizenship and Immigration Services (USCIS) in the Department of Homeland Security also play a significant role.[719] The United States is one of 85 nations that are parties to the Hague Convention.[720] When a U.S. citizen wants to adopt a child from any of these nations, Hague Convention rules apply. In adopting a child from a country that is not a party to the Hague Convention, some rules vary.[721]

Disability Law and the Adoption System

The ADA and the Rehabilitation Act govern the adoption system, both domestic and to a lesser extent international. Title II of the ADA prohibits discrimination by public entities run or funded by state and local governments, such as public adoption agencies.[722] Conversely, Title III of the ADA prohibits any public accommodation from discriminating against people with disabilities by denial of access to goods and services.[723] Title III unquestionably governs access to private adoptions, as it includes "adoption agency" in the definition of public accommodations.[724]

One of the key ADA provisions is that adoption agencies may not use "standards or criteria or methods of discrimination that have the effect of discriminating on the basis of disability."[725] Of particular relevance for adoption agencies is the prohibition against "imposing or applying eligibility criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities from fully and equally enjoying" any services "unless the criteria can be shown to be necessary for the provision" of those services.[726] (These exceptions are discussed below.)

According to the Evan B. Donaldson Adoption Institute, adoption agencies often ask whether they may exclude a person with HIV infection because that person allegedly poses a direct threat to the health and safety of others.[727] The ADA explicitly prohibits discrimination on the basis of HIV infection; adoption agencies may not categorically reject individuals as prospective adoptive parents on this basis.[728]

Additionally, the ADA requires adoption agencies to provide reasonable modifications in policies, practices, and procedures as needed for prospective adoptive parents with disabilities. The agencies must provide auxiliary aids and services when they are necessary to ensure effective communication with prospective parents with disabilities. These mandates apply to the entire adoption process (e.g., application, home study, and interview).

[T]he ADA requires adoption agencies to provide reasonable modifications in policies, practices, and procedures as needed for prospective adoptive parents with disabilities.

Section 504 of the Rehabilitation Act governs adoption agencies that receive federal funding. In at least one reported case, *Doe v. Nebraska*,[729] a prospective adoptive parent with a disability who was discriminated against successfully sued for damages on the basis of the Rehabilitation Act. In this case, a couple was fostering two children in a foster care-to-adoption program. When the social services agency learned that the foster mother was HIV-positive, the agency immediately removed the children. A court ordered the agency to return the children based on its finding that returning them to the family was in their best interest. Subsequently, the agency found another placement for the younger child. The family filed a motion with the court, and the agency was found in violation of the court order. Eventually, the family won back custody of the younger child. Sadly, the mother died eight months later. The adoption was finalized the day before she died. Using the Rehabilitation Act, the estate of the mother and her adopted son sued the county for discriminating against the deceased foster mother. The state of Nebraska argued that it was immune from suit under the 11th Amendment. The court ruled that the couple had won the underlying discrimination claim on the merits, that Nebraska had waived its immunity from suit by accepting federal monies to run its program, and, therefore, the estate could sue under the Rehabilitation Act.

While federal disability laws, such as the ADA and the Rehabilitation Act, do not govern other countries' conduct, they do govern key aspects of international adoption. For instance, "The ADA applies fully to all adoption agencies doing business on U.S. soil so, by law, they must serve and accommodate the needs of adoptive parents with disabilities."[730] This means that private adoption agencies, even if they are engaging in international adoption, must comply with the access and nondiscrimination mandates of Title III. This is particularly relevant for home studies and the application process.

The Rehabilitation Act requires federal agencies to provide programmatic access and reasonable accommodations as necessary. Accordingly, USCIS and other federal agencies

engaged in international adoption must comply with the Rehabilitation Act. This is especially significant for prospective adoptive parents with disabilities during the application and screening process.

Access to the Domestic Adoption System

Many people with disabilities seek to form families through domestic adoption. For some, the type of disability may make adoption the sole means by which parenting becomes possible. Unfortunately, access to domestic adoption is often impeded by discriminatory practices. Many prospective parents with disabilities are categorically denied the opportunity to adopt because of their disability, while others encounter bias and speculation concerning their parenting abilities. Because of the unspoken ranking system among domestic adoption agencies, prospective adoptive parents with disabilities are often completely precluded from adopting or are forced to wait for indefinite periods before a match is found. In light of the growing need for adoptive parents and "[i]n order to place as many children as possible, no one group of prospective parents should ever be categorically excluded."[731]

The Rehabilitation Act requires federal agencies to provide programmatic access and reasonable accommodations as necessary. Accordingly, USCIS and other federal agencies engaged in international adoption must comply with the Rehabilitation Act.

Discrimination and Bias

Despite the ADA and Rehabilitation Act, prospective adoptive parents with disabilities regularly encounter barriers erected by discrimination and bias. According to Elizabeth Bartholet, Harvard Law School professor and one of the nation's leading experts on adoption, "Discrimination is the name of the game in adoptive parenting. Those who procreate live in a world of near-absolute parenting rights. Those who would adopt have no rights. They must beg for the privilege of parenting and do so in a state-administered realm that denies them both the right to privacy and the civil rights that we have come to think of as fundamental. Differential treatment on the basis of age, race, religion, and disability has been outlawed in almost all areas of our communal lives in the United States. Increasingly the law forbids discrimination on the basis of marital status and sexual orientation. It is only in the area of adoption that our system proclaims not simply the right to discriminate on all these bases but the importance of doing so. It is not just the prospective parents who are treated shabbily, but also the children, in whose best interests the system is supposedly designed."[732]

Echoing Bartholet's sentiments in his article "Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act," Dave Shade says, "The adoption process is complex, and because it frequently involves personal judgments by parents, social workers, judges, and other adoption professionals, it is fraught with the opportunity for discrimination."[733]

Categorical Discrimination

The ADA prohibits adoption agencies from using "standards or criteria or methods of discrimination that have the effect of discriminating on the basis of disability."[734] Specifically, adoption agencies are forbidden from "imposing or applying eligibility criteria that screen out or tend to screen out an individual with a disability or a class of individuals with disabilities from fully and equally enjoying" any services, "unless the criteria can be shown to be necessary for the provision" of those services.[735] The limited exceptions to this mandate are discussed later in this chapter.

Despite the ADA mandates, research demonstrates that a significant number of adoption agencies continue to categorically deny prospective parents with disabilities. In 2010, researchers from Northwestern University completed a study that examined the experiences of prospective adoptive parents who were cancer survivors.[736] The study was aimed at the attitudes of the adoption agencies. Of the 27 agencies that were interviewed, 7 admitted that certain medical conditions would prevent people from adopting through their agency. They cited a variety of illnesses and medical conditions that included "contractible diseases; AIDS; active, life-threatening diseases; use of antidepressants; terminal illnesses that shorten lifespan; conditions that require a large amount of narcotics that render the person unconscious; substance addiction; and severe mental conditions like schizophrenia." Agencies were also asked whether they have a policy for dealing with prospective adoptive parents who are HIV-positive. Two agencies responded affirmatively; one said that HIV-positive persons would be disqualified, and the other cited the state law regarding the right of HIV-positive persons to adopt. Extensive research into state laws regarding the potential for an HIV-positive person to serve as an adoptive parent yielded no results.[737] The researchers concluded, "Although existing legislative documents such as the Americans with Disabilities Act (ADA) protect cancer survivors' rights to adopt a child, these protections are largely inconsequential in practice…. [The] network of adoption agencies working with potential parents in the U.S. is characterized by fundamental variability and ambiguity…[and] the current adoption system permits informal prejudice in practice that likely varies from one agency to the next."[738]

Parents' Stories: Christina

Prospective parents with disabilities continue to encounter categorical denials. When Christina,[739] a woman with significant physical and sensory (vision and hearing) disabilities, applied to adopt her niece, she was astounded and appalled by her experience. The social worker at the public adoption agency told Christina that "a handicapped woman can't take care of a handicapped child." Christina's battle to adopt her niece lasted for nearly a year. Eventually, she adopted her niece, after a court-appointed special advocate got involved and the state child welfare agency was almost held in contempt. Since this experience, Christina has adopted two more children and is in the process of adopting another.

Agency Discrimination and Home Studies

In addition to categorically denying prospective parents with disabilities, domestic adoptions frequently engage in other discriminatory practices. Bartholet says that prospective adoptive parents are subject to an unspoken "ranking system." That is, the domestic adoption system ranks prospective parents in terms of relative desirability, "using factors that reflect the system's bias in favor of a biologic parenting model, as well as a socially traditional family model."[740] Pursuant to this ranking system, "Heterosexual couples in their late 20s or early 30s with apparently stable marriages are at the top of the ladder. These are the people who can, if they are not infertile, produce children, and who should in the system's view be parents. Single applicants and those in their late 30s and 40s are placed lower on the ladder, along with people with mild disabilities. Gays, lesbians, and those who are significantly older or seriously disabled are generally excluded altogether."[741]

Similarly, the children in need of adoption are also ranked in a list, which is based on the desirability of the adoptive child. Explained by Kimberly A. Collier in her *Texas Wesleyan Law Review* article, "This list places healthy newborns and infants at the top of the list as being most desirable. The children next on the list are somewhat older or less healthy than those at the top of the list. As the age of the children increases or the health issues become more problematic, the ranking of desirability continues to fall until one reaches the bottom of the list, where the oldest and most seriously disabled children are placed. Once the agency has composed these two lists, it works to match the children with the prospective parents. The parents with the highest ranking are given the most 'buying power,' with the most desirable parents being matched with the most desirable children. Less desirable parents are matched with the less desirable children, and so on down the list."[742] Given the proliferation of discriminatory agency standards, the most coveted adoptable children are least likely to be matched with applicants with disabilities.[743]

Case law, research, and anecdotal evidence demonstrate that disability often counts against prospective adoptive parents or negatively affects their adoption experience. In a national survey of 1,200 parents with disabilities, conducted for TLG by Linda Barker and Vida Maralami, 8 percent reported that they experienced attitudinal barriers that inhibited or prevented adoption.[744]

Most prospective adoptive parents with disabilities are mindful of the discriminatory practices that pervade the domestic adoption law system. According to a disabled couple that adopted, "At the start of our adoption process we were not concerned about whether we were capable and would make good parents, but were rather concerned about whether we would be viewed as capable parents by the adoption counselor at the agency as well as by the birth mother."[745]

Although the potential for discrimination against people with disabilities exists during other stages of the adoption process—such as the placement decision and the judicial finalization—the home study is often where people with disabilities face the greatest vulnerability.[746] According to Shade, prospective adoptive parents with disabilities often face discrimination in one of two ways: "First, the evaluator may simply refuse to approve any adoptive placement,

judging the parents unsuitable to raise any child. Second, the evaluator may limit the approval of an adoptive placement to only those children deemed compatible with the disability of the adoptive parent. The stereotypes and societal attitudes concerning parents with disabilities are pervasive and powerful. Even evaluators trained to assess parental fitness are capable of falling victim to these prejudices. Social worker texts, for example, continue to propagate the paternalistic tendencies that conclude that disability is an important factor in assessing parental fitness."[747]

Most domestic adoptions, whether private or public, include a rigorous preplacement evaluation of the adoptive home known as a "home study."[748] A home study is the principal instrument used to assess the fitness of prospective adoptive parents.[749] Some states require that a state agency complete the home study, while others allow any licensed child placement agency to complete the study.[750] Generally, the evaluator is a social worker, but the credentials and qualifications of home study workers vary greatly among jurisdictions.[751] Further, "the home study process may also vary widely, even within the same locality, depending upon the attitude and diligence of the individual evaluator."[752] The content of a home study can also vary.[753] "Most state statutes describe the required content in very general terms, if at all, leaving the form and content of the study to the evaluator."[754] Given the enormous latitude home study evaluators possess, Shade says, "It seems reasonable to conclude that the individual evaluator will have a tremendous amount of discretion when conducting a home study, perhaps making it easier for discrimination to be a part of the process."[755]

Despite ADA protections, several nonlegal issues limit its usefulness.[756] Shade says, "Situations in which the evaluating agency will also be making the placement decision put the adoptive parents in a terrible quandary: alienating the agency by initiating an ADA claim may jeopardize the placement process, a risk that many adoptive parents may be unwilling to take. Even where two different agencies will be making the home study and placement decisions, adoptive parents may fear that expressing dissatisfaction about the home study process or outcome could be communicated between the different agencies and might jeopardize the adoption. Finally, parents may be afraid to 'cause trouble' during the present adoption out of fear that any future adoptions might be jeopardized. These fears may hinder prospective adoptive parents from seeking legal relief, regardless of the strength of their legal claims and despite specific regulations explicitly designed to protect them from retaliation. Thus, rather than initiating an ADA claim, these parents may be more likely either to re-apply with another agency, or delay their adoption plans in the hopes that they can 'rehabilitate' themselves to the agency's satisfaction."[757]

In sum, the discretion and latitude bestowed on home study evaluators often results in prospective parents with disabilities encountering bias and discrimination. While the ADA unquestionably applies, prospective parents with disabilities often feel ambivalent about bringing it up.

Discrimination by Birth Parents

Birth parents can also play a role in discriminating among potential adoptive parents. In the majority of independent adoptions, birth

parents "determine the ultimate suitability of adopters and, therefore, can openly disfavor against" parents with disabilities.[758] In fact, the right of birth parents to place their child for adoption with whomever they choose, or to authorize another person to do so on their behalf has been embodied in the laws of all but three states (Connecticut, Delaware, and Massachusetts).[759] For Ken[760] (a man with hemophilia, hepatitis C, and HIV infection) and his wife (a wheelchair user), being chosen by birth parents was their biggest concern.

Sara C. Mills examined discrimination by birth parents in her 2011 article "Perpetuating Ageism via Adoption Standards and Practices" in the *Wisconsin Journal of Law, Gender and Society*. According to Mills, "In independent adoptions and those involving private agencies, the opportunity for discrimination against prospective adoptive parents is far more common; this is because agency policies and the wishes of birth parents dictate the choice of applicants."[761]

[T]he discretion and latitude bestowed on home study evaluators often results in prospective parents with disabilities encountering bias and discrimination. While the ADA unquestionably applies, prospective parents with disabilities often feel ambivalent about bringing it up.

Permissible Discrimination or Valid Defenses to the ADA?

In general, adoption agencies may not deny prospective parents with disabilities the opportunity to adopt on the basis of the applicant's disability, but there are exceptions. One factor that can be cited to justify the use of disability-related screening criteria is safety.[762] Pursuant to the ADA, adoption agencies may impose legitimate safety requirements necessary for the safe operation of their services, programs, and activities. However, they must ensure that their safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about people with disabilities.[763]

Similarly, adoption agencies may use the justification of direct threat. Agencies are not required to permit a person to participate in or benefit from their services if that person poses a direct threat to the health or safety of others. However, in determining whether a person poses a direct threat to the health or safety of others, adoption agencies must make an individualized assessment based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence to ascertain the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk.[764] The Evan B. Donaldson Adoption Institute advises agencies, "When such individualized assessments are utilized, the result may well be an acceptance of an individual with a significant disability, such as, for example, a woman who has crippling degenerative arthritis but whose home has been thoroughly adapted to enable her to function and whose husband is actively involved in parenting and home management."[765]

The first court to address the applicability of the ADA to adoption and foster care agencies has weighed in, with a decision supporting the right of adoption and foster care agencies to take disability into account as a "legitimate consideration" in assessing a person's fitness to become an adoptive or foster parent, provided that the agency does not routinely exclude disabled applicants from consideration by reason of their disability. In 1998, the U.S. District Court for the Western District of New York decided *Adams v. Monroe County*; it held that adoption agencies may consider a prospective parent's disability as a "legitimate" consideration.[766] In this case, a blind woman and her husband had qualified to participate in the foster to adoption program in their county, but no child was placed with them during their year with the program. The couple then proactively requested that a four-year-old child they had learned of be placed with them. The agency responded that the child was very active and the wife's disability precluded placement. In a lawsuit alleging violation of the ADA, the court ruled that three elements must be present to proceed with such a claim: (1) demonstrate that the plaintiffs were disabled in the meaning of the ADA; (2) prove that the prospective parents were otherwise qualified for placement of a child (had met all program requirements); and (3) illustrate that they had not received a child on the basis of discrimination. The court ultimately did not find in favor of the plaintiffs, ruling that discrimination had not been proved. The court found that the alleged safety issue related to this particular child, rather than a blanket denial of placement of any child in the home, precluded a finding of discriminatory conduct. The *Adams* precedent has potentially devastating power to prevent prospective parents with disabilities from adoption because of arbitrary "legitimate" considerations raised by adoption agencies.

Patchwork Quilt of State Laws

Despite the protections afforded by the Rehabilitation Act and the ADA, prospective adoptive parents with disabilities face increasing barriers to adopting domestically. To address the egregious practices of adoption agencies, some states have begun to add protections in their state statues.

For instance, Michigan amended its adoption laws in 1994 to prohibit adoption agencies from discriminating against potential adoptive parents on the grounds of age, race, religion, disability, or income level.[767] As noted by Jehnna Irene Hanan, "The benefit of such a scheme is that it opens more potential adoptive homes for waiting children. By providing more placement options, the new law better safeguards the rights of children to a stable and permanent home."[768]

Similarly, Wisconsin's adoption statute states, "Although otherwise qualified, no person shall be denied the benefits of this section because the person is deaf, blind or has other physical handicaps."[769] Idaho's adoption statute also bars discrimination on the basis of disability: "Adoptions shall not be denied solely on the basis of the disability of a prospective adoptive parent."[770] Idaho's adoption statute further states that "the prospective adoptive parent shall have the right to provide evidence to the court regarding the manner in which the use of adaptive equipment or supportive services will enable the parent to carry out the responsibilities of parenting the child."[771]

However, some states specifically deny prospective parents with disabilities the

opportunity to adopt. As recently as December 2011, Virginia erected an enormous impediment by approving regulations that allows adoption agencies to discriminate against prospective adoptive parents based on six categories, including disability.[772] This regulation not only hurts many prospective adoptive parents, but is devastating for the more than 1,200 children currently waiting to be adopted in Virginia.[773] Moreover, this regulation raises significant concern about whether other states will take similar discriminatory action.

North Dakota has a similar statute: "The department of human services may not deny a license because of the applicant's objection to performing, assisting, counseling, recommending, facilitating, referring, or participating in a placement that violates the applicant's written religious or moral convictions or policies."[774] Thus, the state may not refuse to license adoption agencies even if it knows that the agencies will discriminate against certain classes of people.

In light of the patchwork quilt of state adoption laws—especially Virginia's recent enactment, which explicitly discriminates against prospective parents with disabilities—the need for action could not be more timely or clear. Federal protections of prospective adoptive parents with disabilities must be promulgated.

Ensuring Access to Domestic Adoption

In light of the vague and indeterminate state-by-state legal system of adoption and the variability in policies and procedures among adoption agencies, a multipronged approach is necessary to eradicate the discrimination that pervades the adoption system.

The Federal Government, which has been nearly silent about the discrimination experienced by prospective adoptive parents with disabilities, must focus on ensuring the rights of these prospective parents. For example, the HHS Office for Civil Rights Web site contains extensive information on the legal rights and protection from race, color, and national origin discrimination for prospective foster and adoptive parents.[775] However, despite similar civil rights protections, there is no analogous information for prospective foster or adoptive parents with disabilities.

DOJ has addressed the discriminatory practices of domestic adoption agencies in at least one case. In 2002, DOJ announced that it had reached a settlement agreement with Maple Star Nevada, a nonprofit agency in Las Vegas.[776] Pursuant to the agreement, the agency will "allow deaf and hard-of-hearing applicants to be considered for selection as foster parents."[777] Moreover, the agency agreed to provide effective communication, specifically including sign language interpreters. Further, it agreed to adopt new policies to ensure compliance with Title III of the ADA, including a nondiscrimination policy. This settlement agreement resolved a complaint filed by a deaf woman who contacted Maple Star Nevada for information on applying to become a foster parent. "Maple Star allegedly refused to provide an interpreter during the required application process and certification. The deaf applicant was interested in providing foster care services for children with special needs and adolescents who cannot be maintained in large group care or foster care setting."[778]

Accordingly, DOJ, in collaboration with HHS as appropriate, must issue guidance to domestic public and private adoption agencies, reinforcing their legal obligations pursuant to the ADA. Such guidance must address the agencies' duty to provide reasonable accommodations to

prospective adoptive parents with disabilities throughout all phases of the process and the fact that presumptions of parental incompetence based on disability violate the ADA. Further, DOJ, and HHS as appropriate, must investigate all reported allegations of domestic public and private adoption agencies violating the ADA and enforce as appropriate.

Congress must also address the discrimination facing prospective adoptive parents with disabilities. Congress has made laudable progress in addressing discrimination against prospective parents of color. The Multiethnic Placement Act of 1994 (MEPA), as amended by Section 1808(c) of the Small Business Job Protection Act of 1996 (also known as the Interethnic Adoption Provisions or Section 1808) prohibits the use of a child's or prospective parent's race, color, or national origin to deny or delay a child's placement.[779] The law also requires states to provide for the diligent recruitment of potential foster and adoptive families that reflect the ethnic and racial diversity of the children in care for whom homes are needed. Congress must pass similar legislation protecting the rights of prospective adoptive parents with disabilities.

Finally, state courts must ensure that adoption agencies comply with federal disability laws and do not discriminate against prospective parents with disabilities. In re Adoption of Richardson[780] highlights the brutal bias lower courts have against prospective parents with disabilities. This case involved a deaf couple who had previously raised biological children and were denied the right to adopt on the basis of their disabilities. The lower court judge actually said, "Is this a normally happy home? There is no question about it, it is a happy home, but is it a normal home? I don't think the court could make a finding that it is a normal home when these poor unfortunate people, they are handicapped, and what can they do in the way of bringing this child up to be the type of citizen we all want him to be?"[781] The judge then wrote a letter to the county adoption bureau that said in part, "This adoption should be nipped in the bud before these unfortunate people get too attached to the child as, in my opinion, we are not doing right by the youngster in signing and approving an adoption to deaf-mutes."[782] This decision was reversed on appeal, but it illustrates biases that pervade the lower courts.

Unfortunately, few contested cases reach the courts and even fewer reach the appeals courts.[783] According to Mills, one study found that only 0.1 percent of adoption cases nationally are litigated and even fewer involve contested adoptive parents (0.001 percent).[784] It is unclear how many of these contested cases involve discrimination based on disability; probably very few. *Richardson* suggests that many prospective parents with disabilities may need to appeal their decisions because of the bias that exists in lower courts. Litigation, especially appeals, is very costly and likely not an option for many prospective parents with disabilities. State courts, especially lower courts, must appropriately apply federal disability laws to adoption cases.

Surely, "every child has the right to a loving, nurturing and permanent family, and … people from a variety of life experiences offer strengths for these children."[785] And everyone, including prospective parents with disabilities, should have an equal opportunity to provide that family.

International Adoption: A Promising Alternative?

In consideration of the pervasive discrimination in the domestic adoption system, does international

adoption provide prospective parents with disabilities greater opportunities? According to Erika Lynn Kleiman:

> "One of the most common reasons for a person to turn to international adoption is that he has effectively been rendered ineligible as a prospective adoptive parent by domestic agency criteria…. Foreign countries often have less stringent requirements than American agencies. In addition, international home studies are often less rigorous than domestic ones. Admittedly, there are some countries with strict restrictions regarding which people may adopt their children. Nevertheless, the large number of countries that are willing to allow Americans to adopt their orphaned children increases most people's chances of meeting the standards of eligibility for adoptive parents in at least one country. As such, international adoption provides an alternate source of children for Americans who may not qualify as eligible adoptive parents under domestic standards."[786]

As this section reveals, prospective parents with disabilities encounter mixed results with international adoption. Some countries have less stringent requirements, and international home studies tend to be less rigorous. On the other hand, some countries categorically deny prospective parents with disabilities, and people with disabilities often face barriers to accessibility and travel.

Invidious Criteria

While international adoption may provide greater opportunities, nations differ in whether they permit people with disabilities to adopt. Some countries completely disqualify people with disabilities, while others apply more liberal criteria. Some nations are becoming increasingly restrictive in their eligibility requirements for prospective parents. Some of these countries have fewer children available, so they can become more selective about who can adopt.[787] Restrictions are also likely a result of cultural differences in how disability is understood in other nations. The substantial gulf between understanding of disability in much of the United States and that demonstrated by other nations is often displayed when Americans with disabilities attempt to adopt from abroad. Ella Callow, director of the legal program at TLG, offers the following advice: "In choosing which type of international adoption to undertake, people with disabilities must be aware of the realities in other countries. The whole world is not America and most other nations have not focused as much attention on physical accommodation and education to increase societal inclusion. In light of this…[m]any other countries have policies that reflect strongly held beliefs about what constitutes disability, what disabilities will adversely affect the ability to parent and what type of children should go to homes where a parent is disabled."[788]

For example, China recently modified its eligibility requirements, making it impossible for most people with disabilities to adopt from there. The Department of State says that to adopt a child from China:

> "Both partners must be physically and mentally fit, with none of the following conditions: AIDS; mental disability; infectious disease that is actively contagious; blind in either eye; hearing loss in both ears or loss of language function (those adopting children with hearing or language function

loss are exempted from this requirement); nonfunction or dysfunction of limbs or trunk caused by impairment, incomplete limbs, paralysis, or deformation; severe facial deformation; severe diseases that require long-term treatment and that may affect life expectancy, including malignant tumors, lupus, nephrosis, epilepsy, etc.; major organ transplant within ten years; schizophrenia; severe mental disorders requiring medication for more than two years, including depression, mania, or anxiety neurosis; and Body Mass Index (BMI) of 40 or more."[789]

Of the top five sending countries in 2011, three had eligibility criteria that completely or nearly precluded prospective parents with disabilities from adopting children from their countries.[790] China, the top sending country, outright denies prospective parents with disabilities.[791] Russia, which is number three, denies prospective parents with tuberculosis (active or chronic), illness of the internal organs or nervous system, dysfunction of the limbs, infectious diseases, drug or alcohol addictions, psychiatric disorders, or any disability that prevents the person from working.[792] Ukraine, the fifth of the top sending countries, denies prospective parents with substance abuse, syphilis, and HIV infection or AIDS.[793] In contrast, Bulgaria has the fewest requirements for adoptive families and will often accept parents with disabilities.[794]

Of the top five sending countries in 2011, three had eligibility criteria that completely or nearly precluded prospective parents with disabilities from adopting children from their countries.

Because of some countries' stringent eligibility criteria, many prospective adoptive parents with disabilities do not pursue international adoption. For example, Ken and his wife[795] (the adoptive parents mentioned earlier) made a "conscious decision not to explore international adoption because of countries' rules."

Agency Discrimination and Home Studies

Generally, the first step in the international adoption process is to choose an adoption agency. Each agency works with a different set of countries; some focus on a single country.[796] Pursuant to the rules of the Hague Convention, the agency must be accredited by the U.S. government if the child's country is also a participant in the convention. If the child's country is not a participant, the Hague rules do not apply, and the process will follow the laws of the sending and receiving countries.[797] Even when the Hague rules do not apply, a home study and USCIS approval are required.

Linda A. Cronin, in *Action Online: Magazine of the United Spinal Association*, said, "The ADA applies fully to all adoption agencies doing business on U.S. soil so, by law, they must serve and accommodate the needs of adoptive parents with disabilities."[798] Thus, such adoption agencies, even though they are engaging in international adoption, must provide prospective parents with disabilities reasonable modifications, auxiliary aids, and services.

But despite federal disability law protections, the same impediments found in domestic adoption exist in international adoption. These adoption agencies are not likely to be immune to the bias that pervades the domestic adoption system; in fact, they are often the same agencies that facilitate domestic adoption.

Other Barriers to International Adoption

In addition to stringent eligibility restrictions and agency discrimination, prospective adoptive parents with disabilities often encounter barriers related to accessibility, travel requirements, and cost.

Parents' Stories: Jessica and Rebecca

International adoption includes an extensive application and screening process conducted by USCIS. Jessica, a woman with osteogenesis imperfecta, and her husband, who adopted two children from Guatemala, said USCIS "wanted a very specific letter from [Jessica's doctor] that indicated exactly what my medical history was, how my disability impacted my life and my prognosis for the future. They also wanted a letter from family members who would be able to step in and care for my child in an emergency."[799] USCIS also requires a background check, which includes fingerprinting, for all international adoptions. Rebecca,[800] a mother with disabilities, noted that the fingerprinting requirement may preclude some people who do not have fingerprints because of their disability.

As a federal agency, USCIS must comply with Section 504 of the Rehabilitation Act. The agency must provide reasonable modifications in policies, practices, and procedures as needed for prospective adoptive parents with disabilities, as well as auxiliary aids and services when they are necessary to ensure effective communication. Examples include a sign language interpreter for deaf prospective parents or application materials in alternative formats for blind or low-vision prospective parents.

Some prospective adoptive parents may encounter travel requirements that preclude or limit them from international adoption. Some countries require more than one trip, while others allow the children to be escorted to the United States by someone other than the parents.[801] Some nations require longer trips than others. For instance, the Ukraine requires adoptive parents to stay for at least seven weeks.[802] Travel can be difficult for some prospective parents with disabilities, who may need specialized equipment, personal assistance services, accessible hotels, and transportation. This can be cost-prohibitive for some, thus precluding them from international adoption.

Despite significant obstacles, people with disabilities do successfully adopt internationally. The *Chicago Tribune* published the story of a blind couple who adopted two girls, one from India and the other from China (presumably before China changed its requirements).[803] Both girls are also blind. The couple was reluctant to have children, until a pair of nuns collecting money for overseas orphanages told them about a blind orphan in Bangalore, India.[804] After 18 months, they adopted their first daughter; a year later, they adopted their second.[805]

Improving Access to International Adoption

As international adoption continues to expand and become a route to parenthood for many, the United States must ensure that all prospective parents have the opportunity to benefit, including prospective parents with disabilities. NCD recommends that CI, part of the Bureau of Consular Affairs at the Department of State, and the Department of State's Office of the Special Advisor for International Disability Rights work together to expand the rights of people with disabilities to adopt internationally, particularly from nations that have ratified the Hague Convention. Such work will require educating state and private adoption agencies in other countries on the ability of people with disabilities to parent, with or without adaptive parenting equipment, techniques, or supportive services.

Further, DOJ, in collaboration with HHS and the Department of State as appropriate, must ensure that international adoption agencies on U.S. soil are complying with federal disability laws. Similarly, USCIS must ensure that it is complying with its 504 mandates.

Conclusion

Around the world, countless children are waiting for their forever homes. At the same time, many people with disabilities want to provide a loving and nurturing home and family for children. Ignorance, stigma, and misconceptions are forestalling harmonious solutions. The result is devastating: Children spend many years in deplorable conditions in foster care and orphanages, while people with disabilities are robbed of the opportunity to welcome these children into their homes and hearts.

Chapter 11. Assisted Reproductive Technologies

Parents' Stories: Kijuana Chambers

In 2000, Kijuana Chambers, a blind woman from Colorado, filed a lawsuit after being denied access to assisted reproductive technologies.[806] According to the fertility clinic, Kijuana posed a "direct threat" to the safety of her yet-to-be-conceived baby.[807] Just as Kijuana was about to undergo an insemination treatment, the clinic demanded that she get an occupational therapy assessment of her home to make sure it was safe for a baby.[808] After looking into it, Kijuana informed the doctors that she could not obtain such an evaluation.[809] The doctors refused to inseminate and refused all further services until she provided evaluations.[810] After a lengthy battle, the 10th Circuit Court of Appeals denied the appeal in an unpublished decision.[811] According to an attorney for the clinic, the doctors were worried that Kijuana could not care for a baby and turned her down because "it was the right thing to do."[812] "This case is about the moral and ethical responsibility of a physician," the attorney said.[813] Kijuana eventually located another clinic that provided her with fertility treatment, and she now has a daughter.[814]

Kijuana's experience is common. Many prospective parents with disabilities encounter significant, and sometimes insurmountable, barriers to receiving assisted reproductive technologies (ART). Access to ART is often impeded by discriminatory practices against people with disabilities, as well as the growing costs of treatment combined with limited coverage by health insurance. The fact that ART remains largely unavailable to many prospective parents with disabilities is significant because for many it provides the only opportunity to procreate. In fact, as this chapter explains, ART providers may have an affirmative duty to provide treatment, pursuant to the ADA, in some circumstances.

The fact that ART remains largely unavailable to many prospective parents with disabilities is significant because for many, it provides the only opportunity to procreate.

Assisted Reproductive Technologies: A Brief Overview

ART—a mainly unregulated multibillion-dollar industry—is the only type of medical treatment in which the "end goal is the creation of another person."[815] ART includes a wide range of medical technologies designed to treat infertility or otherwise assist in impregnating a woman who is unable to become impregnated through sexual intercourse. Basic ART includes diet alterations, lifestyle changes, and drug or hormone therapy. Approximately 85 percent of infertility cases are resolved through these measures.[816]

More sophisticated and invasive interventions include intrauterine insemination (IUI) and in vitro fertilization (IVF). IUI is a relatively simple nonsurgical procedure in which prepared sperm from a partner or donor is brought closer to the ova through insertion into the woman's uterus during her ovulatory phase.[817] IVF is a more complicated process in which the ova are removed from the woman's body by laparoscopy, fertilized with semen from her partner or donor, incubated in a laboratory dish until an embryo develops, and then transferred to the woman's uterus.[818] Some couples may also require gamete intrafallopian transfer or zygote intrafallopian transfer. All but the most basic ART requires treatment by a physician, typically a reproductive endocrinologist or urologist.[819]

IUI and IVF can also be used to impregnate a surrogate. A surrogate is a third party who gestates the baby to full term with the understanding that she will give the baby to the intended parents. In gestational surrogacy, the woman is inseminated with the intended couple's fertilized egg (using either the couple's gametes or donor gametes); thus, the surrogate is not genetically related to the baby. In partial surrogacy, the woman is inseminated with the intended father's sperm (or donor sperm) for the purpose of fertilizing one of the surrogate's own eggs; in this case, the surrogate is genetically related to the baby.

According to estimates, nearly one in six American couples will experience infertility at some point, and nearly 14 percent of married couples who are not surgically sterile are infertile during any given year.[820] More precisely, 9 out of every 100 women worldwide between the ages of 20 and 44 cannot conceive a child.[821] As Dave Shade notes, "Because disability has only a neutral or negative impact on fertility, people with disabilities who wish to have children are equally or more likely than the nondisabled population to experience infertility. Thus, it would be expected that at least fourteen percent of heterosexual couples trying to conceive, in which at least one partner has a disability, are infertile during any given year, and at least one sixth of such couples will experience infertility sometime during their relationship."[822] It is estimated that approximately 7.3 million couples in America currently experiencing infertility.[823] One study estimates that this number will increase to approximately 7.7 million by 2025.[824]

Disability and Reproduction: Historical Context

As discussed in Chapter 1, the health care profession has a horrid history of curtailing the reproductive rights of people with disabilities. Jaime Anno, a master's in public health candidate, wrote, "While scientific eugenics no longer occurs under that name, the

determination and the practice of controlling the reproduction of some groups and supporting the reproduction of other groups persists in the United States."[825] In an article in the *Berkeley Journal of Gender, Law, and Justice*, Judith Daar wrote, "While the eugenicists of a century ago coerced the 'feeble minded' into surrendering their reproductive capacity through forced sterilizations, today's practices act to deprive the disempowered of their capacity to reproduce by withholding the means necessary to produce a child."[826]

The same beliefs about people with disabilities that once led health care providers to sterilize thousands of women with disabilities now lead them to provide or deny reproductive care on the basis of stereotypes concerning people with disabilities and their sexuality. According to Carrie Killoran, a mother with a disability, "Whether a woman is born with a disability or acquires it later in life, the message she gets from the medical system and society is that she is ineligible for normal societal female roles of lover, wife, or mother."[827]

"Whether a woman is born with a disability or acquires it later in life, the message she gets from the medical system and society is that she is ineligible for normal societal female roles of lover, wife, or mother."

– Carrie Killoran

The misconceptions held by many health care professionals result in diminished access to reproductive health care for women with disabilities. As discussed in the NCD report *The Current State of Health Care for People with Disabilities*, women with disabilities require health services related to sexuality, reproductive care, and childbearing, just as women without disabilities do.[828] However, social misperceptions and stereotypes about disability can make it difficult for women with disabilities to obtain information, medical care, and services to ensure that their reproductive needs are met.[829] Such needs include routine gynecological and breast examinations; screening for sexually transmitted diseases (STDs); contraception; consultations about sexuality and sexual function; fertility consultation and support; obstetrical care during pregnancy, labor, and delivery; and information about healthy parenting and issues related to menopause, including osteoporosis, loss of libido, and insomnia.[830]

Structural barriers to receiving adequate and informed reproductive care include limited professional training and competency of primary care and reproductive care specialists; inadequate or no health insurance coverage for visits to specialists; poor physical access to usable and adapted or specialized examination and diagnostic equipment; and negative or discriminatory provider attitudes.[831]

ART providers are not immune to the eugenics philosophy that continues to pervade the health care system. Carl H. Coleman says, "Our society has a long history of efforts to prevent people with disabilities from having children, a history in which the medical profession played an especially prominent role. While we no longer embrace the coercive eugenics policies of the early twentieth century, the perception that some individuals with disabilities are inherently incapable of being

parents remains common in our society. Hence, there is a real danger that disability-related denials of ART will be based on ignorance or bias against people with disabilities, even more so than when physicians deny individuals with disabilities other types of medical care."[832]

Disability Law and Assisted Reproductive Technologies

ART providers must comply with the ADA as well as the Rehabilitation Act if they receive any federal monies, such as Medicaid or Medicare. Generally, ART providers offer services in hospitals or freestanding medical offices. If the provider treats patients in a public entity, such as a state-run hospital, Title II of the ADA applies; otherwise, Title III of the ADA applies, because it includes "professional office of a health care provider, hospital, or other service establishment."[833]

Title III prohibits any public accommodation from discriminating against people with disabilities by denying access to goods and services. Under Title III, ART providers may not (1) establish eligibility criteria that screen out people with disabilities from equally benefiting from a good or service; (2) fail to make reasonable modifications in policies, practices, or procedures when such modifications are necessary to ensure that people with disabilities have access to the goods or services; (3) fail to take such steps as may be necessary to ensure that no person with a disability is excluded, denied services, or treated differently because of the absence of auxiliary aids and services; (4) fail to remove architectural barriers; or (5) fail to make a good or service available through alternative methods if such methods are readily achievable.[834]

Access to Assisted Reproductive Technologies

In 1942, at the height of World War II, Supreme Court Justice William O. Douglas said, "Procreation…involves one of the basic civil rights of man ... fundamental to the very existence and survival of the race."[835] Although ART can enable many people with disabilities to procreate when they would otherwise be unable to do so, access is often impeded for prospective parents with disabilities because of significant, and sometimes insurmountable, barriers to receiving the vital treatment. Kimberly Mutcherson, professor of law at Rutgers University, said, "To be a reproductive endocrinologist is to wield tremendous power over procreation."[836] Prejudice and social tolerance of inappropriate and unlawful presumptions about disability often result in people with disabilities being denied access to ART, which in many cases violates Title II and III of the ADA. As the use of such treatments expands, providers must not lose sight of their legal and ethical obligations to treat people with disabilities. Moreover, the growing costs of ART, combined with the dearth of coverage for such treatment by health insurance, often prevents people with disabilities from using ART as a means to parenthood.

Discrimination and Bias

In recent years, ART has increasingly become the subject of impassioned widespread debate. Most of the public attention has been on the status of the children resulting from these treatments rather than the process by which patients are accepted for treatment, which has allowed widespread opportunity for discrimination.

Physicians in private practice may decline to provide services to a person for a variety of reasons, such as excessive patient load, the person's inability to pay, or simply because they do not like the person.[837] For ART providers, it is also "legally and ethically permissible for a physician to refuse care to a patient when a medical assessment reveals that the patient cannot be helped with existing technology or that an ensuing pregnancy would seriously compromise the patient's own health."[838] However, refusal to provide care on the basis of factors such as race, ethnicity, or disability violates both professional ethics and the law.[839]

Research demonstrates that ART providers regularly engage in discriminatory practices, particularly in screening potential patients. The Office of Technology Assessment of Congress surveyed 1,213 artificial insemination providers and found considerable potential for discrimination during the patient acceptance process.[840] The survey revealed that one in five patients seeking artificial insemination is rejected.[841] According to the survey, the most common rejection criteria were nonmedical: patient unmarried (52 percent of rejections), "psychologically immature" (22 percent), homosexual (15 percent), or "welfare dependent" (15 percent).[842] When asked, "Have you ever rejected or would you be likely to reject a request for artificial insemination from a potential recipient because she was/has…" respondents demonstrated an alarming willingness to make social judgments.[843] "Sixty-one percent had rejected, or would be likely to reject, an unmarried woman without a partner; 85 percent would reject a psychologically immature woman; 79 percent would reject a woman with a history of a serious genetic disorder; 95 percent would reject a woman with HIV infection; 32 percent would reject a woman with less than average intelligence; and 9 percent of infertility specialist physicians reported that they would reject a woman because she had less than a high school degree."[844] Moreover, the report revealed that more than half of the providers surveyed (52 percent) performed a "personality assessment" on their potential patients, 44 percent screened for genetic diseases, and 74 percent screened for "selected diseases."[845] In at least some instances, the purpose of these screening mechanisms was "to detect diagnosable mental illness or to address more general considerations of fitness for pregnancy and motherhood."[846] While this study addressed only artificial insemination, the surveyed physicians represent the same group of physicians that provides other ART, so the results are applicable.

Mutcherson cites another study on the screening practices of ART providers that demonstrates that "most fertility providers believe that their work obligates them to consider both the welfare of the fertility patient or patients and the welfare of a future child prior to agreeing to help a patient achieve pregnancy."[847] When asked questions about refusing hypothetical patients, providers demonstrated certain values and biases. According to this study, 59 percent of responding program directors said they would be very or extremely likely to refuse service to an HIV-positive woman, while 55 percent had the same response regarding a diabetic woman who had a 10 percent chance of dying as a result of her pregnancy. Sixty percent of the clinics would be not at all likely or slightly likely to turn away couples in which the woman has a history of attempted suicide, and 68 percent

answered similarly regarding a couple in which both members have limited intellectual ability. Finally, only 66 percent would work with a woman with bipolar disorder, whereas 91 percent would work with a couple in which both members had become blind from a car accident.[848]

These studies demonstrate that ART providers regularly engage in discriminatory practices. Mutcherson says, "Given that those living with disabilities have frequently been singled out for ill treatment in the realm of procreation and parenting (including a long history of sterilization abuse), viewing fertility care through the lens of discrimination against the disabled provides a strong vantage point from which to evaluate what duties fertility providers owe to patients, and what duties society owes to those who face unjustified discrimination in their quest to become parents."[849]

The Direct Threat Defense and the Future Child's Interests

Although ART providers must comply with the ADA and may not discriminate on the basis of disability, Mutcherson, in her article "Disabling Dreams of Parenthood: The Fertility Industry, Anti-discrimination, and Parents with Disabilities," examines whether ART providers may attempt to seek safe harbor under the direct threat defense of the ADA. The direct threat provision allows a physician to lawfully refuse care to a patient if the patient poses a direct threat to others.[850]

A direct threat is defined as "significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures, or by the provision of auxiliary aids or services"[851] Pursuant to the ADA and its corresponding regulations, the determination that a person poses a direct threat must be based on an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk.[852] Mutcherson says, "Direct threat evaluations must be made to minimize the denial of services based on irrational fear and stereotypes, yet to allow care to be refused when objective evidence warrants that refusal."[853]

Generally, in this context, threat-to-self claims should fail.[854] For example, in the case of a woman who is HIV-positive, pregnancy presents unique challenges and has been found, in some circumstances, to compromise a woman's health.[855] However, other sources have found that pregnancy can actually improve the health of an HIV-positive woman.[856] Moreover, Mutcherson says, "It is irrefutably the case that thousands of HIV-positive women have given birth—most of them to healthy children—since the start of the epidemic, and it cannot be conclusively shown that pregnancy severely compromises the life span of an HIV-positive woman. Even if pregnancy was detrimental, arguably the decision whether to risk a shortened life span in the interest of having biological children is a choice to be made by the woman seeking pregnancy, and not by a physician. Thus, while a fertility specialist could choose not to assist an HIV-positive woman for fear that her pregnancy would pose undue risk to her own health, the claim of direct threat to the patient is specious at best and subterfuge to conceal

illegal discrimination at worst."[857] Similarly, in the case of a woman with quadriplegia, Mutcherson says, "The direct-threat-to-self claim also falters.... Such pregnancies entail risks, as do all pregnancies, but those risks can be well managed by obstetrical providers, thus negating a plausible claim of direct threat to self. The quadriplegic woman may require a more exacting level of monitoring than would a woman without such a disability, but the same is true for women who are diabetic, over the age of thirty-five, or have a history of miscarriages. Thus, the argument of direct threat to self is a poor one for fertility providers who are hoping to avoid caring for women with substantial physical disabilities."[858] ART providers will almost always fail in raising threat-to-self claims.

ART providers typically deny access under the guise of threat to others, where the defense applies in two ways. *Direct risks* (gestational concerns) are those that would result in transmitting the parent's disability to the child, or the risk of an adverse pregnancy outcome directly linked to the pregnant woman's disability, such as complications leading to fetal death or to a child's disability. *Indirect risks* (child-rearing concerns) are those that could affect the child as a result of how the parental disability affects the ability to parent.

Gestational concerns

ART providers regularly deny people with disabilities access to fertility treatment on the basis of gestational concerns. ART providers sometimes seek to employ the direct threat defense by asserting that the patient's disability presents a risk to the child during gestation.[859] Often, this "threat" is that the child may inherit a parent's disability. In such cases, ART providers must be cognizant of the intent of the ADA, which clearly disallows stereotyping as a permissible factor for consideration. Mutcherson says, "The ADA requires reconsideration of outmoded perceptions that disability is a horrible fate inflicted upon a 'victim.' If the potential harm is already borne by one or both parents (e.g., infertile deaf parents with a significant risk of having a deaf child), the court would be well-advised to place great weight on the wishes of the parents having experience with the disability in question. Moreover, permitting ART providers any significant degree of control in selecting the allowable (desirable?) characteristics in a child raises troubling eugenics concerns and may call for the restriction of the discretion of providers when considering genetic risks."[860]

Generally, gestational concern is outside the expertise of the ART provider,[861] so the provider must seek a review from a qualified expert before escaping liability for a discriminatory denial of access to ART.[862] While the ADA may not require a medical opinion in all direct threat cases, it does require an objective individualized assessment that relies on current medical knowledge or on the best available objective evidence.[863] In most circumstances, an expert opinion would be necessary.

Undoubtedly, ART providers who deny fertility treatment to prospective parents with disabilities because of gestational concerns do so because of their own beliefs about disability. In fact, Elizabeth Pendo, professor of law at Saint Louis University School of Law, Center for Health Law Studies, says that studies have consistently demonstrated that the attitudes of physicians and other health care professionals toward people with disabilities are as negative

as those of the general public, if not more negative.[864] As one study found, "Health professionals significantly underestimate the quality of life of people with disabilities compared with the actual assessments made by people with disabilities themselves. In fact, the gap between health professionals and people with disabilities in evaluating life with disability is consistent and stunning."[865] For instance, Pendo notes, "In a survey study of attitudes of 153 emergency care providers, only 18 percent of physicians, nurses, and technicians imagined they would be glad to be alive with a severe spinal cord injury. In contrast, 92 percent of a comparison group of 128 persons with high-level spinal cord injuries said they were glad to be alive."[866]

Jennifer,[867] a wheelchair user and mother of three children, was astonished when she experienced this attitude. During one of her pregnancies, genetic testing revealed that her child might have Down syndrome. Because of this, her physician encouraged her to terminate her pregnancy. Jennifer could not believe this; after all, she was a person with a disability, and she knew that having a disability was not the end of the world. Similarly, Susan,[868] who has an immune system disorder and is a mother of two children, was upset when her physician encouraged her to terminate a pregnancy after genetic testing revealed a marker for Down syndrome. Like Jennifer, Sarah was hurt and saddened that her doctor believed that a child who might have a disability should be aborted. In the end, neither Jennifer nor Sarah terminated her pregnancy, and neither child was born with a disability, although if they had been, both women told NCD that they would have loved the children just as much.

Related to gestational concerns—and reflecting many ART providers' negative beliefs about disability—is pre-implantation genetic diagnosis, which involves screening embryos created through IVF for the presence or absence of certain genes, such as deselecting for a disability or selecting for a particular sex.[869] According to Adrienne Asch, Edward and Robin Milstein Professor of Bioethics at Yeshiva University and professor of epidemiology and population health and family and social medicine at Albert Einstein College of Medicine, "Using prenatal tests to prevent the births of babies with disabilities seems to be self-evidently good to many people. But for many people with disabilities, the message implicit in the practice of abortion based on genetic characteristics is, 'It is better not to exist than to have a disability. Your birth was a mistake. Your family and the world would be better off without you alive.'"[870] "Disability activists say underlying (mis)assumptions about disability influence women's decisions about whether to abort. They believe families need more accurate information about various disabilities and the lives of people with disabilities. Activists also point out that discrimination has a huge impact on the lives of people with disabilities, and that many of the limits on quality of life come not from medical burdens, but from barriers set up by society, from stigmatization to elevators that don't work."[871]

According to a Web site on gynecologic and obstetric issues confronting women with disabilities, "Because most disabilities result from trauma or the effects of age, it is unlikely that prenatal screening will reduce the gross social cost of disabilities. [Thus], [p]renatal screening that fails to incorporate the subjective

experience of the disabled themselves costs society enormously when it eliminates the contributions of gifted, diverse individuals."[872] Prenatal testing raises the question: Is it better not to exist or to have a disability? Most people living with disabilities would choose the latter; the same cannot be said for many ART providers.

Mutcherson says, "Women with disabilities have far too frequently faced discrimination in their quests to become parents. As reproductive technology creates expanded opportunities for these women, it would be a disservice to them—and the children…they would raise with love and care—to deny them the opportunity of biological parenthood routinely given to so many others."[873] Eugenic agendas that prescribe who is "fit" and "unfit" to reproduce or be reproduced must be challenged.

Prenatal testing raises the question: Is it better not to exist or to have a disability? Most people living with disabilities would choose the latter; the same cannot be said for many ART providers.

Child-rearing concerns

As Kijuana's story at the beginning of this chapter illustrates, ART providers deny treatment to prospective parents with disabilities on the basis of their perceived inability to care for children. Most people are "free to reproduce with a consenting partner without a prior assessment of their child-rearing ability or competency."[874] However, many prospective parents with disabilities who seek ART have found that they are the unfortunate exception to the rule. As Carrie Killoran recounts:

> "My infertility specialist never even considered the effects of my disability on childrearing. His interest seemed exclusively clinical. His nurse practitioner, however, with whom we had many appointments, seemed intent on repeatedly warning us of how hard it was to bring up a child, and how we did not know what we were getting into. This is a typical response for people who cannot imagine life with a disability. Everyone knows that having children is a lot of work, and to most people, choosing to add the difficulties of children to the challenges of disability is incomprehensible. However, we were at an infertility specialist! We clearly were not being whimsical or impulsive in our decision to have a child. I was the oldest in a family with lots of kids, and I had a good idea of what I was getting into."[875]

As Mutcherson says, "Physicians who object to providing care based on amorphous concerns about the parenting skills of the patient and the best interests of the potential child stand on enormously shaky ethical and legal ground."[876] Generally, ART providers do not have the training or expertise to raise or assess child-rearing abilities.[877] Shade says, "The fact that the medical community apparently considers such evaluations both appropriate and necessary evidences the extent to which such social judgments have previously been exercised by ART providers. However well-meaning such judgments may have been, they have undoubtedly been at times discriminatory in practice. Couples without infertility problems need satisfy no social criteria

to implement a decision to have children. To use infertility treatment as a proxy for a parental fitness evaluation is both inappropriate and ineffective."[878]

Some people believe that it is morally wrong to knowingly conceive a child when there is a risk of transmitting HIV to the child and that the reduced life expectancy of the infected parent will disadvantage the child.[879] However, researchers at the Royal Children's Hospital/University of Melbourne argued that "denying HIV discordant couples access to assisted reproductive technologies is unjustified discrimination because couples who have children without reproductive assistance are not scrutinized in the same way."[880] The researchers said, "Couples who conceive naturally do not have to justify their desire to have children,"[881] and "We have no reliable way of predicting who will or will not be a good parent and no agreed upon measure of what makes a good parent."[882]

According to the American Society for Reproductive Medicine (ASRM), ART providers in the United States have traditionally not engaged in any "systemic screening of [a prospective patient's] ability or competency in rearing children."[883] However, ASRM also asserts, "Fertility programs may withhold services from prospective patients on the basis of well-substantiated judgments that those patients will be unable to provide or have others provide adequate child-rearing for offspring."[884] The association also makes the following statement:

> "With the growth of fertility programs and increased access for many people in the population, a wide variety of individuals now seek infertility treatment, including subcategories of patients for whom questions of child-rearing ability might legitimately arise. Many programs have had treatment requests from patients that raise such questions, for example, from persons who have a history of psychiatric illness, substance abuse, or ongoing physical or emotional abuse in relationships. Some patients or their partners may also have a history of perpetrating child or spousal abuse, or they present other factors that lead fertility programs to question whether they are likely to cause significant harm to a future child. In addition, persons with disabilities are increasingly seeking fertility services. While most disabilities do not impair child-rearing ability, there are some situations in which questions about child-rearing ability of persons with severe disabilities could reasonably arise."[885]

Richard F. Storrow, professor of law at the City University of New York, says, "Although it is thought that most practitioners follow [ASRM's ethical] guidelines, the guidelines themselves are in the nature of standards for self-regulation only. This lack of downward pressure on clinics from either the legal system or professional associations means that many clinics have no written policy on access to services."[886]

Most ART providers believe that their work obligates them to consider both the welfare of the fertility patient or patients and the welfare of a future child before agreeing to help a woman get pregnant. In fact, one study cited by Mutcherson that screened 15 practices of ART programs found that although 59 percent of responding ART program directors believed that everyone has a right to have a child, 64 percent of these directors also believed "in their responsibility to consider a parent's fitness before helping them conceive."[887]

Mutcherson said the fact "that only a minority (18 percent) of responding ART programs asked potential patients to meet with a social worker or psychologist during their patient screening process raises serious questions about how these programs accurately and adequately evaluate parental fitness without the aid of trained and skilled providers. This small number of evaluations conducted by social workers and psychologists starkly contrasts with the 80 percent of programs in which potential patients meet with a financial coordinator."[888]

Undoubtedly, as Mutcherson asserts, "Defining the contours of good parenting is a gargantuan task that is rivaled, if not surpassed, by the challenge of determining if any one individual actually possesses good parenting skills. This assessment is even harder when the individual in question has not yet had a chance to put those skills into practice. When a person stands on the verge of procreation, as does one who seeks fertility treatment, any assessment of future parenting skill risks being reductive and simplified, and may limit the number of individuals allowed to reproduce with medical assistance—without necessarily sparing any future child from harm."[889]

Financial Barriers[890]

Parents' Stories: Stacey

Stacey[891] and her husband have been trying to conceive a child for more than a year. Both have physical disabilities. In preparation for conception, Stacey's gynecologist conducted blood tests and an ultrasound, which revealed that her hormone levels and reproductive organs were "great for conceiving" and her uterus could carry a baby.

Despite a year of trying, which has included ovulation kits and several other over-the-counter conception instruments, prenatal vitamins, exercise, and diet changes, Stacey and her husband have not conceived. Feeling "in the dark" about why they are unable to conceive, they would like to receive fertility treatment. Unfortunately, their health insurance (Medicaid and Medicare) does not pay for fertility treatment. Because of their limited incomes, they cannot afford the cost of treatment. Thus, because of significant financial barriers, Stacey and her husband may never be able to have a child and may never know why they could not conceive.

The cost of ART treatments significantly impedes many people with disabilities from accessing these technologies. (ASRM lists the average price of an IVF cycle in the U.S. as $12,400; the association does not say whether this includes medications.)[892] Resolve: The National Infertility Association reports that the average cost of an IUI cycle is $865 and the average price of an IVF cycle using fresh embryos (not including medication) is $8,158.[893] On average, medications for IVF are $3,000–$5,000 per fresh cycle.[894] People with disabilities typically have lower incomes, face higher health care costs, and seek health care services more often than people without disabilities.[895] Specifically, 30 percent of adults with disabilities aged 25 to retirement are living in poverty, which is twice the rate of their nondisabled counterparts.[896] In 2008, 26.1 percent of the poor population between

the ages of 16 and 64 had a work disability. Of those with a severe work disability, 33.6 percent were poor, compared with 14.1 percent with a less severe work disability and 9.1 percent with no work disability.[897] Under these conditions, the financial burden of ART is a significant barrier. Medicaid and Medicare, the primary health insurers for people with disabilities, do not cover fertility treatment services.

Congress created Medicaid in 1965 "to enable each State, as far as practicable, to furnish medical assistance to individuals whose income and resources are insufficient to meet the costs of necessary medical services."898 State Medicaid agencies may not "arbitrarily deny or reduce the amount, duration, or scope of a required service . . . to an otherwise eligible recipient solely on the [basis of] diagnosis, type of illness, or condition."[899] Medicaid is the nation's largest group insurance program; it covers eight million people with disabilities.[900] Half of all women with disabilities are covered by Medicaid.[901] The lack of ART coverage under Medicaid and Medicare means that even if ART is accessible in theory, it is inaccessible to many people with disabilities in practice, because they cannot afford to pay for the services.

Medicaid's failure to provide coverage for ART is inconsistent with its willingness to provide coverage for the male erectile dysfunction medication Viagra. Although federal law allows states to refuse coverage for fertility drugs, in July 1998, HHS sent a letter to the nation's governors ordering them to pay for the costs of Viagra under state Medicaid programs.[902] The head of the Health Care Finance Administration reasoned that "Viagra had been approved by the FDA for the treatment of impotence and that impotence drugs were not allowed to be excluded from coverage pursuant to the statute because they were 'medically necessary.'"[903] State governors expressed concern that the mandate forced them to cover Viagra for men while covering virtually no birth control or fertility drugs for women.[904]

Although opponents may argue that Viagra treats general erectile dysfunction, the reality is that Viagra assists reproduction in cases in which a man cannot otherwise achieve an erection to release sperm. Medicaid's mandate to cover a male fertility drug but not female fertility drugs discriminates against women with disabilities. The key role of Medicaid in providing health care services to women with disabilities necessitates that Medicaid and Medicare cover ART.[905]

Medicaid and Medicare, the primary health insurers for people with disabilities, do not cover fertility treatment services.

Coverage of fertility treatment by private health insurance is minimal. According to a 2006 survey of 931 employers conducted for Resolve, approximately 20 percent of employers cover ART.[906] Fifteen states have passed laws requiring that insurance companies provide coverage for some level of infertility treatment—either that treatment be provided as a basic health plan benefit (mandate to cover) or that insurance companies at least offer infertility coverage to purchasers (mandate to offer).[907] The 12 states that require insurance companies to cover infertility treatment are Arkansas, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, Montana,

New Jersey, New York, Ohio, Rhode Island, and West Virginia.[908] California, Louisiana, and Texas mandate that insurance companies offer infertility coverage to policyholders.[909] New Jersey should be applauded for its progressive approach to ensuring reproductive rights by including under its covered services IVF in which the embryo is transferred to a gestational carrier or surrogate.[910]

Although these state efforts are commendable, their impact is limited. First, coverage for treatment varies greatly, ranging from the initial consultation and diagnosis to IVF.[911] Even a plan that covers IVF may cap the numbers of cycles or the dollar amount it will pay.[912] Second, some insurance plans restrict coverage to certain individuals or relationships. For example, Maryland law requires coverage of in vitro fertilization but only if the "spouse's sperm" is used.[913] Finally, the federal Employee Retirement Income Security Act exempts self-insuring businesses (the majority of employers) from state insurance regulation.[914] Therefore, even in the 12 states listed above, fertility coverage may be scarce.

Coverage for ART is often opposed on cost grounds. However, IVF and other reproductive technologies account for only 0.03 percent of U.S. health care costs.[915] Some studies show that the addition of ART treatment to a group health plan has a marginal effect on premiums.[916] In fact, such insurance coverage might even be more cost-effective, because insurance premiums that indirectly provide coverage for "hidden" infertility benefits (e.g., surgery to remove scarring in a woman's fallopian tubes or varicose veins removal for men) may be adequate to cover more effective and often less expensive treatments such as ovulation induction, IUI, and IVF.[917]

These projections are not merely theoretical. The cost of infertility services as a percentage of total health premiums went down after the 1987 Massachusetts mandate.[918] Another study found the additional cost to be an estimated $1.71 per month.[919] In addition, Mercer's 2006 National Survey of Employer-Sponsored Health Plans found that 91 percent of employers reported no measurable increase in their health plan cost after including infertility coverage.[920] Responses did not vary significantly between employers that did and did not cover IVF.[921]

Medicaid's mandate to cover a male fertility drug but not female fertility drugs discriminates against women with disabilities.

Ensuring Access to Assisted Reproductive Technologies

In "Accessing Reproductive Technologies: Invisible Barriers, Inedible Harms," Judith F. Daar writes, "Only by insisting on access for all can we realize Justice Douglas' view of procreation as a basic human right."[922] She concludes that "stigmatizing would-be parents by depriving them the opportunity to reproduce is dangerously reminiscent of our eugenics past, an era in which misguided judgments about parental fitness culminated in the involuntary sterilization of thousands of Americans."[923]

Significant attention must go to ensuring access to ART for prospective parents with disabilities. Specifically, DOJ should issue guidance to ART providers, reinforcing their legal obligations pursuant to the ADA and addressing their duty to provide access and reasonable

Bias Among Artificial Insemination Providers

The Office of Technology Assessment of Congress surveyed more than 1,200 artificial insemination (AI) providers and found the following percentages of providers had rejected or would be likely to reject a request for AI because she was / has:

- An unmarried woman without a partner 61%
- A woman with a history of serious genetic disorder 79%
- A woman with HIV infection 95%
- A woman with less than average intelligence 32%
- A woman with less than a high school degree 9%

accommodations throughout all phases of the process and reminding them that presumptions of parental ability based on disability violate the ADA. DOJ must also investigate all reported allegations of ART providers violating the ADA and enforce the law as appropriate. HHS—collectively, the Office on Disability, CDC, NIH, and Office of the Surgeon General—should issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations. ART professional organizations, such as the SART and the ASRM, must issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations. Finally, CMS must identify and implement mechanisms to pay for ART for Medicaid and Medicare beneficiaries with disabilities.

Assisted Reproductive Technologies as an Accommodation

ART enables certain people to procreate in cases in which reproduction would otherwise be difficult or impossible. Providing these technologies to people with disabilities is a method for breaking down a socially created barrier to procreation. Interestingly, ART may be more desirable than adoption to some prospective parents with disabilities, because the process of adoption is riddled with stigmatization, demeaning investigations, and reluctance.[924] In fact, women with disabilities may be more interested in ART than are their nondisabled counterparts.[925] This section examines the *affirmative* duty of ART providers to treat prospective parents with disabilities, in some situations, under the auspices of ADA-mandated reasonable accommodations. It explores the obligations of countries that have ratified the Convention on the Rights of Persons with Disabilities and the application of its "effective and appropriate measures" provision to ART.

ADA Duty to Provide Reasonable Accommodations[926]

Accessibility to good reproductive health care and services means more than ramps.[927] Provision of assisted reproductive technology is similar to other ADA-mandated accommodations in the context of reproductive rights. In his article "Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination," Michael Stein, an internationally recognized

disabilities rights expert, explains that ADA-mandated accommodations are consistent with other antidiscrimination measures in that each accommodation remedies the exclusion of a class of people from an opportunity by questioning the inherency of established norms. He argues that disability-related accommodations must operate as antidiscrimination provisions to alter social attitudes toward the disabled. Most important, society must recognize that these measures are not just accommodations, they are a right. Surrogacy is a method for eliminating socially created barriers to reproduction for persons with disabilities. Barrier-free access to surrogacy should be available as a matter of right, not a privilege or special accommodation.[928]

Accessibility to good reproductive health care and services means more than ramps. Provision of assisted reproductive technology is similar to other ADA-mandated accommodations in the context of reproductive rights.

Many advocates have looked to the ADA to secure meaningful access to health care for people with disabilities. The purpose of Title III is to ensure that no person with a disability is denied goods or services offered to the public, including health care providers such as ART providers, because of a disability.[929] Pursuant to Title III, discrimination includes failure to make reasonable modifications in policies, practices, or procedures when such modifications are necessary to ensure that people with disabilities have access to the goods or services.[930] Health care providers must take affirmative steps to ensure accessibility for people with disabilities. For ART providers, this may include the use of ART as a reasonable accommodation.

United Nations Convention on the Rights of Persons with Disabilities[931]

Articles 23 and 25 of the CRPD have several positive implications for people with disabilities seeking ART.

Article 23, Respect for home and the family, obligates States Parties to take effective and appropriate measures to eliminate discrimination against people with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.[932] Three rights must be advanced to eliminate discrimination: (1) the right of all people with disabilities who are of marriageable age to marry and to found a family; (2) the right of people with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education, and the means necessary to enable them to exercise these rights; and (3) the right of people with disabilities, including children, to retain their fertility on an equal basis with others.[933] Article 23 also provides that States Parties shall ensure the rights and responsibilities of people with disabilities with regard to guardianship, wardship, trusteeship, adoption of children, and similar institutions, where these concepts exist in national legislation.[934] Third, States Parties shall render appropriate assistance to people with disabilities in the performance of their child-rearing responsibilities.[935] The terms "effective and appropriate measures" and "means

necessary" create a positive duty on the part of States Parties to provide accommodations to people with disabilities in the realm of reproductive choice.

Article 25 of the CRPD protects the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Specifically, States Parties shall provide people with disabilities with the same range, quality, and standard of free or affordable health care and programs as provided to other people, including in the area of sexual and reproductive health and population-based public health programs. This provision also requires health care professionals to provide care of the same quality to people with disabilities as to others, including raising awareness of the human rights, dignity, autonomy and needs of people with disabilities through training and the promulgation of ethical standards for public and private health care. This is particularly important in light of reports from people with disabilities of receiving lower standards of care and frequently encountering unawareness among practitioners, despite seeking medical attention more regularly than people without disabilities.

Article 25 also prohibits discrimination against people with disabilities in the provision of health insurance and prevents discriminatory denial of health care or health services on the basis of disability. The aim of this provision is similar to that of the ADA; it is particularly relevant where practitioners employ methods of discretionary access to reproductive health care (discussed earlier under Discrimination and Bias).[936] Without guidelines, health care providers are free to make arbitrary judgments about people with disabilities.

Examples of Assisted Reproductive Technologies as Accommodations

An Accommodation for People with HIV Infection

The disability most often used as a basis for denying access to ART is HIV infection.[937] In fact, until recently, most medical societies supported the denial of ART to people who are HIV-positive.[938] Over time, however, both the risk of perinatal transmission and the prognosis for HIV-positive people have changed dramatically.[939] These developments have led to reconsideration of policies discouraging the provision of ART to people who are HIV-positive.[940]

In February 2002, ASRM reexamined its policy on providing ART to HIV-positive patients. In a revised policy statement, ASRM noted the dramatic reduction in the rate of HIV transmission from infected women to their offspring, as well as the potential for "specific methods for sperm preparation and testing" to reduce the risk of transmission from infected men to uninfected women. As long as the provider has the clinical and laboratory facilities necessary to care for HIV-positive patients, the new policy states, "One can argue that health care providers are not acting unethically if they have taken all reasonable precautions to limit the risk of transmitting HIV to offspring or to an uninfected partner." Citing the ADA, the report concludes that "unless health care workers can show that they lack the skill and facilities to treat HIV-positive patients safely or that the patient refused reasonable testing and treatment, they may be legally as well as ethically obligated to provide requested reproductive assistance."[941]

ART helps HIV-positive people have a baby when they might otherwise not be able to without posing a significant risk of transmitting the

disease to the baby. For example, when the male partner is positive and the woman is negative, a technique known as sperm washing can be used to diminish the risk of transmission.[942] After sperm washing, the sperm can be combined with the woman's ova using IVF or intracytoplasmic sperm injection (direct injection of the sperm into a selected oocyte).[943] Alternatively, the couple can use donor gametes and ART to impregnate the female partner. This example illustrates how and why ART should be viewed as an appropriate accommodation for people with disabilities.

Surrogacy as an Accommodation[944]

In certain cases of disability, where a woman is unable to carry a baby to full term, surrogacy may be her only means of procreating. Moreover, a recent study implies that at a certain point, surrogacy is a better option than other infertility treatments financially, and physically for the woman, and that it increases the chance of having a healthy baby. *Fertility and Sterility Journal* recently published a study that found that cycle-based fertility treatments, such as IUI and IVF, may have a point of diminishing returns.[945] The study found that after two or three cycles of artificial insemination, the chances of a successful pregnancy may decrease.[946] These realities support the proposition that surrogacy should be included among the appropriate accommodations offered to people with disabilities who are pursuing reproduction.[947] Denying people with disabilities the opportunity to procreate using the assistance of a surrogate is an unnecessary limitation on the right to create a family.

Conclusion

Mutcherson states, "As the country debates the ethics of fertility treatment and worries about rogue fertility providers, it is critical to also raise voices in defense of those who face both natural and socially constructed barriers to parenting."[948] ART providers possess enormous power and must not be permitted to exert control on the basis of bias and speculation. Similarly, financial barriers must be eradicated to allow more people with disabilities access to these technologies. ART has the power to transform lives through procreation; for some people with disabilities, it is their only option.

Chapter 12. The Impact of Disability on Parenting

People with disabilities face significant barriers to creating and maintaining families. These obstacles—created by the child welfare system, the family law system, adoption agencies, assisted reproductive technology providers, and society as a whole—are the result of perceptions concerning the child-rearing abilities of people with disabilities. But are these views informed? Does disability affect one's ability to parent?

Social science research examining the effect of disability on parenting is scarce. Historically, the absence of data has encouraged the bias against parents with disabilities. Ora Prilleltensky, professor at the University of Miami and a person with a disability, says, "Despite the growing numbers of disabled adults who are having children, parents with disabilities continue to be primarily ignored by research and social policy. The sparse literature that can be found on the topic typically focuses on the relationship between parental disability and children's well-being. In some cases, a negative impact is hypothesized, studied and 'verified'; in other cases, the correlation between indices of dysfunction in children and parental disability is explored; and in others yet, the negative impact on children and the need to counsel them is taken as a given."[949]

Correlation and causation are often confused in the research, resulting in an impression that children's problems are caused by parents' disabilities.

Drs. Megan Kirshbaum and Rhoda Olkin of TLG write, "Much of the research on parents with disabilities has been driven by a search for problems in these families. The pathologizing assumptions framing such research presuppose negative effects of the parents' disabilities on their children. The perennial pairing of parents with disabilities and problems in children perpetuates the belief in deleterious effects of parental disability on children. Research reveals the widespread belief among professionals that disability severely limits parenting ability and often leads to maladjustment in children."[950] Kirshbaum and Olkin believe that such research may perpetuate negative beliefs in the general population. Correlation and causation are often confused in the research, resulting in an impression that children's problems are caused by parents' disabilities. Contextual problems—such as poverty, the parents' history of abuse, substance use, and a lack of adequate supports—

are frequently ignored, so any problems found by researchers end up being attributed to disability.[951]

However, high-quality studies indicate that disability alone is not a predictor of problems or difficulties in children and that predictors of problem parenting are often found to be the same for disabled and nondisabled parents.[952] According to Dave Shade, "The available evidence suggests that although parents with disabilities may have a very different approach to parenting, the presence of a disability (physical or mental) is a poor correlate of long-term maladjustment in children.... Thus, although the data are far from clear, it seems safe to conclude that many parents with disabilities previously thought unable to raise a child at all may actually be able to do so, and that many more parents with disabilities may succeed in raising their children if provided appropriate support services."[953] Echoing Shade, Paul Preston, director of the National Center for Parents with Disabilities at TLG, says, "The implications of being raised by a disabled parent have been the source of numerous studies, public conjectures and professional scrutiny – all of which touch upon the fundamental rights of disabled people to be parents as well as the fundamental rights of children to be raised in an environment conducive to maximal development. Despite the lack of appropriate resources for most disabled parents and their children as well as persistent negative assumptions about these families, the vast majority of children of disabled parents have been shown to have typical development and functioning and often enhanced life perspectives and skills."[954] In fact, clinical experience proposes that predictors of problem parenting may be the same as those for nondisabled parents; particularly, a history of physical, sexual, or substance abuse in the parent's family.[955]

Parents with Psychiatric Disabilities

Parents with psychiatric disabilities experience the most significant discrimination when they attempt to exercise their fundamental right to create and maintain families. Is this discrimination justified? Do psychiatric disabilities affect parenting abilities? According to Preston, "While studies on this population suggest that parental psychiatric disability is itself a significant risk factor for children, many of the additional findings are compromised by over-generalizing about psychiatric disabilities. These and other investigators also suggest that the effects of parental psychopathology and social deprivation on children are difficult to separate and probably synergistic. These studies reiterate the importance of differentiating among types of psychiatric disability, enumerating risk factors as well as assessing family support and resources when investigating the impact of parental disability."[956] Similarly, in her article "Planned Failure: California's Denial of Reunification Services to Parents with Mental Disabilities," Nina Wasow says, "Social science research does not prove that people with mental disabilities cannot use services or reunify with their children; psychologists tend to over-predict dangerousness and lack the tools to assess parental competence accurately; and the social and cultural forces at play in the child welfare system lead experts to focus on certain parental weaknesses."[957]

In 1998, Diane T. Marsh, professor of psychology at the University of Pittsburgh at Greensburg, released her findings from a national survey she conducted to determine the impact of serious mental illness on parenting.[958] She

Parents with Psychiatric Disabilities

"When adult children were asked whether there had been any positive consequences of growing up with parental mental illness, …[t]hey mentioned becoming better and stronger people, having greater compassion and tolerance, acquiring knowledge and skills, developing healthier attitudes and priorities, achieving stronger family bonds, experiencing pride and satisfaction as their parent recovered, and gaining greater appreciation of life."

Diane T. Marsh and Rex M. Dickens, *How to Cope with Mental Illness in your Family: A Guide for Siblings, Offspring, and Parents*, (New York: Tarcher/Putnam, 1998), note 266, 30.

wrote, "When adult children were asked whether there had been any positive consequences of growing up with parental mental illness, a majority answered affirmatively. They mentioned becoming better and stronger people, having greater compassion and tolerance, acquiring knowledge and skills, developing healthier attitudes and priorities, achieving stronger family bonds, experiencing pride and satisfaction as their parent recovered, and gaining greater appreciation of life. Even when paying a high price for parental mental illness, children may derive much satisfaction from this vital relationship."[959]

Furthermore, according to Stephanie Gwillim, "Despite the increased risks associated with having a parent with a mental illness, the majority of children raised by parents with mental illness will never develop the psychiatric disorder of their parents. In fact, research has suggested that children are at heightened risk for psychopathology when taken from their parents and put into foster care. Long-term separation from a parent can result in a negative impact on the well-being and functioning of both children and parents. Thus, removing a child from his or her parent—in some situations—can ultimately cause more harm than good."[960]

Parents with Intellectual or Developmental Disabilities

Parents with intellectual or developmental disabilities face similarly significant and detrimental discrimination, which raises the question, do intellectual and developmental disabilities affect parenting ability? According to Preston, research has historically been focused on the pathological bias against parents with intellectual and developmental disabilities, "pointing out that much of the literature on parents with intellectual disabilities has failed to distinguish between characteristics that facilitate and those that inhibit parenting abilities. Most of these studies have focused only on identifying parents with intellectual disabilities who provide inadequate childcare, rather than identifying predictors of adequate childcare such as coping and skill acquisition—despite the fact that a substantial number of parents with intellectual disabilities have provided adequate care."[961]

According to professors at the University of Minnesota School of Social Work, "Despite disproportionately greater involvement in the child welfare system, a growing body of research on the outcomes for children of parents with disabilities does not necessarily support the assumption that parents with disabilities are

more likely to abuse or neglect their children. Studies have found that children of parents with intellectual and developmental disabilities can have successful outcomes."[962]

Chris Watkins notes, "Almost all studies have found a sizeable percentage of parents with developmental disabilities to be functioning within or near normal limits. In addition, many studies have found that parents labeled mentally retarded can and do benefit from training and support. Even researchers and commentators who have reached the most negative conclusions about cognitively disabled parents caution that such parents must be evaluated as individuals before reaching conclusions about their parental adequacy, or their ability to benefit from training and support."[963]

Several researchers have used qualitative methods to investigate life experiences and outcomes of children of parents with intellectual disabilities.[964] In Denmark, J. Faureholm interviewed 20 young adult children of mothers with intellectual disabilities.[965] Despite the difficult circumstances of their growing up, including being bullied and ostracized by their peers, most of the children discovered an underlying personal strength that enabled them to overcome these experiences, and all but one maintained a close and warm relationship with their parents. Similarly, in England, internationally recognized researchers Tim Booth and Wendy Booth also interviewed adult children of parents with "learning difficulties."[966] They said, "The majority recalled happy, if not necessarily carefree, childhoods. Only three regarded their childhoods as wholly unhappy." Significantly, most of the interviewees expressed positive feelings of love and affection toward their parents, and all maintained close contact with their parents. Tellingly, those who had been removed by the child welfare system had subsequently reestablished and maintained contact with their birth parents. "In both studies, family bonds endured despite time and circumstance intervening."[967]

Recent research further demonstrates the absence of a clear correlation between low IQ and parental unfitness.[968] In fact, studies have indicated that it is impossible to predict parenting outcomes on the basis of the results of intelligence testing.[969] Thus, Chris Watkins says, "The available research suggests that factors unrelated to disability often have a more significant impact on parental fitness than does disability itself. The research also suggests a tremendous variance in the impact that disability has on parental fitness. Importantly, parenting services have been shown to make a difference for many parents with insufficient parenting skills. While few conclusions can be drawn about the parenting abilities of developmentally disabled parents as a group, it is clear that individual inquiry is required before decisions are made to remove children from parents."[970]

[S]tudies have indicated that it is impossible to predict parenting outcomes on the basis of the results of intelligence testing.

Parents with Physical or Sensory Disabilities

Parents with physical or sensory disabilities also face significant impediments to creating and maintaining families as a result of

misconceptions about their parenting abilities. Does research support the belief that physical and sensory disabilities affect parenting ability? As with psychiatric and intellectual disabilities, research regarding parents with physical and sensory disabilities has historically been based on negative hypotheses and suggested outcomes.

In 1981, researchers F. M. Buck and G. W. Hohmann completed one of the first major studies to contradict the prevailing negative research.[971] They found that children whose fathers had spinal cord injuries displayed normal development in all areas investigated (personal adjustment, sex role identification, body image, health patterns, athletic interests, interpersonal relationships, parent-child relationships, values and attitudes).

In fact, according to Paul Preston, emerging research on parents with disabilities that has adopted a similar nonpathological framework, has revealed "a notable lack of norms and role models for parents and their children; more fluid and more flexible family roles; identification of external social and environmental obstacles as barriers to positive family functioning rather than as a result of the parent's disability; greater problem-solving skills among family members; and, a desire for greater public awareness and more informed practice. Most of these investigations conclude there is average to better-than-average development and functioning among children of disabled parents and found positive outcomes as well: enhanced coping and problem-solving skills; greater acceptance of difference; and, more positive attitudes towards disability."[972]

Further, according to Kirshbaum and Olkin, "Anecdotally, and in at least three studies, positive outcomes for older children of parents with disabilities have been cited. These include learning early the value of family and friends, displaying greater flexibility in family roles, finding humor even in dark situations, and putting quotidian problems in perspective. As children of parents with stigmatized conditions, they tend to learn about oppression, empowerment, and civil rights from an insider perspective and at an early age. Furthermore, children of parents with disabilities share in the disability experience and through it a connection to the disability community, a source of possible enrichment. But in focusing on the differences between parents with and without disabilities it is easy to lose sight of the similarities. Ultimately parenting is about loving, guiding, caring, and nurturing, disability status aside."[973]

The supposition that children of parents with disabilities will be "parentified" (i.e., forced to care for their parents at a young age) is pervasive and persists in research. Rhoda Olkin, in her book *What Psychotherapists Should Know About Disability*, criticizes the exaggeration of this issue in research, distinguishing parentification from responsibility and interdependence in families. However, she acknowledges that parentification sometimes occurs, delineating factors to be considered in evaluating the appropriateness of children performing tasks for their parents with disabilities. She points out that when tasks seem unsuitable the problem may lie with inadequate social resources to support the family. Psychologist Lisa Jo Cohen addressed parentification in her dissertation.[974] Her exploration of the assumption that school-age children of parents with visual or physical disabilities are their parents' caretakers revealed the opposite to be true; mothers reported using

Ana Torres-Davis, NCD Attorney Advisor, and her son, River, enjoying the beach at Cape Hatteras, NC.

vigorous caution when assigning tasks to their children. Parents often were reluctant to ask their children to do tasks common to children of parents without disabilities (e.g., taking out the garbage) if the parent felt this was in any way necessitated by the parent's disability.

TLG conducted similar research, comparing 246 teens with parents with diverse disabilities to teens with parents without disabilities.[975] Their research found no differences in the number of household chores reported by teens or parents across groups with or without disabilities. Moreover, few differences were found between parents with and without disabilities. For example, they agreed on how many friends their teens had, bedtimes, how active their teens were after school, and church or temple attendance. They ate dinner with their children most nights of the week, monitored their teens' music and homework, were equally likely to have experienced a significant stressor in the past year, and described their families similarly. Finally, parents with disabilities reported that their teens were more comfortable around people with disabilities than did parents without disabilities.

Paul Preston and Jean Jacobs of TLG are concluding the first phase of an eight-year national study of young adult children of parents with disabilities.[976] The study targets young adults ages 17–21 who were raised by at least one parent with a significant disability. During the first three years of the study (2009–2011), more than 1,000 high school seniors and college students participated. Study participants are from all 50 states, and parental disabilities include physical, intellectual, visual, hearing, cognitive, and psychiatric disabilities among people of diverse ethnicities. Preliminary findings from project data document numerous positive outcomes for these young adults. The majority of participants rated their overall experience of having a parent with a disability as positive: 58 percent positive to very positive; 34 percent mixed; and 7 percent negative to very negative. The majority of participants cited specific advantages to having a parent with a disability compared with their friends and peers who did not have a parent with a disability, including learning better life skills (74 percent), becoming more compassionate (71 percent), respecting differences (71 percent), becoming more independent (70 percent), having a wider range of experiences (63 percent), becoming more aware of what is fair and just (59 percent), and becoming more resourceful (51 percent). The highest rated challenge of having a parent with a disability was financial; 70 percent reported limited finances at home. In contrast, only 39 percent of these young adults thought they had too many responsibilities at home. Using Rosenberg's validated measure of self-esteem, the mean score of participants was 34.03 (SD = 5.17), reflecting a high esteem level in the sample as a whole. This compares with a mean of 30.20–34.40 in studies of healthy young adults whose parent did not have a disability.

Ora Prilleltensky also examined the issue of parentification; specifically, whether it actually exists. Prilleltensky's study did not find any indication of this phenomenon among the children and families of participants.[977] She noted that, if anything, people with disabilities in her study indicated a desire to shield their children from the burden of care.[978] As far as enhancing children's well-being, in participants' accounts of the child-rearing practices they use and their overall relationship with their children, the emphasis was on consistent parenting practices. A number of mothers mentioned reliance on verbal explanations and instructions. Other narrative accounts in the literature suggest that such children tend to respond to verbal instructions from an early age.[979] According to Prilleltensky, an important consideration is the relationship between child-rearing practices and the level of formal and informal supports. She concludes:

> "The experience of study participants suggests that the welfare of children need not be compromised due to parental disability. Study participants gave numerous examples from their daily lives that describe their attempts to ensure their children's welfare. They also described loving relationships and positive communication with the children, as well as their pride in children who are well-adjusted, caring, and appreciative of human diversity. Alongside these accounts, and sometimes intertwined with them, are indications of how stressors such as poverty and lack of support can compound difficulties related to the disability. It is safe

to say that in the presence of internal and external resources and supports, parental disability in and of itself need not present a significant risk factor. On the other hand, the high rate of poverty, single parenthood and attitudinal barriers that characterize the lives of many women with disabilities may indeed, if unmitigated, present a risk to family well-being."[980]

Conclusion

Current research, limited though it is, demonstrates that disability does not necessarily have a negative effect on parenting. Certainly, much more research in this area is needed; specifically, research that does not pathologize parental disability in a negative way. Moreover, research should focus on the effect of supports for parents with disabilities.

Chapter 13. Supporting Parents with Disabilities and Their Families in the Community

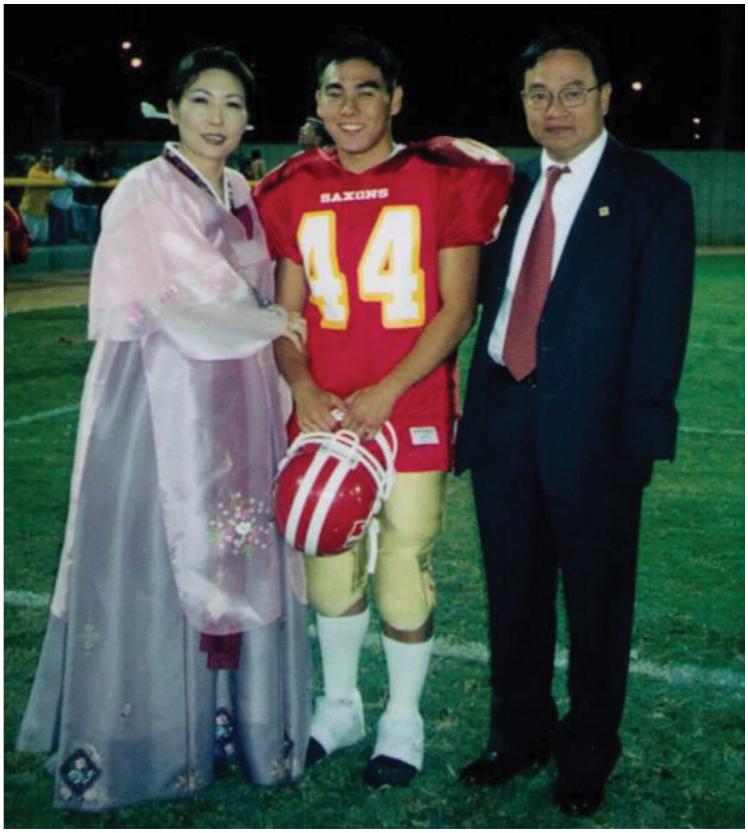
An African proverb, "It takes a village to raise a child," recognizes the reality that parents, whether or not they have a disability, cannot and should not parent alone. Indeed, parents without disabilities rely on a variety of formal and informal supports to help them with their child-rearing responsibilities. Lightfoot and LaLiberte say, "Formal supports that are typically used among North American parents include paid daycare, housecleaning, paid tutoring, or even take-out restaurants. Typical informal supports include grandparents providing a night out for parents (respite care), neighbors shoveling snow off the driveway of a new parent (chore services), or parents joining together for carpooling to soccer practice (transportation services)."[981] Parents with disabilities must have similar supports available to them and their families.

Lisa, who has cerebral palsy and is a mother of two daughters, says, "When parenting with a disability, I think it's important to embrace the fact that we are all interdependent and we each have different skills to contribute in raising happy, healthy children…. It's that interdependence with other people that is so essential in raising children. Everyone has different skills, but we share what we can give."[982]

Supporting parents with disabilities and their families in the community is not only the right thing to do, it is legally mandated. In the 1999 case *Olmstead v. L.C. ex rel. Zimring*,[983] the Supreme Court recognized the importance of community integration of people with disabilities. In this landmark case, the Court held that unnecessary segregation of people with disabilities violated the ADA. The *Olmstead* decision sparked a national effort to maximize community placement and integration of people with disabilities. Susan Stefan, disability attorney, says, "Family integration is not only a natural corollary to community integration, it is a fundamental component of community integration."[984] Accordingly, all supports for parents with disabilities and their families must be community-based.

Appropriate supports are crucial to the lives of many parents with disabilities and their children. Lindsay,[985] a mother with physical disabilities and a traumatic brain injury, affirms the significance of services: "Given my lack of trust in 'the system' and sparse community support resources, I cannot be both a full-time parent and a good parent. I share custody with my ex but only spend weekends with my kids. With proper support, I know I could be a good, full-time parent."

This chapter explores various supports that must be available to parents with disabilities and their families. Many of the supports discussed here already exist and need only be expanded or modified to better serve parents with disabilities



Former NCD Member Joe Pak standing on a football field with his wife and his son after a high school football game.

and their families; others must be established. If these families receive the proper supports, most will undoubtedly thrive.

Personal Assistance Services

Personal assistance services (PAS) are a crucial support for more than 13.2 million people with disabilities.[986] PAS help people with activities of daily living (ADLs), such as eating, bathing, dressing, and toileting, as well as with instrumental activities of daily living (IADLs), such as grocery shopping, cooking, and cleaning.[987] PAS typically fall into two categories: informal (unpaid) services provided by family members, friends, or neighbors; and formal services that are typically paid by public funding, private insurance, or out of pocket.[988]

PAS have the potential to be of great help to parents with disabilities and their families. In a national survey of 1,200 parents with disabilities conducted for TLG by Linda Barker and Vida Maralami, nearly four-fifths (79 percent) reported a need for some type of personal assistance, and more than half (57 percent) reported needing help with parenting tasks.[989] This survey revealed that parents with various disabilities would benefit from PAS: Approximately 60 percent of parents with psychiatric or physical disabilities reported that they would benefit from assistance with parenting activities, and approximately 50 percent of those with sensory or developmental disabilities said they would benefit.[990]

According to this survey, parents with disabilities need assistance with a variety of

parenting tasks. They need the most help enjoying recreational activities with their children (43 percent).[991] Forty percent reported needing assistance with "chasing and retrieving their children" and 40 percent reported needing assistance with traveling outside their home.[992] Other areas in which parents reported needing assistance were lifting/carrying children, organizing supplies/clothing, disciplining children, playing with children, bathing children, childproofing the home, and advocating for children.[993]

Cost is the most significant barrier for parents with disabilities who need PAS to help them with parenting activities. Pursuant to the Social Security Act, states may elect, as an optional benefit, to provide personal care services. According to the Centers for Medicare and Medicaid Services *State Medicaid Manual*:

> "Personal care services (also known in States by other names such as personal attendant services, personal assistance services, or attendant care services, etc.) covered under a state's program may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages which enable them to accomplish tasks that they would normally do for themselves if they did not have a disability. Assistance may be in the form of hands-on assistance (actually performing a personal care task for a person) or cuing so that the person performs the task by him/herself. Such assistance most often relates to performance of ADLs and IADLs. ADLs include eating, bathing, dressing, toileting, transferring, and maintaining continence. IADLs capture more complex life activities and include personal hygiene, light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. Personal care services can be provided on a continuing basis or on episodic occasions."[994]

Government-funded PAS do not allow attendants who are assisting parents with disabilities to also care for their nondisabled children, which creates a significant challenge for these parents.[995] According to the survey, only 10 percent of respondents who needed parenting help used government-funded PAS for parenting tasks.[996] The rest of the respondents reported finding other ways to address this need. The most common solution, reported by 68 percent of parents, was to get unpaid help from family or

Personal Attendant Services for Parenting Tasks

According to a national survey of 1,200 parents with disabilities, of those respondents who needed parenting help:

- 10% used government-funded PAS
- 68% used unpaid help from family or friends
- 43% paid for extra assistance out of pocket
- 35% went without some personal care or household help to pay for parenting assistance
- 19% felt unable to provide all the care their children needed

Linda Toms Barker and Vida Maralami, *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities* (Berkeley, CA: Through the Looking Glass, 1997), note 185, 6-8, 6-9.

Parenting Assistance in Other Countries

Canada – A parent who requires personal care is also eligibile for "nurturing assistants" who help with child care tasks.

Sweden – People who qualify for personal care based on function may also use their personal care hours for any tasks required, including child care.

friends,[997] although 43 percent reported paying for extra assistance out of pocket.[998] Equally troublesome—and a clear sign of their devotion to their children—35 percent of parents reported going without some personal care or household help they needed for themselves.[999] Finally, 19 percent of the parents reported that they felt unable to provide their children with all the care they needed.[1000]

Other Western nations do not have this problem. In Canada, for example, a parent who requires personal care is also eligible for services that will help with child care tasks.[1001] The service providers who help with such tasks are called nurturing assistants.[1002] However, not all disabilities entitle an individual to personal care,[1003] and lack of information regarding this service can be a barrier for parents.[1004] In Sweden, the right to personal care is based on function, so access to care is not limited by diagnosis.[1005] Once qualified, people with disabilities may use their personal care hours for whatever tasks they require, including child care.[1006] Personal care is mainly for parents with physical disabilities, although parents with intellectual disabilities may use it as well.[1007] The debate in Sweden is not over the right to parenting support services; rather, attachment theory has triggered a discussion about the impact of third party caretaking on children.[1008]

PAS have potential to greatly assist parents with their disabilities and their families, and the benefits of PAS go beyond improving quality of life—they have been found to be cost-effective, too. Several states have conducted small pilot projects in which foster care money is put toward well-coordinated aid to parents in crisis—because of substance abuse, disabilities, or other challenges—in hopes of keeping their children out of the foster care system.[1009] Santa Clara, one of the first California counties to try the new approach, calculated that for every dollar it spent on the intensive program, it saved $1.72 in federal, state, and county funds earmarked for foster care, not counting court costs involved in arranging foster care.[1010] Adaptive parenting equipment and home modification can also prove cost-effective by reducing the need for PAS hours.

The importance of PAS for parenting was emphasized by several of the parents who spoke to NCD. Rachel,[1011] a widowed mother and wheelchair user with a physical disability, often uses PAS to assist her in parenting. Although she acknowledges that she is not supposed to, she has her attendant help with parenting activities such as meal preparation, transporting her daughter, recreation activities, and being available if her daughter has a behavioral incident. Rachel, who is on a limited income, pays her attendant extra for this assistance and wishes Medicaid allowed PAS hours to be used for parenting. Christina,[1012] a single mother of three children, all of whom also have disabilities,

uses PAS to help her with parenting activities. Christina is a wheelchair user with significant physical and sensory (visual and hearing) disabilities. She has consumer-directed attendant services, which she uses to care for her whole family. She is on a very limited income and pays out of pocket for some of these services. Like Rachel, Christina wishes PAS were available to assist in parenting; she wants Medicaid to add parenting to these services. Jessica[1013] has also used PAS to help her with parenting activities. She is a wheelchair user and has a physical disability; her husband is a little person. When their twins were newborns, Jessica hired an assistant to help her care for her children, which she and her husband paid for out of pocket. She, too, wishes PAS covered parenting. Other parents also reported using PAS to assist them; many of them forgo their own care so the assistance can help with parenting.

Some parents with disabilities expressed the need for PAS to assist them with parenting on an intermittent basis—something like respite care. Susan,[1014] a mother of two children, wishes intermittent PAS were available to provide respite during the episodic illnesses she experiences owing to her disability (immune system disorder). Lindsay,[1015] a mother of two children, reported needing PAS but not being able to get them. Lindsay has a physical disability and an acquired brain injury. She wishes PAS could help her with tasks such as reminding her to take her medication and taking her children out when she feels "sad." Ora Prilletensky, in her article "A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities," noted that in a recent study she had conducted, one mother reported that when her children were younger, she was often hospitalized. With no one to care for them during the regular hospitalizations, she was forced to turn to child welfare. Reintegration was always challenging, and her children lacked consistency.[1016]

PAS are important for many parents with disabilities. This critical support can either make or break a family. So, why are services funded only if the child also has a disability? To address this significant need, CMS must expand its definition of ADLs to include parenting activities, so that funded PAS can be used to help consumers with their parenting responsibilities.

Housing

Having a home is crucial to creating and maintaining a family. However, securing accessible, affordable, and appropriate housing is a significant barrier for people with disabilities. In fact, it is nearly impossible for people with disabilities living on Supplemental Security Income (SSI) to obtain decent, safe, affordable, and accessible housing in the community without a permanent housing subsidy.[1017] Workers must earn $15 an hour over a 40-hour work week to afford a one-bedroom rental at the national average.[1018] This means that people with disabilities who receive SSI would have to triple their income to afford housing. A recent government report estimated that at least 43 percent of homeless adults in shelters—approximately 421,000 people—identify as people with a disability.[1019] The unique needs of parents with disabilities and their families further

For parents with disabilities, the lack of affordable accessible housing frequently affects child custody.

Housing Challenges for Parents with Disabilities

In a national survey of 1,200 parents with disabilities:

- 64% -- some kind of challenge related to finding appropriate housing.
- 33% -- housing was too expensive
- 25%+ -- housing lacked sufficient space
- 25% -- difficulty finding accessible housing
- 25% -- accessible housing doesn't accommodate children

Linda Toms Barker and Vida Maralami, *Challenges and Strategies of Disabled Parents: Findings from a National Survey of Parents with Disabilities* (Berkeley, CA: Through the Looking Glass, 1997), note 185, 6-8, 6-9.

compound the challenges of securing accessible, affordable, and appropriate housing.

The Barker-Maralami survey mentioned earlier, of 1,200 parents with disabilities, revealed several significant housing barriers experienced by these parents and their families. Forty-three percent of the parents who responded identified at least one problem in finding appropriate housing for their families.[1020] And when researchers reviewed the responses to other questions in the survey, they found even more reports that housing was an issue: Nearly two-thirds (64 percent) of the respondents mentioned some kind of challenge related to finding appropriate housing.[1021]

Parents with disabilities experience a variety of difficulties in securing housing appropriate for raising a family.[1022] In addition, a third of parents with disabilities responded that housing was too expensive, and more than a quarter reported that housing lacked sufficient space (especially storage space) and had rooms that were too small to accommodate their physical needs.[1023] One-quarter reported difficulty finding housing that was accessible, and many others reported that housing was poorly suited to families with children—too few rooms, lack of safe outdoor play areas, or located on busy streets with traffic.[1024] Twenty-five percent of the parents said that accessible housing does not accommodate children.[1025] It appears that housing developers and housing program administrators lack awareness that people with disabilities are not all single, living alone, with an attendant or a roommate.[1026] For some parents, the need for physical access limits the availability of appropriate family housing.[1027]

Because accessible housing often does not accommodate children and housing designed for families often does not provide the accessibility features that many parents with disabilities need, most parents (60 percent) reported having to make modifications to their housing so that it better met their needs.[1028] The cost to make necessary housing modifications is a significant barrier for many parents with disabilities and their families. Since very limited—if any—public assistance is available for modifying housing, 84 percent of parents reported having had to pay for the modifications themselves.[1029] Nearly 60 percent reported that they were unable complete some housing modifications owing to lack of funds.[1030] Barker and Maralami concluded, "Given the lack of accessible housing that is appropriate for raising families, and the lack of sufficient income to pay for housing changes, many families simply have to do without many of the housing features that they feel are necessary or would make their lives easier."[1031]

In light of the range of housing barriers and the scarce resources available to pay for home modifications, it is not surprising that fully a third of the survey respondents articulated specific building changes that would be useful to them for parenting.[1032] Although wheelchair access was a key issue for many parents with disabilities, the biggest unmet need reported was space. More than half of the parents said that larger or more rooms would help them in parenting.[1033] Providers of baby care adaptations have found that limited space is a common barrier to installing appropriate equipment in homes. Barker and Maralami write, "The other changes that would help are all associated in one way or another to physical barriers. Many of these would be barriers regardless of whether the respondents were raising children. However, it is important to note that many families find themselves in housing arrangements that are inaccessible because the housing that is built to be accessible to individuals with physical disabilities does not accommodate families with children. Also, access to outdoor play areas at home is a particularly important issue for disabled people who are raising children because of the added transportation and logistical difficulties of taking children to a park or recreation program for outdoor play."[1034]

Home is of great importance for most families—a place of cherished memories, warmth, and comfort. But for many parents with disabilities and their families, home is more likely to mean inaccessibility and unaffordability. For parents with disabilities, the lack of affordable accessible housing frequently affects child custody. A significant increase in affordable, accessible, and integrated housing is required for parents with disabilities and their families, as well as increased funding for home modifications. Specifically, HUD must require public housing authorities to have at least 50 percent of their accessible units in family housing developments. Such units must comply with all relevant federal disability access requirements and must include the same family-oriented space and appointments found in other units. HUD should develop a national modification fund to pay for reasonable modifications that are necessary to make private units accessible for parents with disabilities and their families. HUD should also develop a program for parents with disabilities who are first-time homeowners.

[P]eople with disabilities are more likely than people without disabilities to report that they have inadequate transportation: 34 percent versus 16 percent, respectively—a gap of 18 percent.

Transportation

Having appropriate and accessible transportation is critical for parents with disabilities and their families, but research demonstrates that people with disabilities are more likely than people without disabilities to report that they have inadequate transportation: 34 percent versus 16 percent, respectively—a gap of 18 percent.[1035] The realities behind these statistics reveal lives severely limited by the lack of transportation options. Some people with disabilities who would otherwise be able to work cannot do so because of inadequate transportation. Others cannot shop, socialize, go to religious services, or even leave their homes. Some people with

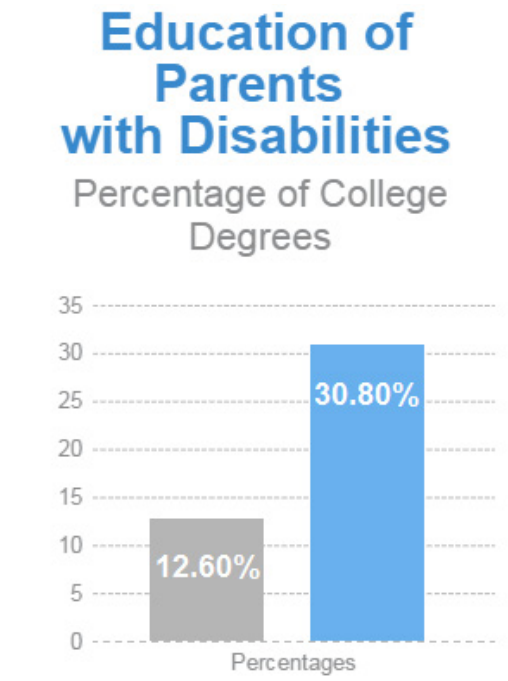
disabilities who need medical services are confined to institutions solely because of the lack of safe, reliable transportation options to get them to these services.1036 For parents with disabilities and their families, transportation remains a significant barrier.

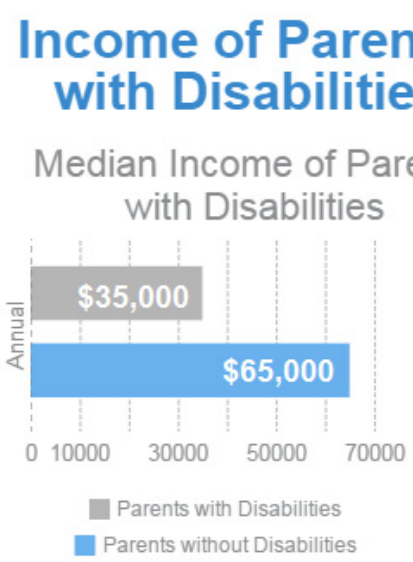
Transportation affects all areas of the lives of parents with disabilities and their families—from child care to housing to participating in a child's education to accessing a child's medical care. It was the barrier encountered by the largest number of parents in the aforementioned national survey:[1037] 79 percent of survey respondents identified transportation as a barrier at least once in the survey.[1038]

Not surprisingly, the majority of respondents with physical or sensory (mostly visual) disabilities identified transportation as an issue. However, it was also raised as a significant concern by parents with other disabilities.[1039] As the study revealed, although parents with physical or sensory disabilities are the most likely to report transportation problems, more than half of parents with psychiatric or intellectual disabilities also reported problems with transportation.[1040]

Parents with disabilities use a variety of modes of transportation. Interestingly, the survey found that parents whose primary disability is physical are more likely to use their own car or van than parents whose primary disability is not physical (85 percent versus 64 percent).[1041] Surveyors speculate that this may be due in part to limited accessible public transportation in many parts of the country.[1042] Far fewer parents with physical disabilities reported using public transportation than parents with other disabilities (13 percent versus 33 percent).[1043] The survey found that parents with sensory disabilities were much more likely to use "other" forms of transportation than parents with other disabilities;[1044] these included family and friends, taxis, and walking.[1045]

The study further noted that many parents with disabilities used paratransit services, with little variation by on disability.[1046] Unfortunately, paratransit comes with its own set of barriers. A national study conducted by TLG that is near completion was prompted by recommendations of the Bay Area Parents with Disabilities and Deaf Parents Task Force in 2006.[1047] The study followed years of parent complaints and confusion about policies that affected their ability to use paratransit to travel with their young children. Critical concerns for parents were policies stating that only one companion could accompany a parent on a ride; lack of driver assistance with carrying and installing car seats; inability to store car seats on paratransit vehicles; and not being able to schedule chain trips in which the paratransit driver waits for the parent during day care or school drop-offs. Preliminary data analyses from the national study show that although paratransit agencies vary in their policies and practices, a majority responded that they currently cannot guarantee space for more than one child companion; do not assist with car seat installation; do not carry car seats from a location beyond the curb; do not allow parents to store car seats on paratransit vehicles; and do not allow for 10-minute "scheduled waits" for parents to drop off their children. An additional barrier for parents in using paratransit is the high cost: Agencies are authorized to charge parents and their children twice the price of the fixed-route fare.[1048] Although individual agencies may try to accommodate the needs of parents by ensuring that entire families can ride together and providing assistance beyond what is required with carrying and installing car





seats, these practices need to be codified so that receipt of the services does not depend on the goodwill of drivers but is mandated by paratransit policy. The current lack of assistance parents receive from drivers when using paratransit and the significant cost of travel can make paratransit difficult, if not impossible, for parents traveling with their children.

The Department of Transportation's Federal Transit Administration (FTA) has issued only one Letter of Finding to a parent who was denied the right to bring her child on paratransit.[1049] While the finding was for the parent, noting that assistance in loading the child safety seat and allowing the child was required for her to access the service, Letters of Finding are not precedential in nature according to the FTA, although they may be helpful to others who are dealing with the same issue involving similar facts.[1050]

Appropriate and accessible transportation is crucial to the lives of parents with disabilities and their families. Nevertheless, it remains one of the most challenging areas for many parents with disabilities and their families. To adequately support these families, significant attention must be given to improving transportation. The Department of Transportation must issue guidance to paratransit providers on their legal obligations to transport parents with disabilities and their families to support the successful execution of parenting and employment roles by people with disabilities.

Public Benefits and Poverty

The financial status of people with disabilities is bleak: Since 1981, the income gap between households with and without a person with a work limitation (the Current Population Survey definition of disability) has grown steadily, from a difference of about $19,000 in 1980 (in 2008 dollars) to nearly $28,000 in 2008.[1051] Median earnings for people with disabilities dropped 7 percent from 2008 to 2009, 2 percent more than the drop for persons without disabilities (5 percent).[1052] Further, the number of people with disabilities who live in poverty is three times the number of people without disabilities.[1053]

Parents with disabilities and their families are not protected from this harsh reality. In fact, the most significant difference between parents with disabilities and parents without disabilities is economic: The median family income for parents with disabilities is $35,000, compared with $65,000 for parents without disabilities.[1054] Research also indicates that more parents with disabilities are unemployed (48 percent versus 22 percent).[1055]

Parents with disabilities are more likely than parents without disabilities to receive public benefits.[1056] A recent survey revealed that 52 percent of parents with disabilities receive SSI.[1057] Specific data are limited regarding other public benefits parents with disabilities and their families receive; however, in 2010, 3.6 million households (20 percent of all households) with a person with a disability received SNAP each month.[1058] Presumably many of those households included parents with disabilities. And it is likely that a substantial number of parents with disabilities and their families receive Social Security Disability Insurance (SSDI), Medicaid, and Medicare.

Advocates and researchers have focused some attention on Temporary Assistance for Needy Families (TANF), which research suggests a significant number of people with disabilities receive (presumably many are parents with disabilities).[1059] TANF was created through the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA); it provides a small monthly cash benefit to low-income families. Pursuant to PRWORA, parents who receive TANF must work a certain number of hours (determined by the age of their children).[1060] PRWORA also imposed a five-year lifetime limit on assistance. Advocates and researchers contend that these rules disproportionately affect parents with disabilities, particularly parents with psychiatric or intellectual and developmental disabilities, a group that includes a substantial portion of TANF recipients.[1061] Without appropriate family and work supports to overcome barriers to employment, parents with disabilities, especially single mothers, may be unable to comply with the PRWORA/TANF regulations, resulting in a loss of benefits to their families.[1062] Advocates say that the work requirements do not specifically consider disabilities as a barrier to work.[1063] In addition, low-paying work and lack of job training programs for people with disabilities are common obstacles to employment,[1064] and people with disabilities still face significant discrimination in the hiring process, further hindering their ability to comply with the work requirements. Finally, some parents with disabilities may need long-term employment support, such as career planning and training.[1065]

The financial status of parents with disabilities and their families is particularly significant, because they often have additional expenses connected to their disability (e.g., medication, adaptive equipment, transportation, and housing modifications).[1066] Parents with disabilities also often have additional expenses for assistance in caring for their children (e.g., specialized transportation or PAS). According to the TLG report *Visible, Diverse, and United: A Report of the Bay Area Parents with Disabilities and Deaf Parents Task Force*, "The working poor and even those families of medium income might not qualify for financial assistance or for certain types of services because their family income disqualifies them for services (e.g., free school lunches). Yet, these families often cannot afford

services, equipment, etc., without reduced fees or sliding scale because of extra out-of-pocket disability expenses."[1067]

Many parents with disabilities expressed frustration with the system. According to Rachel,[1068] a disabled mother with one child, the biggest barrier is that "the system keeps people with disabilities poor." She pointed out that parents with disabilities who receive SSI benefits get no additional SSI monies if they have children. Rachel believes that "a kid in poverty is going to have problems."

Unfortunately, states are taking drastic actions that further undermine parents with disabilities and their children. Recently, New Hampshire has begun counting SSI income in calculating household income to determine welfare eligibility.[1069] Nearly 1,200 families will lose this aid and another 420 will have their benefits greatly reduced. Idaho is the only other state to do this. Other states—such as Minnesota, West Virginia, and North Carolina—have tried or considered counting SSI.

Research demonstrates that parents with disabilities and their families have a substantial likelihood of living in poverty, and they depend heavily on public benefits. Public benefits must be appropriate and accessible for these families. SSA must begin an exploratory project to determine how to better serve SSI and SSDI beneficiaries, focusing on ways to increase financial assistance to parents with disabilities and their families. NCD recommends that the HHS ACF provide additional supports to parents with disabilities who receive TANF, including job training, child care, and transportation. State vocational rehabilitation agencies also must assist parents with disabilities who receive TANF.

Health Care

Proper health care, especially reproductive health care, is crucial for people who want to create and maintain families, but women with disabilities face significant barriers to receiving accessible, affordable, and appropriate health care.

The health care profession has a long-standing history of curtailing the reproductive rights of people with disabilities. While the eugenics movement is considered a thing of the past, many health care providers hold on to stereotypes about people with disabilities and their sexuality. According to Carrie Killoran, a mother with a disability, "Whether a woman is born with a disability or acquires it later in life, the message she gets from the medical system and society is that she is ineligible for normal societal female roles of lover, wife, or mother."[1070]

Studies have consistently demonstrated that the attitudes of physicians and other health care professionals toward people with disabilities are as negative, if not more negative, than those of the general public.[1071] One study found that "health professionals significantly underestimate the quality of life of people with disabilities compared with the actual assessments made by people with disabilities themselves. In fact, the gap between health professionals and people with disabilities in evaluating life with disability is consistent and stunning."[1072] For instance, "In a survey study of attitudes of 153 emergency care providers, only 18 percent of physicians, nurses, and technicians imagined they would be glad to be alive with a severe spinal cord injury. In contrast, 92 percent of a comparison group of 128 persons with high-level spinal cord injuries said they were glad to be alive."[1073]

The misconceptions and negative attitudes held by many health care professionals about

people with disabilities and reproduction have significant and detrimental effects on the health of these people. According to Michael Stein, an international disability expert, because of the "nonsexuality myth" harbored by many health care professionals about people with disabilities, women with disabilities often receive inadequate and inaccessible health care.[1074] "The prevailing presumption is that if women with disabilities will not or cannot engage in sexual activity, then they do not need access to gynecological health care."[1075] For example, people with disabilities are almost never considered to be in need of information about HIV and treatment for it.[1076] As a result, although people with disabilities are nearly as likely to be sexually active as people without disabilities, their HIV infection rate is up to three times higher.[1077] Similarly, women with disabilities are less likely to receive information on contraception.[1078] One study found that only 19 percent of women with physical disabilities received sexuality counseling.[1079]

Women with disabilities are often coerced into terminating their pregnancies, as well as being strongly discouraged from ever becoming pregnant. For instance, Rachel,[1080] an adoptive mother with physical disabilities, was told by a nurse in 1994 never to have children because they would have disabilities, although her disability is not inheritable. This encounter left Rachel "forever over medical personnel." Similarly, Susan,[1081] now a mother of two children, was told at age 17 never to have children because of her disability (an immune system disorder).

When women with disabilities are provided with reproductive health care services, it is often sterilization. The literature suggests that women with disabilities "are more likely to have hysterectom[ies] at a younger age than are women without disabilities, and more likely than their able-bodied counterparts to have a hysterectomy for non-medically necessary reasons, such as birth control, personal convenience, or at the request of a parent or guardian."[1082] Women's accounts suggest that the idea of having a hysterectomy often comes from health care providers, not the woman herself.[1083] A study conducted by the Center for Research on Women with Disabilities at Baylor College of Medicine reported that women with physical disabilities had a higher rate of hysterectomy (22 percent versus 12 percent for those without disabilities) and were more likely to have this procedure done at a younger age.[1084]

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Moreover, women with disabilities often encounter pressure from doctors and society to abort a pregnancy because of the possibility of passing on disabilities to their children—even if the disability is not inheritable.[1085] During Lindsay's[1086] first pregnancy, her doctor assumed that because of her disability (which at the time was only physical) she was "high-risk" and encouraged her to have an abortion. After that encounter, she transferred her care to midwives, whom she reports were very supportive.

Further, although the Rehabilitation Act and the ADA require that health care programs, institutions, and offices offer physical and

programmatic accessibility, very few are fully accessible.[1087] Structural barriers to receiving adequate and informed reproductive care include limited professional training and competency of primary care and reproductive care specialists; inadequate or no health insurance coverage for visits to specialists; poor physical access to usable and adapted or specialized examination and diagnostic equipment; and negative or discriminatory provider attitudes.[1088]

According to one qualitative study, health care providers sometimes expressed surprise that women with disabilities would be sexually active. As a result, they frequently did not discuss the use of contraceptives or evaluate the women for STDs. Some women with disabilities report that they avoid regular visits to the gynecologist because services are so difficult to obtain.[1089] One study reported that a gynecologist caring for a woman who uses a wheelchair assumed she was not sexually active and, therefore, saw no need to test for STDs.[1090] Further, research shows that women with disabilities are less likely to receive pelvic examinations, including a Pap test, although these tests are considered routine care for adult women.[1091]

Parents' Stories

Cassandra's Story

Women with disabilities often face significant barriers to receiving proper prenatal care as well as access during the delivery of their children. Cassandra,[1092] a wheelchair user with significant physical disabilities, reported receiving improper prenatal care, including not being weighed during her entire pregnancy because her doctor did not have an accessible scale, and not receiving proper examinations because no one in her doctor's office would help her transfer from her wheelchair to the examination table. She also faced attitudinal barriers. For example, on learning that she was pregnant, her doctor said, "How did that happen?" Cassandra was also referred to a physical therapist to assess her ability to parent. As a result of these experiences, she believes that the core of the problems many parents with disabilities face is with the medical community. She wishes health care professionals had training to understand disability.

Samantha's Story

Samantha,[1093] a mother of one child, also encountered significant physical barriers to proper health care during her pregnancy. At 31 weeks and again while she was in labor, she was unable to transfer from her wheelchair to the gurney because the gurney did not go low enough. Women with disabilities also face programmatic barriers to receiving proper health care.

Danielle's Story

Danielle,[1094] a mother of three children, reported to NCD that her doctors and the hospital at which she delivered would not provide sign language interpreters for her.

Many of the barriers people with disabilities face when receiving health care are a result of health care professionals not fully understanding how to care for this community. For instance, many women with disabilities are encouraged to have a cesarean section "simply because of anxiety on the provider's part."[1095] As the risk and rate of cesarean sections are known to be excessively high, this ongoing policy of recommending the procedure unnecessarily for women with disabilities is especially troubling.[1096] In *The Disabled Woman's Guide to Pregnancy and Birth*,[1097] based on interviews with 90 women with physical disabilities, Judith Rogers, a mother of two who has cerebral palsy, devotes an entire chapter to exploring the assumptions that can lead to recommendations of unnecessary cesarean deliveries for mothers with disabilities. She also covers the decision to have a baby; parenting with a disability; emotional concerns of the mother, family, and friends; nutrition and exercise in pregnancy; a look at each trimester; labor and delivery; the postpartum period; and breast-feeding.[1098] She notes, "My husband and my daughter are both doctors. And in the 30 years between their medical school experiences, nothing has been added regarding disability."[1099] She sums up the attitudinal bias this way: "The medical community sees us and thinks, 'If it doesn't work on the outside, how can it work on the inside?'"[1100]

In the same vein as the assumptions regarding the need to rely on cesarean delivery for women with disabilities, many women with disabilities are unnecessarily referred to high-risk pregnancy specialists. According to one expectant mother with a disability, when she visited the specialist her physician had referred her to, she was told that her pregnancy was not high-risk but that many providers make that assumption if the mother has a disability. The specialist said, "You're probably the least high-risk woman to come into my practice, but you make providers nervous because you're not in their textbooks."[1101]

Health care professionals must not only comply with their legal obligations to be fully accessible but must also provide reasonable accommodations. For example, an accommodation for a pregnant woman who is blind or has low vision, or a woman with intellectual disabilities, might be a private tour of birthing facilities.[1102] For women who are deaf or hard of hearing, appropriate accommodations might be to identify the interpreter before delivery or to meet with labor and delivery staff and discuss the best ways to communicate (e.g., transparent masks for lip reading).[1103]

In addition to structural and programmatic accessibility barriers, many women with disabilities do not receive appropriate preconception care because of financial barriers. According to the CDC, preconception care is "a critical component of health care for women of reproductive age."[1104] In a Kaiser Foundation study, Usha Ranji and Alina Salganicoff write, "The goals of preconception care are (1) to promote and improve the health of women of reproductive age prior to conception, and (2) to improve pregnancy-related outcomes. Preconception care not only improves the health of a woman prior to pregnancy but also optimizes the health of the fetus during pregnancy."[1105] Despite the importance of preconception care, Medicaid (the largest health insurer of people with disabilities) does not recognize it as a defined category of covered care.[1106] In

fact, a recent survey revealed that although state Medicaid programs generally cover contraceptives, most do not provide any further preconception care.[1107] Kathryn,[1108] a wheelchair user and little person, was stunned to learn from her physician, a few months before she became pregnant, that Medicaid would not pay for a pre-pregnancy consultation.

Accessible, appropriate, and affordable health care, particularly reproductive health care, is crucial to the well-being of parents with disabilities and their families. However, for most it remains largely inaccessible and inappropriate. The Agency for Healthcare Research and Quality (AHRQ), under its mandate to undertake research on priority populations, should promote research that clearly identifies the barriers encountered by women with disabilities when they seek reproductive health care. The Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education (LCME) should convene a workgroup to identify specific disability competencies that should be required of health care professionals before graduation from medical and residency training programs, and should translate these competencies into specific course recommendations that can be adopted by medical training programs. Further, DOJ must increase its monitoring and enforcement of the ADA and Section 504 of the Rehabilitation Act for health care facilities and programs. Finally, CMS must identify and implement mechanisms to pay for comprehensive preconception care for Medicaid and Medicare beneficiaries with disabilities.

Peer Supports

Most parents and prospective parents rely heavily on their peer support network. Peer support provides the opportunity to exchange ideas and experiences with others who are facing similar situations. Peer supports also provide parenting role models.

The importance of peer supports for parents and prospective parents with disabilities may be even greater because of the limited information available on parenting with a disability. As one expectant mother with a disability said, "Perhaps what I have found the most helpful during my pregnancy has been the advice and input from other women with disabilities who have 'been there, done that.' I am fortunate to call many women with disabilities my colleagues and friends, and pregnancy has been a special time for me to reach out to those who are also mothers. Speaking with mothers with disabilities has helped me gain perspective on the experience of pregnancy. Even though physically our experiences are different, other women with disabilities have faced the same societal and attitudinal barriers that I am currently dealing with."[1109] Nearly all the parents who spoke with NCD mentioned the importance of peer supports, often noting that peers were more supportive than their families of their quest to become parents.

"Perhaps what I have found the most helpful during my pregnancy has been the advice and input from other women with disabilities who have 'been there, done that.'"

Most parents, and people who are considering becoming parents, do not have to look far to find positive role models. However, parents and potential parents with disabilities do not have the same opportunities. Researchers have found that

parents who are blind or have low vision often try to parent according to "sighted ways of functioning" when they do not have role models with similar disabilities.[1110] According to one mother, "The kind of support one can get from other mothers with visual impairments is not available … in the sighted community."[1111] Research has found that parents with intellectual disabilities tend to be isolated and to have limited social networks.[1112]

Some disability organizations and have begun to create networks for parents with disabilities. For example, deaf parents are included in forums and presentations on families at national and worldwide organizations for people who are deaf or hard of hearing, including the World Federation of the Deaf, the National Association of the Deaf, Deaf Seniors of America, and Deaf Way.[1113] Similarly, in 2000, the Committee on Parental Concerns and the National Federation of the Blind announced dual sponsorship of a blind parent mailing list that creates a forum for blind parents to share their experiences and offer peer-based support and information.[1114] The National Multiple Sclerosis Society provides parenting information for its consumers.[1115] TLG has developed a national parent-to-parent network as part of its national centers for parents with disabilities. The organization has also facilitated peer support groups for parents with diverse disabilities for 30 years. Although some communities have found it difficult to establish groups for parents with intellectual disabilities, a particularly successful group established 11 years ago has led to the design of a training module—*Designing Support Groups for Parents with Intellectual Disabilities*—to support replication elsewhere.[1116]

Peer-professional staffing in programs that serve parents with disabilities—such as the programs at TLG—is an important vehicle for conveying the wisdom of peers and providing role models. Publications by parents with disabilities, including publications by parents who compile input from other parents, are another such vehicle.[1117]

Throughout the world, families headed by parents with intellectual disabilities tend to be less affluent and more isolated. As a result, the community connections and discretionary income necessary to create memory-making family trips, outings, and recreation are often limited or nonexistent. This situation has an effect on the quality of family life. Hanna Björg Sigurjónsdóttir of the University of Iceland designed and recently concluded a three-year project that funded the creation of family peer groups facilitated by professionals in the community.[1118] Sigurjónsdóttir summarized the project as follows: "The groups engaged in family days and weekends, the aim of which was for parents and children to get to know each other across families and for family members within each family to enjoy each other's company, have fun together, and build up collective memories. The project is responsive to the families' needs and makes it possible to focus on issues that they are dealing with currently in their lives as parents. The year culminated with a community family snow trip that provided a chance for activities, celebration, and fun. The parents and children were also able to invite members of their extended families or close family friends, to provide them with an opportunity to give something back to those who often provided their social support system."[1119] American sensibility tends to view such a program as a privilege, but other nations approach the idea of community integration and family support with creativity and an eye for

quality of life that is completely absent from our own approach.

The Internet, especially social networking sites such as Facebook, has greatly assisted parents with disabilities who want to connect with their peers. Many of the parents who spoke with NCD use the Internet to connect with other parents with disabilities. But although the Internet provides wonderful opportunities to connect with other parents with disabilities, its usefulness has limits. For instance, a 2010 survey conducted by the Kessler Foundation and the National Organization on Disability found that 85 percent of adults without disabilities access the Internet compared with only 54 percent of adults with disabilities—a gap of 31 percent.[1120] For some parents with intellectual and other cognitive disabilities that affect reading ability, the Internet remains largely inaccessible.

[A]lthough the Internet provides wonderful opportunities to connect with other parents with disabilities … 85 percent of adults without disabilities access the Internet compared with only 54 percent of adults with disabilities …

Despite increasing opportunities for peer support, many of the parents who spoke with NCD desire a more formal and organized network. For instance, Ken,[1121] a father with HIV infection, hemophilia, and hepatitis C, told NCD that while Facebook has helped him connect, he wishes there were a more established group, similar to the national organization Parents, Families and Friends of Lesbians and Gays (commonly referred to as PFLAG). Ken also expressed interest in having a conference for parents with disabilities and their families. He said that he and his wife, a wheelchair user, are always looking for "concrete examples of how it's been done." Kathryn,[1122] a mother who is a little person and a wheelchair user, wishes more peer supports and social gatherings were available for parents with disabilities and their families. Kathryn also believes that the lack of role models is a significant barrier for parents with disabilities. Lindsay,[1123] a mother with physical disabilities and an acquired brain injury, has found very few role models for parents with acquired brain injuries.

Raising children can be very stressful. For parents with disabilities, limited peer supports often leave them discouraged and lacking necessary information. Peer support networks can be easily developed or expanded at a minimal cost and would be supportive for many parents. NCD recommends broader dissemination of national networks and Listservs, blogs, and so on. A primary national network should include peer staffing, provide peer-to-peer links, gather information, and provide links to other networking efforts, including those in state Web sites. This network should also maintain an accessible Web site and "warm line" (during business hours) with cross-disability, legal, and crisis intervention expertise. State sites should include peer staffing and peer-to-peer networking and should link to the national network. State sites could also maintain accessible Web sites and warm lines with cross-disability and crisis intervention expertise, and links to resources in their regions. Peer support groups could be located in independent living centers and programs that specialize in parents with disabilities or deafness. These local parent support groups

could provide the ongoing peer connections that are important for the alleviation of isolation in communities. Collaboration among national, state, and local services should be a priority, including training and dissemination of information.

Disability and Mental Health Service Providers

Disability and mental health service providers play a significant role in the lives of many people with disabilities, but the services they offer typically do not address their needs as parents. In fact, research demonstrates that the majority of mental health agencies have no idea which of their clients are parents, and 80 percent have no policies for pregnant clients or clients who are parents.[1124] Presumably, similar findings would be revealed with other disability service providers. Given the amount of time parents with disabilities spend with service providers, it is clear that their role as parents must be acknowledged and supported.

Mental Health Service Providers

As noted earlier in this report, parents with psychiatric disabilities lose custody of their children at the highest rate of any disability community: 70 percent to 80 percent. The National Co-morbidity Study of 1990–92 found that more than 44 million Americans (one out of every four people) have a mental illness, with 65 percent of the women being mothers and 52 percent of the men being fathers.[1125] Such high rates of parenting mean that the issue of custody loss is affecting a significant portion of the psychiatric disability community. In 2006, Park, Solomon, and Mandell conducted the largest study ever done comparing Medicaid-eligible mothers with and without claims for psychiatric services to examine their involvement with the child protective service system in Philadelphia.[1126] The authors concluded that the behavioral health systems and the child protective systems are gateways into each other's services.[1127] Viewed this way, the failure to help such a large portion of the psychiatric disability community retain intact families represents a failure of our community integration ideals. The synergistic dynamic between mental health and loss of custody requires attention.[1128]

[T]he behavioral health systems and the child protective systems are gateways into each other's services.

The literature generally agrees that the key to addressing this problem is to provide services around parenting before any involvement with the child welfare system. The Invisible Children's Project of the National Mental Health Association (now Mental Health America) generated best practices in working with parents. These include the need for family-focused case management that help parents with finances and access to affordable housing; planning for emergency and nonemergency child care; referral to parent support groups and parenting classes; referral to resources for the children; referral to parent-friendly medication counseling and treatment services; vocational training; and crisis financial aid. These findings—combined with imperatives related to recovery-oriented services and the availability of evidence-based practices for provision of mental health services and supports—contribute to the urgency to address this issue now.

In addition, strong potential exists for collaboration between disability-community-

based services and providers of infant mental health services. Spearheaded by ZERO to THREE, a national nonprofit organization that informs, trains, and supports professionals, policymakers, and parents in their efforts to improve the lives of infants and toddlers, infant mental health is a rapidly growing specialty that offers extremely early home-based preventive intervention, often beginning during pregnancy or at birth. Infant mental health clinicians typically work with parents and their infants and toddlers to support secure attachment relationships between parent and child. Developmental screening and guidance are usually included. Maternal depression and its impact on infant-parent relationships and interaction is a particular focus of these specialists; it is critical to address this promptly to prevent long-term negative effects on children.

Depression is a significant issue, not just among parents with psychiatric disabilities but in women with other disabilities. Studies have shown that women with severe mobility disabilities are more than six times more likely to experience depression than women without disability.[1129] Professionals often conflate the effects of depression with the disability of mothers, which undermines the appropriateness of services and the evaluation of capability.

Intellectual Disabilities Service Providers

With a removal rate second only to that in the psychiatric community, this disability community loses children at a rate of 40 percent to 80 percent. According to the President's Committee on Intellectual Disability, "It is estimated that between 7 and 8 million Americans of all ages, or 3 percent of the general population, experience intellectual disabilities."[1130] The 1.5 million parents with intellectual disabilities represent 2.3 percent of all parents with children under age 18.[1131]

Little focus has been directed at providing parenting support and services as part of general support for people with intellectual disabilities in the community. In 2000, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act.[1132] An extensive 12-section chapter titled "Family Supports" contains not one mention of parents with intellectual disabilities.[1133]

In 2000, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act.[xxiii] *An extensive 12-section chapter titled "Family Supports" contains not one mention of parents with intellectual disabilities.*

State-level implementation of services to people with intellectual disabilities varies greatly. Parenting support is often not on the roster of services and, if it is provided, the model is left to the discretion of the agency. For example, in California the Lanterman Act of 1965 guarantees community integration services to people with disabilities; the mandate is implemented via 21 regional centers that serve approximately 250,000 people.[1134] Some centers, such as the East Bay Regional Center, list parenting training as a service and contract with at least one infant mental health agency to provide parenting support.[1135] Others, such as the San Diego Regional Center, do not list parenting support as a service at all.[1136] It is common in

the state system to rely on unsophisticated independent living skills workers to provide "training."[1137]

Parents who do not have adequate supports are at much higher risk of losing custody or rights to their children. This issue arises upon entry into the child welfare system, too: When case plans are designed, the child welfare agency typically flounders as it attempts to find evaluation, assessment, and intervention providers who are familiar with people with intellectual disabilities, and the services designed for people with intellectual disabilities are typically not focused on parenting.

The Arc notes that there "is a great for need community service agencies to create and provide individualized services based on each family's needs."[1138] McConnell, Llewellyn, and Bye surveyed service providers and identified four principles associated with effective services to parents with intellectual and developmental disabilities:

- Services need to be responsive to the parents' individual needs and focus on the whole family to ensure that interests of both parents and children are served.
- Services must include long-term, ongoing supports, because the needs of children change and parenting skills must change as children mature.
- Services must consider the special learning needs of the parent. Learning must occur in the home, be repetitive, use demonstration, and use resources that require little or no reading.
- Services must help parents become part of their community.[1139]

Service Providers for People with Physical Disabilities, Blindness, or Deafness

Organized government support is scarce for people who have a physical disability or who are blind or deaf. Centers for Independent Living (CILs) are "grassroots, advocacy-driven organizations run by and for people with disabilities. They focus on civil rights, the independent living philosophy, and inclusion. All Centers provide individual and systems advocacy, information and referral, peer support, and independent living skills training."[1140] CILs are funded under Title VII, Part C, of the Rehabilitation Act of 1973, as amended, and exist in every state.

CILs are a crucial support for many people with disabilities by providing four core services: (1) individual and systems advocacy; (2) information and referral; (3) peer support; and (4) independent living skills training.[1141] CILs have the potential, with training, to support parents with disabilities, especially to advocate regarding transportation, housing, financial advocacy, and assistive technology issues, and to offer parent support groups.

Rehabilitation centers rarely provide parenting skills training, instead focusing on self-care skills training. The National Federation of the Blind has a Committee on Blind Parents with a very active Listserv, and the Hadley School for the Blind offers a series of parenting classes as correspondence courses to people all over the country. In general, though, schools for the blind and the deaf do not focus on parenting skills in their curricula and do not offer parenting training to their consumer communities at large.[1142] Perhaps existing parenting education courses offered at hospitals

and by local agencies could be modified to address the needs of blind parents, who tend to learn the most from other blind parents.[1143]

Parents with physical disabilities, blindness, or deafness may receive services from state agencies, such as state vocational rehabilitation agencies and agencies for the blind and deaf. These agencies must be aware of their consumers' roles as parents and, where possible, provide services that benefit the entire family. Further, these agencies must gather data on parents with disabilities.

Early Intervention and Prevention

Early intervention and prevention programs have the potential to provide significant support to parents with disabilities and their families. Federal legislation mandates family-centered early intervention (EI) services for infants and toddlers (age zero to three) with established diagnoses of developmental delay.[1144] Some states also serve infants and toddlers who are deemed to be at risk for developmental delays.[1145] Risk factors may be physical (e.g., low birth weight or exposure to infectious disease) and contextual (e.g., living in poverty or having a parent who is compromised by illness).[1146] Research demonstrates that early intervention and other prevention model programs have positive effects on children, particularly with regard to cognitive and language outcomes.[1147] Programs that focus on parental participation appear to be more effective than those that minimize or disregard the role of parents.[1148]

Head Start (HS) is the largest provider of early childhood education in the United States.[1149] Established more than 30 years ago, it exemplifies the whole-child perspective of family-centered interventions, working toward wellness for all families.[1150] Head Start is a multifaceted program that provides child care, preschool education, health and social services, disability services for children, and parent involvement opportunities to low-income families.[1151]

Although nationally Head Start does not identify parents with disabilities in its system, it plays a critical role in the lives of many parents with disabilities and their families. According to a 1997 survey, 85 percent of Head Start programs in a six-state region reported serving parents with disabilities.[1152] Thus, "HS staff have consistent, frequent contact with families with disabilities and may be influential in providing social support, referrals, [and] information, and modeling appropriate interaction styles with children."[1153] The survey revealed that these Head Start programs provided the following services to parents with disabilities: 85 percent provided or made referrals to community agencies; 78 percent provided educational information in different ways; 76 percent provided social support; 48 percent adapted materials; and 18 percent used other strategies (e.g., increased access to classroom and used interpreters).[1154] The same study identified a significant need for the development of policies, more expertise, and training.

Programs such as Head Start have great potential to support parents with disabilities. For example, parents with psychiatric disabilities often need strong natural support networks; Head Start staff could play a critical role in offering friendship and support, information, and instruction in parenting skills to these families.[1155] Staff could also play a role in enabling parents with intellectual disabilities to nurture and care for their children in the most effective ways.[1156] Further, "Head Start staff can play critical roles as advocates for parents in their caretaking

roles by (1) supporting parents as the primary spokespersons for themselves, (2) providing child development and parent education classes, (3) reinforcing parenting skills already learned, (4) linking the parents to pertinent services such as assistive technology, and (5) providing adaptive equipment that facilitates and eases caretaking of children."[1157] Although Head Start is expected to have access to assistive technology and adaptive equipment for children with disabilities, the system has not addressed the needs of parents with disabilities. This is a crucial area for training and the expansion of resources to serve parents with disabilities and their children.

Early Head Start (EHS) potentially can play an even greater role in supporting parents with disabilities and their children than Head Start, because it offers home-based preventive and supportive services beginning in pregnancy and continuing until the child is three years old, as well as centers for infants and toddlers. To maintain continuity of services, many organizations offer both Early Head Start and Head Start. Both programs are available across the country, serve very low-income families, and are expected to implement ADA requirements. Both are required to serve at least 10 percent children with disabilities, and both could use more expertise regarding parents with disabilities and their families. As part of its new national center, TLG offers training to the national Early Head Start system on parents with disabilities and their children. The organization has created a model Early Head Start that focuses on families with disabilities in parent or child.

Each Early Head Start or Head Start develops its own criteria for enrollment, but national priorities include very low income, SSI or other public assistance, homelessness, or foster care.[1158] Children of parents with disabilities may have disabilities of their own and thus may be prioritized to meet the 10 percent requirement for enrollment of children with disabilities in each program.[1159] Children who do not qualify as having a disability may, in some locations, gain priority for enrollment because of a parent's disability; however, enrollment based on parental disability is not guaranteed.[1160] For example, Kathryn's[1161] daughter qualified for early intervention and therefore EHS/HS because she was born premature, not because of her parents' disabilities (both are little people and wheelchair users). Kathryn believes that eligibility should be "family based," meaning that it should include parental disability.

Early intervention and other prevention model programs appear to have the potential to fully accommodate parents with disabilities. "For example, the program's traditional flexibility and accommodation is well suited to meeting the needs of families with disabled parents."[1162] Furthermore, EHS/HS already provides many of the components necessary to serve parents with disabilities: outreach networks, access to educational specialists, individually tailored educational plans, and close ties to a range of social services.[1163] In addition, EHS/HS's target population—children and families in poverty—is similar in many ways to families in which a parent has a disability: "Both groups are parenting in compromised circumstances that often include low-income, unsafe housing, unemployment or underemployment, and inadequate social networks."[1164] Efforts must be made to ensure that parents with disabilities and their children are considered for services and that the system provides training and resources to meet their needs.

Protection and Advocacy System

People with disabilities have a long-standing history of experiencing discrimination and segregation. To combat this discrimination, P&A agencies are federally mandated to provide legal representation and advocacy on behalf of people with disabilities.[1165] P&As, which "collectively, are the largest providers of legally based advocacy services to people with disabilities in the United States," provide their services "through a variety of vehicles: individual representation; education of policy makers; advocacy for groups; information and referral services; rights education; and self-advocacy training."[1166] "The fundamental mission of the P&A System is to respond to allegations of abuse and neglect and other violations of the rights of persons with disabilities."[1167] P&As achieve their objectives by "pursuing legal, administrative, and other appropriate remedies under all appropriate Federal, state and local laws."[1168] There are 57 P&As—one in each state and territory, and a Native American P&A.[1169]

Parents with disabilities that are involved with the child welfare or family law systems, often face insurmountable barriers to retaining effective and affordable legal representation. The majority of P&As do not represent parents with disabilities in termination or custody disputes. While they have been instrumental in advocating for legislative changes to child custody law and the provision of adaptive baby care equipment in California,[1170] they rarely accept child welfare or child custody cases. The National Disability Rights Network, the umbrella organization for state P&A agencies, lists criminal justice and juvenile justice cases as issues for which it will provide services, but not family, probate, or child welfare cases.[1171] This is troubling, because there is no right to counsel in the latter type of cases. In a national study of 102 parents with disabilities who were experiencing child welfare or child custody difficulties, only 24.5 percent contacted P&A for help; most of those who did not contact P&A said they were unaware of the service.[1172] Of those who did contact P&A, none received any assistance.[1173] The P&As' hesitation probably reflects the fact that the need is so great—the agencies might believe that they would drown in a flood of cases if they began handling child welfare and child custody cases. However, a few P&As have begun to make parenting rights a priority, and it is hoped that more will follow suit.[1174]

Given the P&As' extensive experience representing people with disabilities, a stronger collaboration between P&As and the attorneys who represent parents in termination and custody proceedings would undoubtedly generate more positive results for these parents.[1175] P&As must make parenting rights a priority.

Conclusion

Regardless of whether or not they have a disability, all parents need supports, both formal and informal, to help them in parenting. And yet, interdependent parenting practiced by parents with disabilities is perceived as inadequate. With proper supports—such as PAS, housing, transportation, benefits, health care, peer support, early intervention and prevention, P&As, and CILs—most parents with disabilities and their families will have greater opportunity to live and grow together.

Chapter 14. Promising Practices to Prevent Unnecessary Removal and Loss of Children

Programs that serve the needs of parents with disabilities are scarce. Nevertheless, despite limited funding and little national attention given to parents with disabilities and their families, a number of programs and support services have begun to emerge. This chapter highlights several of these programs. Collectively, they show promise, long-term sustainable impact, and the potential for replication. The various levels of support they offer—from parent groups to weekly home visits to residential—represent the spectrum of community services needed to address diverse family situations. Generally, the programs highlighted in this report are small, local programs that are part of larger disability services organizations. For the most part, they provide services to parents with a certain disability (e.g., intellectual disabilities or psychiatric disabilities but not both). Despite their small size and limited focus, these programs show the enormous potential for serving parents with disabilities and their families. With more funding, programs like these can grow and develop nationwide to serve a currently underserved segment of the American people: parents with disabilities and their families.

Through the Looking Glass, Berkeley, California

Founded in 1982, in Berkeley, California, Through the Looking Glass is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent, or grandparent has a disability. For nearly 10 years before its establishment, TLG founders had provided disability-culture-based counseling services to couples and families with older children in the early independent living movement at the Berkeley Center for Independent Living.[1176]

TLG plays a central role in the national disability community, networking and providing resources, training, and technical assistance regarding parents with disabilities and their children. It has helped identify unmet needs and issues that can be pursued in research and clinical services. TLG's national networking role evolved through the 1980s; beginning in 1993, it led to the establishment of other national centers for parents with disabilities and their families. These centers have conducted research and developed legal expertise, and have provided dissemination, professional training, technical assistance, publications, two international conferences, and a parent-to-parent network

for parents with disabilities.[1177] Currently, TLG's National Center for Parents with Disabilities is directing an NIDRR-funded project: Families with Disabilities Through the Life Cycle: Disability Culture Perspectives. The many subprojects will include national training for the Early Head Start and Independent Living systems regarding parents with disabilities and their children.

Since its inception, TLG has provided primarily home-based infant mental health care, family support, case management, early intervention or developmental services, and disability resources to families in which parents or children have diverse disabilities. It has also conducted numerous research and demonstration projects focused on parents with disabilities and their children primarily funded by NIDRR.[1178] Staff includes social workers, marriage and family therapists, psychologists, occupational and speech therapists, developmental specialists, rehabilitation counselors, nurses, childbirth educators, doulas, early childhood educators, attorneys, and researchers. Nearly 80 percent of the culturally and linguistically diverse staff has personal or family disability experience.

In the mid-1980s, TLG began providing alternative assessments when parents with disabilities were involved with child protective services. According to its founders, "It was startling to discover the degree of pathologizing and the lack of disability expertise in child protection evaluation practice."[1179] One adapted parenting assessment is the Adapted Baby Care Assessment for Parents with Physical Limitations or Disabilities, a tool developed by occupational therapists and infant mental health specialists at TLG. This assessment involves multiple days of observation of the parent caring for the child in the home and on outings into the community. The occupational therapist assesses the parent's baby and child care abilities in all areas of care. Through this process, contextual barriers and helpful strategies are identified that would foster the parenting care abilities. The final report documents the parent's current functioning as well as strategies and adaptive equipment that could support and improve this functioning. In the assessment protocol, the parent will be provided with adaptive equipment and trained on the use of physical strategies, then reassessed.[1180]

A parallel assessment approach has been used when parents have vision, cognitive, or intellectual disabilities. All assessments include thorough observation of parent-child interaction over multiple days, interventions and adaptations, and more observation to assess their impact. The assessments have been used in child welfare, family court, and adoption situations.

TLG has been used by social service organizations, families and advocates to establish whether, with proper adaptive equipment and services, the removal of a child can be prevented.

The volume of calls reporting discriminatory practices in custody litigation became so great that, in 2004, TLG established the Legal Program for Parents with Disabilities.[1181] The program handles approximately 900 contacts a year with families or professionals involved in such cases throughout the United States.[1182]

In 2011, TLG served 400 families in the San Francisco East Bay, primarily during weekly or biweekly home visits, and its National Center provided training or technical assistance to almost 19,000 people.

TLG's preventive early intervention has kept thousands of families from ever becoming involved in situations in which their parenting

or custody is questioned. For example, TLG's tailored services to parents with intellectual disabilities and their children have achieved a significantly lower rate of out-of-home placement (2 percent to 7 percent) of children of parents with intellectual disabilities since 1990, compared with the 40 percent to 80 percent national rate.[1183]

TLG's current cross-disability services roster includes the following:[1184]

- Pregnancy and birth support – Occupational therapy and childbirth educator staff with expertise in the unique health and attitudinal challenges facing mothers with disabilities during pregnancy and birth support and work with the expectant mother and her partner to prepare for both the physical experience of the birth and the practicalities that follow (including securing and learning to use adaptive baby care equipment).
- Parent-child intervention – High-frequency, high-duration, home-based and relationship-based interventions are tailored to families, blending infant mental health, family systems, and parenting education approaches with case management, developmental services, parenting adaptations, and disability resources.
- Evaluation and assessment – Occupational therapists and mental health staff conduct parenting assessments of parents with all categories of disability using observation-based and home-based assessment of parent-child interaction and relationships, and piloting adaptations.
- Developmental assessment and early intervention – Home-based, relationship-based services are provided for infants and young children with delays or disabilities and their parents, with and without disabilities.
- Early Head Start for families with disabilities – Center- and home-based services are provided by early educators and therapists with support from TLG disability specialists in a universally designed center at the Ed Roberts Campus. This is the first EHS that specifically targets families with disability in parents or children.
- Psychotherapy – Provided for individual children who have parents with disabilities or disabilities themselves, and for family units.
- Support groups – Provided for mothers with intellectual disabilities or physical disabilities.
- Playgroups – Provided for parents with intellectual disabilities and their children who have speech and language delays.
- Legal services – Provided for parents with disabilities facing loss of child custody, as well as attorneys, social workers, and others involved in such cases.
- Tutoring and academic scholarships – Provided for the children of parents with disabilities.
- Consultation to early childhood centers – Mental health, developmental, and occupational therapists specializing in disability provide ongoing consultation to numerous centers in the community, many that include children whose parents have disabilities.

- Social media – These include a blog for parents with disabilities, a Facebook page, and a Twitter feed that streams national and international disability legal and policy developments, including those that involve parenting cases.

Thresholds Mothers' Project, Chicago, Illinois

Founded in 1976, Thresholds Mothers' Project was one of the nation's first programs to serve parents with psychiatric disabilities and their families.[1185] The project "seeks to stabilize and normalize the family unit and provide a social support network for its members."[1186] To support parents with disabilities, the Mothers' Project includes three distinct programs: a teen parenting program, a therapeutic nursery, and a Projects for Assistance in Transition from Homelessness (PATH) program.[1187]

The teen parenting program generally receives referrals from the state child welfare agency. Participants are mothers who were abused and involved in child welfare as children; mothers are eligible for the program until they reach age 21. The teen parenting program includes transitional living and helps parents apply for and secure benefits, employment, and housing.[1188]

The therapeutic nursery is available for the children of parents enrolled in any Thresholds program, as well as community members. Children may attend until age five. The nursery is primarily funded by Chicago public schools, through EI funding.[1189]

The PATH program, which is funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), serves mothers who are homeless or on the brink of homelessness. It is an outreach program aimed at helping mothers locate housing and other necessary supports.[1190] The program's Parenting Assessment Team provides ongoing evaluation of the parenting capacity of its members.[1191]

The Thresholds Mothers' Project is nationally known. In 1993, Tipper Gore, President Clinton's mental health policy advisor, recognized the program as one that "sets an example for the nation to follow" by teaching independent living and parenting skills. Through its programs,[1192] Thresholds serves nearly 75 mothers and 90 children annually.[1193] According to Marc Fagan, associate director of child and adolescent services, the project's overarching goal is "maintaining the bond between child and parent, even if the parent does not have custody."[1194] Fagan reports that children are very rarely removed from parents by child welfare while they are receiving supports from Thresholds.

Invisible Children's Project, Orange County, New York

In 1993, the Mental Health Association (MHA) in Orange County, New York, began an effort to raise awareness of the needs of families in which a parent has a psychiatric disability.[1195] The MHA developed the Invisible Children's Project (ICP), a program that "aims to integrate essential services for these parents, to increase their ability to function as parents and assist them in creating a safe and nurturing environment for their children."[1196]

The objective of ICP is to support parents with psychiatric disabilities in their parenting efforts and to keep the family together. Critical program components include family case management with 24-hour emergency services; affordable housing and financial assistance; respite care for parents; planning for parental hospitalization so

children are not placed in foster care; advocacy on behalf of the child with schools, social services, and the courts; parent skills training; support groups for parents; vocational training; and supported education services (e.g., classes and mentoring).[1197] Other program features include support during pregnancy and postpartum periods, art therapy with children, and cash for special requests (e.g., toys, camp, and birthday parties).[1198]

ICP receives its funding through a variety of funding streams, including local and state dollars from the Department of Mental Health, HHS, HUD, United Way, and private contributions.[1199]

Since its inception, ICP has served more than 175 people in New York. In an evaluation conducted by the New York Psychiatric Institute, more than 90 percent of the families served by ICP rated the overall quality of service as good or excellent and would recommend it to a friend.[1200] The data demonstrated that the program is particularly effective in helping consumers obtain better housing and improve their parenting skills. Recent internal program evaluations reveal a notable decrease in parental hospitalization and an increase in the ability of participants to hold a job and get off public assistance. Of significant note is the decline in the number of children placed in foster care as a result of the project.[1201] ICP is a nationally recognized, award-winning, interagency program that the National Mental Health Association is helping to replicate nationwide.[1202]

Family Initiatives at Employment Options, Marlborough, Massachusetts

Family Initiatives, a program of the Employment Options clubhouse in Marlborough, Massachusetts, offers a continuum of four programs for custodial and noncustodial parents with psychiatric disabilities: Family Project, Family Options, Young Parents Support Service, and the Clubhouse Family Legal Support Project (CFLSP).[1203]

Family Project offers a variety of supports and services to custodial and noncustodial parents with psychiatric disabilities who are receiving care through the Massachusetts Department of Mental Health.[1204] The project is an integral part of the clubhouse; through advocacy, the family generalist staff works with parents to rebuild relationships with their children and empower them to reestablish their identity as parents.[1205] Some of the parents involved with the Family Project have lost contact with their children and require legal consultation. The project works closely with the Clubhouse Family Legal Support Project to help parents achieve their goals:

- Parenting recovery supports and skill building – Staff and peers help parents increase their understanding of their children, improve their parenting skills, and build skills and resources to support their recovery.
- Visitation support – Staff work with parents who do not have custody of their children to plan visits that will be developmentally appropriate, interactive, and pleasurable for parents and their children. Staff also provide supervised visitation and transportation to these visits.
- Parent peer support group – Parents meet regularly to discuss the challenges of attending to their own well-being and recovery.

- Liaison with Clubhouse Family Legal Support Project – Staff facilitate contact and communication between parents and attorneys, in support of the parents' efforts to gain visitation and custodial care.
- Liaison with community – Staff and parents work together to facilitate a better understanding among the parent's community, including schools, housing, public safety, child welfare, and religious/community groups.[1206]

Family Options is a comprehensive program that provides strengths- and community-based care designed to meet the needs of parents with psychiatric disabilities and their children.[1207] The program offers family coaching, a wraparound team process, a 24-hour support line, a parent support group, and flexible funding to meet unique family and individual needs.[1208] Referrals to Family Options come from both the child- and adult-focused service sectors, with the majority from child welfare.[1209] The program is staffed by a director with extensive wraparound experience; three family coaches, each of whom works with a maximum of eight families at a time; a parent peer coordinator; and a consulting research and clinical psychologist.[1210]

Young Parents Support Services provides parent coaching and peer mentoring for young pregnant and parenting adults with psychiatric disabilities.[1211]

CFLSP offers legal advice and representation for parents who are trying to increase their contact with their children. The project teaches parents how to use their custodial rights and provides statewide training for attorneys on the legal issues facing parents with psychiatric disabilities.[1212] CFLSP was established in 1999 to help club members work toward rebuilding their families.[1213] The project brought a family law practitioner with experience representing low-income clients to join the Mental Health Legal Advisors Committee (MHLAC) and Employment Options as a full-time project attorney. Working with MHLAC and Employment Options, the attorney provides legal representation to clubhouse members who are at risk of losing custody and all contact with their children.[1214]

The project was launched by an attorney who had discovered that these cases were not being taken by legal service agencies, pro se clinics, pro bono attorneys, or private attorneys.[1215] Legal service agencies in Massachusetts were unable to provide representation because of limited resources and were therefore forced to decrease their family law staff and caseload to cover only matters that involve domestic violence. For this reason, MHLAC was "the only game in town if you were a male."[1216] In attempting to refer these cases elsewhere, legal services agencies discovered that other agencies were either reluctant or ill-equipped to handle cases involving parents with psychiatric disabilities. Further, legal service agencies had tried to obtain representation for parents with psychiatric disabilities through pro se clinics and private bar referrals. Unfortunately, pro se clinics were not useful for clients with psychiatric disabilities in family law matters. Moreover, most low-income parents with psychiatric disabilities cannot afford private attorneys, and thus rarely receive representation from the private bar.[1217] Even pro bono attorneys were reluctant to take these cases, because they "lack specialized training in mental health law, clinical knowledge,

and the parenting support services available in Massachusetts."[1218]

Positive Parenting Resource Center at United Arc of Franklin and Hampshire Counties, Greenfield, Massachusetts

The Positive Parenting Resource Center, which was established through an innovation grant from the Massachusetts Department of Mental Retardation, provides services and support to families headed by parents with intellectual or developmental disabilities.[1219] The center provides the following services:

- Individualized parent support – Includes home-based parent education, parent skills training, case management, service advocacy and family support.
- Parent education and support groups – Sessions focus on child development, parent/child communication, health and wellness, family literacy, basic household and financial stability, positive discipline and limit setting, safety factors, prevention of abuse and neglect, and access of community resources. Most groups have a target parent population; for example, parents with young children or parents of teens. Groups have educational themes and draw from a primary curriculum such as The Nurturing Parent or The Family Game.
- Supervised visitation – Available to families referred by child protective services whose children are in foster care.
- Intensive structured supported family living – Available to families referred by child protective services who need a broadly supportive environment for reunification of parents and children or to attain stability in family life. The United Arc owns an apartment building with five apartments available for families and two adjacent apartments that house staff offices, group meeting space, and living quarters for an onsite supportive neighbor.
- Mentoring support – Family Friends volunteers are matched with families to provide additional support and guidance to both children and parents.
- Grandparent support – Networking, support groups, and individualized home visits are available to grandparents who have primary responsibility for raising a grandchild.[1220]

The Positive Parenting Resource Center is funded through a variety of sources, including state funding from the Department of Children and Families, Children's Trust Fund, Community Foundation of Western Massachusetts, and private grants. Any family in which the parent is identified as having an intellectual or developmental disability may be referred to the center.[1221]

Ashbury House, San Francisco, California

Ashbury House is a residential treatment program in a social rehabilitation model, serving mothers who have mental health treatment needs, frequently with co-occurring substance abuse treatment needs. Ashbury House serves homeless women who have lost custody or are at risk of losing custody of their children owing to their psychiatric disability and who need comprehensive mental health services and parenting education to maintain or regain custody. Onsite day treatment includes parenting

education, individual and group counseling, crisis intervention, peer support, activities of daily living, medication support, ambulatory medical support by a nurse practitioner, and referrals to social services, vocational rehabilitation, housing and community treatment. Ashbury House is wheelchair accessible.[1222]

When Ashbury House opened in 1995, it was one of the first programs of its kind in the country. Before it opened, mothers were generally not allowed to keep their children with them while in a residential treatment program, and if a mother needed that level of mental health treatment, she was forced to give up her children. Ashbury is a yearlong program in which clients learn to manage their disability and improve their life skills; they also learn parenting skills, well-baby care, and how to identify and develop strategies for times when their mental illness may negatively affect their parenting.[1223]

Promising Models for Funding and Structure

This section examines two additional models for funding and structure of successful national programs that serve parents with disabilities and their children.

Family Support 360 Projects

The Family Support 360 initiative is an example of how state parenting support centers could be funded and developed nationally. The specific project discussed, Green Mountain 360, is an example of a promising practice.

Through the Family Support 360 (FS 360) initiative, the Administration on Intellectual and Developmental Disabilities (AIDD)—a program of the Administration for Community Living under HHS—provided "planning and implementation grant opportunities to create one-stop centers to assist the families of individuals with what they phrase as developmental disabilities. In fiscal year 2004, 21 entities were funded for five years to implement Family Support 360 Centers. They were required to be designated as the lead entity for their State/Territory by their Governor and to work in partnership with the developmental disability (DD) network (DD Council, Protection and Advocacy System, and University Center on Developmental Disability), family members, policymakers, and others in their State/Territory. They identified and geared their services to one un-served population and assisted them in locating and navigating public human services agencies, and connecting to private community organizations."[1224] These projects were to be defined by their holistic approach to family units and were to be family-centered and family-directed to the greatest possible extent. They included assessment of the family unit and creation with the family of a family service plan that describes the services the family might access and how to secure them. Families were assisted in securing and using a range of services, such as health care, child care, early intervention, education, employment, marriage education, financial education, transportation, housing, respite care, and assistance in maintaining parental rights. Staff were available to help if the family hit a barrier in the process.[1225]

One of the initial grantees focused on families in which a parent had a developmental disability: Green Mountain 360 in Vermont.[1226] Green Mountain provided peer navigators with expertise in disability and human services to help participants identify and use preventive and reunification services. Green Mountain worked to ensure that the human services system

developed and maintained equitable statewide capacity to deliver collaborative, flexible, coordinated supports that were safe for families who have a parent with a disability; helped parents with disabilities retain custody of their children with appropriate supports; and provided communication support to help parents make relevant facts and wishes known to the court. The model was successful: In the five years the grant ran, Green Mountain serves 750 families. The rate of removal of minor children was less than 5 percent.[1227]

None of the current 360 projects fund projects focused on serving families in which parents have disabilities. However, portions of the Green Mountain model have been funded by state legislation to continue acting as a triage point for the intersection of parents with intellectual disabilities and their families and human services agencies in the state.[1228] Sage Haven Center, LLC, in Fairfax, Vermont, continues to provide accommodated parenting assessments and evaluations in the context of child welfare cases, with regular recommendations for the use of peer navigators.[1229]

Sage Haven is a private mental health counseling practice specializing in intellectual and developmental disabilities.[1230] Services include individual, group, and family counseling by therapists skilled in treating individuals with intellectual or developmental disabilities and co-occurring emotional or behavioral disorders; consultation; training; and competence-based parenting assessments(C-BPAs). Sage Haven subcontracts a multidisciplinary team (the Vermont Parent Assessment Team) of doctoral and master's level psychologists, social workers, counselors, and other qualified professionals (with more than 60 years of combined experience) to conduct the assessments. C-BPAs evaluate parents' ability to nurture, protect, and meet the changing needs of their children. Family assessment specialists work in partnership with parents and service providers to assess individual parenting needs, while ensuring that parents' rights are respected and children's welfare is protected. The information gathered in C-BPAs helps determine the support needed for a parent to be successful and may assist with custody decisions. To conduct C-BPAs, family assessment specialists (1) use nationally recognized tools to evaluate parents' skills and the factors that have been found to affect parenting; (2) observe parent-child interactions in home and community settings; (3) interview parents to gather social histories and determine the need for support; (4) interview service and support providers; and (5) review records. They take cultural context and diversity into account and use current clinical and research evidence to inform their reports and ensure best practice.[1231]

Another successful program is the Vermont Communication Support Project (VCSP), which serves people with disability-related communication barriers that prevent them from fully participating in civil court and administrative proceedings, including those involving parental rights and responsibilities, Child in Need of Services (CHINS), and TPR.[1232] A communication support specialist is trained to understand the communication needs of people with learning disabilities, traumatic brain injuries, developmental disabilities, autism spectrum disorders, mental illness, aphasia, and other stroke-related conditions. VCSP began very informally nearly 15 years ago when a public defender in Chittenden County contacted the Disability Law Project to brainstorm about help

for a client with intellectual disabilities who had difficulty understanding and communicating in the confusing environment of a court proceeding.[1233] The Disability Law Project connected the attorney with a former special educator who was able to help prepare the client and simplify the language and concepts during the proceedings. The proceedings went smoothly for all, the court clerk began calling the Disability Law Project for help with other cases, and several other retired special educators stepped up to help. In 1999, a grant to the Defender General's Office, combined with a small memorial fund at the Vermont Parent Information Center, provided funds to develop a training curriculum for communication support specialists and staff to administer the project. VCSP was initially housed in the Defender General's Office. For a while, VCSP operated as an independent project funded by the Vermont Developmental Disabilities Council; eventually it moved to the University of Vermont's Center on Disability and Community Inclusion. It has been a project of Disability Rights Vermont since June 2008. VCSP has received funding at various times from DOJ, the Vermont Developmental Disabilities Council, and the state of Vermont. Currently, it is supported by grants from DOJ and the state.

The communication support specialists are independent contractors paid by courts and administrative agencies as a necessary accommodation under the ADA. Preparation time with an attorney is paid for by the attorney.[1234] The role of the specialist is to assist people with cognitive disabilities who might otherwise be confused by proceedings or who have difficulty expressing themselves by preparing them for proceedings, simplifying language and abstract concepts, checking for understanding, using alternative means of communication, and alerting the judge or hearing officer if the client does not understand or needs a break. The communication support specialist's role is that of neutral communication facilitator, analogous to a sign language interpreter for the deaf.

Between January 1, 2008, and June 30, 2011, VCSP received 253 requests for services; 206 became active cases, and 47 did not qualify for services or were unable to document their disability for a variety of reasons. Many, if not most, of these cases involved numerous hearings or meetings. VCSP was involved in at least 497 hearings, meetings, and mediations between January 1, 2008, and June 30, 2011.[1235]

Healthy Start, Australia

The idea of a national system of interdisciplinary organizations to build capacity and directly provide support to parents with disabilities is not unprecedented. International research demonstrating limited system capacity in Australia to support parents with intellectual disabilities triggered the development of a national—and replicable—response.

The Australian government funded a capacity-building model known as Healthy Start: A National Strategy for Children of Parents with Intellectual Disabilities. Healthy Start is an Early Childhood–Invest to Grow initiative, funded under the Stronger Families and Communities Strategy.[1236] "Healthy Start is an organizational-level intervention to reduce risk and promote a healthy start to life for children of parents with intellectual disabilities. The focus of the intervention is on the limited capacity of the service system to deliver evidence-based practice to these parents. Healthy Start aims to build system capacity by developing local

area networks developed and led by local champions, implementing a national technology-based network, and by actively disseminating knowledge and innovation."[1237] The components of Healthy Start are adaptation to community context, peer networking, access to knowledge and innovation, leadership and managerial support, and building capacity.[1238] The designers of the system note that "innovative, cross-disciplinary, and intersectoral practitioner networks are at the heart of this capacity-building model. These networks bridge the gap between research knowledge and practitioner knowledge as a basis for planning and coordinating local service development."[1239]

So far, 69 learning hubs have been established, covering every Australian state and territory. The information-rich Web site is available to the participating local agencies and professionals. A graduate-level unit of study on parents with intellectual disabilities is open to those facilitating hubs, as well as two evidence-based parenting programs, involving workshop training of 464 practitioners throughout Australia.[1240] "Local learning hubs are now implementing a range of innovative plans to build capacity to support parents with intellectual disabilities and their young children in their own local areas, bringing together knowledge from research with knowledge of local area needs."[1241]

Conclusion

Throughout the United States, agencies have developed innovative, evidence-based programs that support parents with disabilities and the well-being of their children. Yet a gap still exists between the research on what needs to be provided to these families to support them, the excellent work of a few programs, and the vast number of families with no access to support.

There is an urgent need for a national approach like the Healthy Start National Strategy in Australia. Further investigation is needed into how the United States could adopt a more sustained and robust version of the 360 project funding and development model, starting with demonstration project funding in 10–12 states. The development of collaborative projects and agencies that reflect the best of the promising practices highlighted here, with multidisciplinary and cross-disability features, is our best hope for creating capacity to meet the needs of this population of parents and their children in a consistent and comprehensive manner.

Chapter 15. Remedial State and Federal Legislation of Interest

"Law is an expression of the society in which it arises."[1242]

State Legislation of Interest

To address the barriers people with disabilities face in creating and maintaining families, some states have modified their legislation affecting custody. The efforts of grassroots disability organizations in Idaho and Kansas have led to significant alterations in state statutes governing custody of children in dependency and family court proceedings.[1243] California passed legislation that requires the state's Medicaid program to include adaptive baby care equipment in the list of durable medical equipment it covers.[1244] Other states have also addressed the disparities facing parents with disabilities and their families by amending their legislation, albeit not as comprehensively as Idaho or Kansas. These disability-specific legislative changes should be models for similar legislation at the state and federal level.

Idaho

The Idaho State Independent Living Council (SILC) undertook a groundbreaking effort to change legislation that was devastating the lives of parents with disabilities and their families. As a grassroots organization, the Idaho SILC gathers information on the issues most important to its consumers and includes these issues in its annual State Plan on Independent Living. In 2000, many consumers reported a rising fear of unjustified removals of children from their parents with disabilities. Led by Kelly Buckland, the executive director of Idaho SILC at the time, the Fathers and Mothers Independently Living with their Youth (FAMILY) Committee was established to address this problem.[1245]

In collaboration with TLG and local legislators, the FAMILY Committee drafted legislation for introduction during the 2000 state legislative session. The legislation passed the Senate unanimously but was defeated in the House Health and Welfare Committee. The FAMILY Committee met over the summer of 2000 and made minor revisions to address the concerns of the Idaho Prosecutors Association. The legislation was reintroduction in 2001; again, the bills passed the Senate but failed in the House Health and Welfare Committee.[1246]

Following another round of revisions, draft legislation was sent to legislators, magistrates, and committee members for a final review before the 2002 legislative session began. Eventually, four successful bills were passed over the 2002 and 2003 legislative sessions, modifying every custody-related section of the Idaho Statutes.[1247]

Collectively, these bills 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 a child without showing a nexus between the disability and detriment to the child. The bills made the following language additions and removals in the divorce, separation, and dependency statutes:

- Added a nondiscrimination statement regarding parents with disabilities.[1248]
- Defined "disability, supportive services, and adaptive equipment."[1249]
- Added a section that makes evidence relevant and admissible regarding the services and adaptive equipment available to enable parents with a disability to care for their children.[1250]
- Added language requiring anyone who conducts a parenting evaluation to consider the use of adaptive equipment and supportive services for parents with disabilities and requiring the evaluator to have (or be assisted by someone who has) expertise in such equipment and services.[1251]
- Removed references to disability as a factor to be considered in custody determinations.[1252]
- Added a section requiring a written statement by the court should it decide that disability is a relevant factor in a custody determination.[1253]

Because of the FAMILY Committee's efforts, statutes governing adoption and probate guardianships of children were also modified.[1254]

To date, two cases involving the new legislation have reached the appellate level.[1255] In *Doe v. Doe*,[1256] the court was unable to reach the merits of the case because it determined that the new legislation was not to be applied retroactively. In *Lieurance-Ross v. Ross*,[1257] a father appealed the decision of a family court magistrate that he could not be awarded custody of his children because he had a general guardianship as a result of stroke-impaired cognitive functioning. In a decision that demonstrated what the court had learned from the new legislation, the conclusion included a discussion of adaptive parenting equipment and services and stated the following:

> "[Because] 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 that affect the parent's ability to care for his or her child."[1258]

Kansas

Undoubtedly inspired by Idaho's success, the State Independent Living Council of Kansas (SILCK) embarked on a process of protecting the rights of parents with disabilities and their families through legislative amendment.[1259] Following the 2003 Kansas Disability Conference, at which numerous parents with disabilities shared stories of losing their parental rights,

SILCK decided to pursue this injustice during the 2004 legislative session.

Over the previous seven years, the Judicial Council had been focused on revising the Kansas Code for Child in Need of Care (CINC). Although the council had not considered the issue of discrimination against parents with disabilities, SILCK secured technical assistance from Ella Callow, director of TLG's legal program, and engaged members of the council to support the proposed changes. Nondiscriminatory language had not been included in the original bill, but testimony from SILCK to amend and add such language was supported by attorneys, Judicial Council members, and the state Judiciary Committee.[1260]

As a result of the timing of the CINC revision project, SILCK was able to introduce and pass effective remedial legislation for parents with disabilities and their families swiftly and without much revision. SB 230 passed during the 2005 legislative session and went into effect in 2006. This legislation included four significant safeguards for parents with disabilities in the new Chapter 38 of Article 22 "The Revised Kansas Code for Care of Children." These 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 that led to discrimination by allowing the removal of a child without showing a link between the parent's disability and detriment to the child.[1261] The legislation added the following language:

- A nondiscrimination statement regarding parents with disabilities that more fully encompassed them in the policy directive to protect the privacy and unity of the family.[1262]
- A statement that the disability of a parent will not constitute a ground for finding the child dependent or for removing the child from the parent without a specific showing of a causal relationship between the disability and harm to the child.[1263]
- 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.[1264]
- A mandate that custody determinations under the code will consider the availability and use of accommodations, specifically adaptive equipment and support services.[1265]

While more limited in scope (because it was part of a revision of one specific code—the dependency code), the Kansas legislation includes some significant protections for parents with disabilities. Because it requires that causation between harm to the child and the disability be established, the code principally necessitates the provision of proper services and the performance of adapted evaluations and assessments. These legislative changes set the stage for modification of other relevant Kansas codes, such as those affecting domestic relations, adoption, and guardianship.[1266]

California

Acknowledging the importance of adaptive baby care equipment for some parents with disabilities, California's Protection and Advocacy system, in collaboration with TLG, sponsored AB 2152 in 2000.[1267] This legislation caused adaptive baby care equipment to be included in the list of

durable medical equipment covered by Medi-Cal (California's Medicaid program). The legislation is groundbreaking because it expands references to "conditions that interfere with normal activity" to include those that interfere with the ability to parent; identifies such conditions as meeting the definition of significant disability and thus rendering services medically necessary; and expands the rights of Medi-Cal beneficiaries to include receiving adaptive parenting equipment within the definition of durable medical equipment.[1268] The legislative language addresses the problem of the cost-prohibitive nature of some adaptive equipment. As yet, there has been no test case. There was a funding crisis at the time the legislation was passed that resulted in confusion as to whether the new legislation would be funded. However, recently the state government has indicated that the legislation can be acted upon.[1269]

Efforts by Other States

Other states have also amended legislation in an attempt to remediate the discrimination experienced by parents with disabilities and their families. For example, on July 12, 2011, Missouri Governor Jay Nixon signed into law HB604 and SB555, which strengthen the rights of parents with disabilities and their families.[1270] These bills came on the heels of a recent case in which a couple lost custody of their daughter for 57 days because they were blind.[1271] This legislation prohibits discrimination on the basis of disability "without a specific showing that there is a causal relationship between the disability or disease and a substantial and significant risk of harm to a child." The legislation applies to termination of parental rights and custody as well as foster and adoptive parents.

In 2009, Maryland passed legislation protecting the rights of parents with disabilities. HB 689/SB 613 prohibits discrimination on the basis of disability against parents, guardians, or caregivers who are involved in adoption, custody, or Children in Need of Assistance cases.[1272]

In 2007, Vermont changed its state law, which now includes language mandating that in child welfare, there should be an appropriate balance between protecting children and respecting the rights of a parent or guardian, including a parent or guardian with disabilities, and recognizes that people with a disability can be successful parents. The rules also include the possible use of adaptive equipment and supports. The Vermont state statute requires that the strengths and needs of parents with disabilities be considered in child welfare proceedings.[1273] Specifically, Vermont State Code 52 § 4922(b) states:

> "The rules shall strike an appropriate balance between protecting children and respecting the rights of a parent or guardian, including a parent or guardian with disabilities, and shall recognize that persons with a disability can be successful parents. The rules shall include the possible use of adaptive equipment and supports."[1274]

Rhode Island eliminated disability language in its termination of parental rights statute in 2000.[1275]

In 1997, Arkansas wrote the ADA into its child welfare statute. Pursuant to Ark. Code Ann. § 9-27-341, a court may terminate parental rights only after it has found by clear and convincing evidence that "despite a meaningful effort … to rehabilitate the parent and correct the conditions that caused removal, those conditions have not been remedied by the parent"; provided, however, that "the department shall make reasonable accommodations in accordance

with the Americans with Disabilities Act…to parents with disabilities in order to allow them meaningful access to reunification and family preservation services."

Federal Legislation of Interest: Indian Child Welfare Act

On November 11, 1978, the Indian Child Welfare Act (ICWA) of 1978 was enacted.[1276] Its purpose was to establish standards for the placement of Native American children in foster and adoptive homes and to prevent the breakup of Indian families. ICWA established minimum federal standards for the removal of Native American children from their families; required Native American children to be placed in foster or adoptive homes that reflect Native American culture; provided for assistance to tribes in the operation of child and family service programs; created exclusive tribal jurisdiction over all Native American child custody proceedings when requested by the tribe, parent, or Indian custodian; and granted preference to Native American family environments in adoptive or foster care placement.[1277] Moreover, ICWA contains the strongest language in favor of family preservation. ICWA requires proof by clear and convincing evidence for any temporary foster care placement and proof beyond a reasonable doubt for termination of parental rights.[1278]

As noted by Callow, Buckland, and Jones:[1279]

> "While the Indian Child Welfare Act (ICWA) is clearly not aimed at the disability community, the impetus for the ICWA arose from circumstances similar to those surrounding families with parents who are disabled. 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 midway through the last century. Both groups suffer extreme levels of poverty and little is understood about their cultures, leading to generalized stereotyping and discrimination. Most importantly, both groups have been subjected to involuntary sterilization programs and the massive removals of their children."[1280]

Congress passed the act in response to the alarming rate at which Native nations were losing custody of their children;[1281] indeed, testimony from the 1974 hearings before the Subcommittee on Indian Affairs of the Senate Committee on the Interior and Insular Affairs included evidence that 25 percent to 35 percent of Native children were being removed from their families.[1282] The systemic removal of Native children was believed to be the result of misconceptions and stereotypes about poverty and about the child care practices of Native communities.[1283]

In passing ICWA, Congress specifically said:

> "…that there is no resource that is more vital to the continued existence and integrity of Indian tribes than their children and that the United States has a direct interest, as trustee, in protecting Indian children who are members of or are eligible for membership in an Indian tribe; (4) that an alarmingly high percentage of Indian families are broken up by the removal, often unwarranted, of their children from them by nontribal public and private agencies and that an alarmingly high percentage of such children are placed in non-Indian foster and adoptive homes and institutions; and (5) that the

States, exercising their recognized jurisdiction over Indian child custody proceedings through administrative and judicial bodies, have often failed to recognize the essential tribal relations of Indian people and the cultural and social standards prevailing in Indian communities and families."[1284]

The dearth of information about parenting in the Native American culture is comparable to the limited knowledge and understanding about the disability culture in general, adaptive equipment, supportive services, and the strengths of parents with disabilities.[1285] Because of these and other similarities between the causes of custody loss in the two communities—such as poverty, illiteracy, bias, and discrimination—portions of ICWA that provide remedy for the Native American community should be borrowed to strengthen new legislation to protect the rights of parents with disabilities and their children.[1286]

The following portions of ICWA—with attention to necessary disability adaptations—can be applied in remedial legislation to address the issues of lack of knowledge about adaptive equipment, services, and assessments; problems with the mandated timelines in dependency cases; lack of adequate legal counsel in the dependency process; and a lack of adequate and timely adapted services in the dependency courts:[1287]

- Mandatory written notification—with return receipt requested—must be provided to parents when a dependency action is instituted. No action may be taken until 10 days after receipt of the notice by the parent. Upon request, the parent shall have the right to an additional 20 days to prepare for any such proceeding.[1288]
- Mandatory appointment of counsel for the parent during any removal, placement, or termination proceeding.[1289]
- Requirement that states provide evidence of active efforts to prevent the removal of a child or the termination of a parent's rights.[1290] 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.[1291]
- Requirement that no removals or terminations may occur in the absence of a determination (supported by clear and convincing evidence in the cases of removals and by reasonable doubt in the cases of termination) that failure to remove or terminate will seriously emotionally or physically damage the child.[1292] Part of the showing must include the testimony of a qualified expert witness.[1293]

Conclusion

To protect the rights of parents with disabilities and their children, states must follow the impressive work done in Idaho, Kansas, and California—as well as the efforts of the other states mentioned here—by passing similar legislation. Moreover, federal legislation similar to ICWA must be enacted. Together, the language of these statutes provides cohesive and comprehensive remedy to the common causes of children being removed from parents with disabilities in family or dependency court. A discussion of model state and federal legislation follows in the next chapter.

Chapter 16. Need for Legislation to Ensure the Rights of Parents with Disabilities and Their Families

With respect to fundamental liberty, the U.S. Constitution limits a state's right to interfere with a person's most basic decisions about family and parenthood.[1294] And yet, 37 states have child welfare laws[1295] and nearly every state has child custody and guardianship laws[1296] that invidiously classify parents with disabilities and authorize removal and detention of their children or termination of their custody or parenting rights on the basis of the parent's disability. This situation creates an atmosphere of doubt for the disability community and is not ethically or legally tenable. In the words of Supreme Court Justice John Paul Stevens, "Liberty finds no refuge in a jurisprudence of doubt."[1297]

Julie Petty enjoys a dance with her six-year-old son Warren.

These laws serve no purpose and have no effect other than to lessen the status and human dignity of parents and prospective parents with disabilities in the United States, and to officially classify their relationships with their children as inferior to those of other parents. After nearly 25 years of state court decisions involving these discriminatory laws and the policies and practices they engender, it is clear that existing federal regulations (the Bill of Rights,[1298] the Rehabilitation Act of 1973,[1299] the Americans with Disabilities Act,[1300] and the Code of Federal Regulations[1301]) are not adequate to ensure the rights of parents with disabilities and their children.

History of Efforts to Challenge or Defeat Laws Harmful to Parents with Disabilities

The strongest law and argument to protect this population of families should be found in child welfare cases, where the Constitution is so strongly implicated. Yet even in child welfare

Eli Gelardin, Christina Mills and their daughter, 4 month old, Olivia, at the 9th Annual Disability Capitol Action Day in Sacramento, California.

jurisprudence, no successful antidiscrimination strategy has emerged.

Due Process

Parent litigants have unsuccessfully raised the due process clause of the 14th Amendment in both on-the-face and as-applied challenges to discriminatory laws and related policies.[1302] Parenting is a fundamental right, and legislation that affects this right is subject to strict scrutiny on judicial review.[1303] Theoretically, this interest is defeasible only by a compelling state interest and a rigorous procedural process.[1304] However, some state laws allow child welfare systems and courts to deny reunification services—the key procedural safeguard to retaining parenting rights in child welfare cases—even to nonoffending parents on the basis of the parent's disability.[1305] Often this disallowance is based solely on speculation that parental disability may be detrimental to a child at some point in the future. There is a contradiction between the treatment of parents with disabilities and that of parents without disabilities: In child welfare cases generally, such speculation is unacceptable; however, in cases that involve parents with disabilities, speculation is acceptable. At least one circuit has held that due process is violated and social workers can lose their immunity to lawsuit if they remove a child while consciously disregarding the "great risk that there has been no abuse."[1306]

Some courts have avoided addressing this issue by holding that strict scrutiny does not apply on judicial review of the laws authorizing the policy, because there is no fundamental right to reunification services, despite their centrality to avoiding loss of a fundamental right.[1307] This reasoning is equivalent to saying that if an African American citizen is allowed to vote but prevented by law from entering a voting booth, no violation of a fundamental right has occurred and strict scrutiny should not be applied during judicial review of the legislation. Other courts have held that a rigorous procedural process is in place to protect parents with disabilities because, in their state, the law disenfranchises parents with disabilities from participating in reunification services only after two psychologists have established that they are

"Liberty finds no refuge in a jurisprudence of doubt."

unlikely to benefit from such services.[1308] This is equivalent to saying that if an African American is allowed to vote but kept by law from voting unless he or she can pass a literacy test, no violation of a fundamental right has occurred and strict scrutiny is satisfied because a process is in place. The Voting Rights Act of 1965[1309] explicitly forbade such procedural obstructionism in voting policy; it should not be tolerated in child custody or child welfare policy.

Equal Protection

Parent litigants have been similarly unsuccessful in using the equal protection clause of the 14th Amendment as a defense against discriminatory state laws. *City of Cleburne v. Cleburne Living Center*[1310] established that disability is not a suspect classification and, in theory, a simple rationality test is the only hurdle a state is required to clear.[1311] However, although the *Cleburne* court said "rational," the analysis applied in the decision is widely recognized to represent something more akin to heightened scrutiny ("active rationality" or "rationality with a bite").[1312] There was hope that after passage of the ADA, this intermediate scrutiny would be formally recognized as the proper level of judicial review in disability cases because of the congressional direction it represents—a direction the *Cleburne* court complained that it lacked.[1313] This has not occurred, and no court to date has struck down on the basis of irrationality any child custody or child welfare law alleged to discriminate against parents with disabilities. This despite the fact that the laws cannot be proved to be substantially related to the objective of promoting child welfare as *there is no evidence that child maltreatment is more prevalent among parents with disabilities*.[1314]

Rehabilitation Act and Americans with Disabilities Act

Parent litigants have achieved only slightly more success in raising the Rehabilitation Act or the ADA as a defense against discriminatory laws. Pursuant to both laws, state actors, including child welfare agencies and courts, may not discriminate against people with disabilities; rather, they must accommodate them and provide, where needed, more, different, or adapted services and programs to satisfy the requirements of the law.[1315]

State legislatures, child welfare systems, and juvenile, family, and probate courts have resisted the implications of both acts for child welfare or custody statutes. This resistance persists despite the established legal principle that a state statute is void if it contravenes any express provision of a valid federal statute, even in areas traditionally within the purview of the state, where the congressional intent is clear.[1316] Not one court has voided one of these laws for violation of the ADA on the basis that it discriminates against parents with disabilities or their children (who are theoretically protected from discrimination by association by both the ADA and the Rehabilitation Act).[1317] It is almost uniformly accepted that violation of the ADA is not a defense to termination of parental rights,[1318] and few courts have found services unreasonable for failure to provide accommodations.[1319]

Parents with disabilities cannot win these cases without legislation specific to them. Two possible avenues exist for creating such legislation: federal legislation in the form of an amendment to the ADA or a stand-alone federal law, or a concerted and organized national campaign to uniformly introduce a model-based

state law in each state. Both approaches have strengths and weaknesses.

State Legislation

This type of legislation is clearly addressable at the state level, as shown in Idaho, Kansas, and California. The state law approach avoids constitutional complications in that family and domestic law is historically within the purview of the states. The drawback of state-by-state legislative efforts is the enormity of the undertaking, the complexity of organizing on so many fronts, and the risk that a significant number of the efforts will fail and the patchwork quilt of laws will remain.

Federal Legislation

The federal law approach, whether as an amendment to the ADA or as a stand-alone piece of legislation, avoids the drawbacks of state legislative efforts. It would provide national uniformity and, therefore, predictability to litigants and systems. However, a constitutional complexity exists: Opponents would likely argue that the commerce clause does not support federal intrusion into traditional state subject matter. The spending clause—in which the Adoptions and Safe Families Act is grounded—is a better possibility, but it would require funding that is unlikely in the current economic climate.

However, Section 5 of the 14th Amendment does empower Congress to "to enforce, by appropriate legislation" the provisions of the 14th Amendment.[1320] The two-part Section 5 review framework enunciated by the Court in *Tennessee v. Lane*[1321] both synthesized and modified elements of the analysis developed in six previous Supreme Court cases.[1322] Former Supreme Court clerk Kevin Schwartz, in his *Yale Law Review* article "Applying Section 5: Judicial Conditions on the Congressional Enforcement Power," referred to this analysis as a "juricentric enforcement model." Schwartz wrote, "The Court asks, first, whether Congress's [Section]… 5 power is appropriately invoked and, second, whether the actual Section 5 law crafted by Congress is an appropriate remedy."[1323]

To satisfy the first prong, there must be a history or pattern of state violations of the fundamental liberty Congress is seeking to protect.[1324] Second, the violations must be unconstitutional according to previous Section 5 decisions by the Court.[1325] To satisfy the second prong, the legislation must create a "congruent and proportional" response to the violations.[1326] The model legislation could satisfy both prongs.

Regarding the first prong (constitutional violation offensive to the court), parenting is a judicially identified fundamental liberty with a robust Supreme Court jurisprudence to support the requirements of due process where the state is interfering in the family sphere. Numerous state statutes deprive parents with disabilities of due process on the basis of their classification as disabled. A historic record exists of violations in the form of congressional testimony regarding the need for passage of the ADA, current data documenting disparate impact in the child welfare system, and extensive anecdotal evidence from individuals aggrieved by disability discrimination in child welfare and child custody proceedings. All these forms of "evidence" support finding a pattern of state violation under the *Lane* analysis.[1327]

Regarding the second prong (congruent remedy) the model legislation is certainly no more far-reaching than Title II of the ADA, which was upheld as applied in *Lane*. The Court noted in

that case that "within the limits of practicability, a state must afford to all individuals a meaningful opportunity to be heard in its courts,"[1328] and endorsed Congress's remedial conclusion that "failure to accommodate persons with disabilities will often have the same practical effect as outright exclusion."[1329] It is logical that a court would find that within the limits of practicability, a state must afford all parents meaningful access to the services, programs, and activities of child welfare system and dependency, family, and probate courts. As this report has shown, the failure to accommodate people with disabilities often has the same practical effect as outright exclusion.

Conclusion

Whether action is taken at the state or federal level, as an amendment or a new law altogether—the need for action could not be more timely or clear.

Recently, the media have reported that some survivors of the eugenics era are seeking justice for the state's denying them the possibility of having children, and the public has been outraged on their behalf. But what will it take for our society to become outraged and act to prevent the removal of existing children from parents with disabilities? People must be helped to see that, in the disability community, prevention of procreation and removal of children are two sides of the same coin, tossed in time from one generation to the next.

NCD recommends that Congress enact legislation similar to ICWA, in accordance with the language set forth in Appendix C of this report, to ensure the rights of parents with disabilities and their children. Alternatively, a legislative amendment to the ADA (in accordance with the language set forth in Appendix D) and other relevant federal acts governing child welfare, child custody, adoption, and assisted reproductive technologies will be necessary to effect the intention of the ADA at the national level. Moreover, states are urged to immediately amend state statutes with the language set forth in Appendix C.

Chapter 17. Findings and Recommendations

The foregoing chapters have examined the experiences of parents with disabilities and their families. Research and anecdotal evidence shared by parents with disabilities demonstrate the significant, and systemic, barriers facing people with disabilities wanting to create and maintain families. Further, a review of promising practices and supports demonstrate the potential of these families when provided necessary services. Finally, an analysis of state and federal legislation of interest revealed ways that parenting rights can be protected. This chapter sets forth major findings and concrete recommendations flowing from the study and charts a strategy for the future. If these recommendations are followed, people with disabilities will be fully able to possess their fundamental right to create and maintain families.

FINDING 1: There are few accurate and comprehensive sources of information on the prevalence of parents with disabilities. Despite increasing numbers of people with disabilities creating families, there is a paucity of data and research on the prevalence of parents with disabilities, their needs, and their experiences. Reasons for this lack of information include the lack of attention paid to the needs and experiences of parents with disabilities and their families, the dearth 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.

Recommendations

- **The Administration should issue an Executive Order establishing an Interagency Committee on Parents with Disabilities.**

  NCD recommends that the Administration issue an Executive Order establishing an Interagency Committee on Parents with Disabilities. Members of this committee should include NCD; the Department Health and Human Services (HHS), specifically the Administration for Community Living (ACL), including the Administration on Intellectual

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and Developmental Disabilities (AIDD) and the Administration for Children and Families (ACF); Department of Labor (DOL), specifically the Office of Disability Employment Policy (ODEP) and Employment and Training Administration (ETA); Department of Justice (DOJ); Substance Abuse and Mental Health Services Administration (SAMHSA); Social Security Administration (SSA); Department of Agriculture (USDA); Department of Transportation (DOT); Centers for Medicare and Medicaid Services (CMS); Department of Housing and Urban Development (HUD); National Institute for Disability and Rehabilitation Research (NIDRR); Department of Education (ED); Department of Veterans Affairs (VA); and Rehabilitation Services Administration (RSA).

- **Congress, the Administration, and federal agencies should gather effective data on parents with disabilities and their families.**

  NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on parents with disabilities and their families. Federal agencies—including but not limited to the Federal Interagency Forum on Child and Family Statistics, HHS, SAMHSA, SSA, USDA, CMS, VA, and HUD—should collect data on the parents with disabilities and the families they serve. The Centers for Disease Control and Prevention (CDC) should conduct a surveillance survey to determine the prevalence of parents with disabilities. Similarly, key systems that serve people with disabilities—such as state disability and veterans agencies, Centers for Independent Living, disability and mental health providers, and paratransit agencies—must collect data on the parental status of their clients/consumers.

- **Congress, the Administration, and federal agencies should fund research on parents with disabilities and their families.**

  NCD recommends that Congress appropriate funding specifically for research on parents with disabilities and their families. Further, NCD recommends that federal agencies such as the Interagency Committee on Disability Research (ICDR), AIDD, the National Institutes of Health (NIH), and SAMHSA emulate and collaborate with NIDRR in dedicating funding to research on parents with disabilities and their families, focusing on their needs and how best to support them. This will necessarily involve demonstration projects and evaluative service models.

FINDING 2: The child welfare system is ill-equipped to support parents with disabilities and their families, resulting in disproportionately high rates of involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights.

Parents with disabilities and their children are overly, and often inappropriately, referred to child welfare services and, once involved, are

permanently separated at disproportionately high rates. Parents with disabilities have their children removed at disproportionately high rates owing to a number of factors, including (1) state statutes that include disability as grounds for termination of parental rights (TPR); (2) the disparate impact of certain provisions of the Adoption and Safe Families Act of 1997 (ASFA); (3) perceived limits on the application of the Americans with Disabilities Act (ADA), especially at the termination phase; (4) bias, speculation, and the "unfit parent" standard; and (5) a lack of training in relevant systems regarding parents with disabilities.

Recommendations

- **States must eliminate disability from their statutes as grounds for termination of parental rights and enact legislation that ensures the rights of parents with disabilities.**

  NCD recommends that states eliminate disability from their dependency statutes as grounds for TPR. Further, NCD recommends that all states enact legislation, in accordance with the language set forth in Appendix C of this report, to ensure the rights of parents with disabilities.

- **Congress should address the disparate treatment experienced by parents with disabilities by adding specific protections for parents with disabilities in the Adoption and Safe Families Act.**

  NCD recommends that Congress amend ASFA by adding specific protections for parents with disabilities. Specifically, language must be added to the (1) "15/22" rule, allowing for additional time for parents with disabilities; and (2) the "reasonable efforts" provision to keep children with their parents, both to prevent or eliminate the need for removal of the child from the family and to make it possible for the child to return to the family following removal by eliminating the bypass provision (which allows states to bypass efforts to reunify families in certain situations) as applied to parents with disabilities and ensuring that child welfare agencies comply with the law and make reasonable efforts to prevent the removal of children and provide reunification services for parents with disabilities and their families.

- **Congress should address the disparate treatment experienced by parents with disabilities resulting from the focus on permanency by shifting funding priorities at the federal level so that states have a greater incentive to provide prevention and preservation services.**

  NCD recommends that Congress shift funding priorities at the federal level so that states have a greater incentive to provide services to families while the children are maintained in the home, as research has shown that in-home services are most effective, particularly for people with disabilities.

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- **DOJ, in collaboration with HHS, should issue guidance to states (specifically child welfare agencies and dependency courts) on their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ, in collaboration with HHS, issue guidance to states (specifically child welfare agencies and dependency courts) reinforcing their legal obligations pursuant to the ADA. Such guidance must address (1) the applicability of the ADA to TPR proceedings; (2) the duty of child welfare agencies and dependency courts to provide reasonable accommodations to parents with disabilities; and (3) presumptions of parental incompetence based on disability violate the ADA.

- **HHS and DOJ should gather data on parents with disabilities and their interaction with child welfare and dependency court systems.**

  NCD recommends that HHS and DOJ collect annual data on parents with disabilities and their interaction with child welfare agencies and dependency courts. Such data must include (1) disability, (2) exact involvement, (3) services and reasonable accommodations provided, and (4) outcome.

- **DOJ, in collaboration with HHS, must investigate all allegations of child welfare agencies or dependency courts that violate federal disability laws and enforce them as appropriate.**

  NCD recommends that DOJ include such matters in its enforcement priorities; violations of parental rights must be considered violations of civil rights. HHS (which has institutional expertise in the functioning of the child welfare system and courts) and DOJ's Civil Rights Division should collaborate to enrich investigations into alleged violations of the Rehabilitation Act or the ADA by these entities with respect to parents with disabilities and their children. This could be effected through a memorandum of understanding establishing a synergistic partnership (such as the interagency agreement between the DOJ Civil Rights Division and the Department of Transportation) or the creation of a special section integrating expertise from the two departments (such as the Housing and Civil Enforcement Section of the DOJ Civil Rights Division).

- **The HHS Children's Bureau should collaborate with NIDRR in funding and directing NIDRR's National Center for Parents with Disabilities and Their Families.**

  NCD recommends that the HHS Children's Bureau collaborate with NIDRR in funding and directing NIDRR's National Center for Parents with Disabilities and Their Families. NIDRR has funded such centers since 1990, with regular competition for awards every three to five years. The added funding and direction would allow the National Center to develop additional knowledge and provide additional technical assistance to federal, state, and local agencies and tribes to improve outcomes for families with parents with disabilities in the child welfare and family court systems.

FINDING 3: Parents with disabilities who are engaged in custody or visitation disputes in the family law system regularly encounter discriminatory practices.

Parents with disabilities who are seeking or defending custody or visitation rights often encounter a family law system that is riddled with practices that discriminate against them. Such practices include (1) a system that is pervaded with bias; (2) inconsistent state laws, many that overtly discriminate against parents with disabilities, others that fail to protect them from unsupported allegations that they are unfit or create a detrimental impact on their children solely on the basis of presumption or speculation regarding the parental disability; and (3) a lack of expertise or even familiarity regarding parents with disabilities and their children.

Recommendations

- **Family court professionals—including judges, attorneys, and evaluation personnel—should receive training related to parenting with a disability.**

  NCD recommends that all family court professionals—including judges, attorneys, and evaluation personnel— receive training on a regular basis on parents with disabilities and their children. This training should be a mandatory component of continuing education requirements for such professionals.

- **DOJ should issue guidance to family courts on their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ issue guidance to family courts, reinforcing their legal obligations pursuant to the ADA. Such guidance must address (1) the applicability of the ADA to custody and visitation proceedings, (2) the courts' duty to provide reasonable accommodations to parents with disabilities, and (3) presumptions of parental incompetence based on disability that violate the ADA.

- **States must modify their custody and visitation statutes to eliminate language that discriminates against parents with disabilities.**

  NCD recommends that states eliminate parental disability as a factor that courts can consider when determining the "best interest of the child" in custody and visitation disputes. Further, NCD recommends that all states enact legislation, in accordance with the language set forth in Appendix C of this report, to ensure the rights of parents with disabilities.

FINDING 4: Parents with disabilities who are involved in dependency or family proceedings regularly face evidence regarding their parental fitness that is developed using inappropriate and unadapted parenting assessments. Resources are lacking to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques.

Parents with disabilities who are involved in dependency or family proceedings regularly face (1) evidence regarding their parental fitness that is developed using inappropriate and unadapted parenting assessments and (2) a national dearth of resources to provide adapted services and adaptive parenting equipment, and to teach adapted parenting techniques. Even when such resources exist, dependency and family courts do not often use them.

Recommendations

- **State statutes, rules of court, and professional standards must require that parenting assessments be fully accessible to parents with disabilities.**

  NCD recommends that state statutes, rules of court, and professional standards must require evaluators to thoroughly investigate whether they are in compliance with the 2012 American Psychological Associations Guidelines for Assessment of and Intervention With Persons With Disabilities, and whether they need to modify the evaluation process or incorporate parenting adaptations to provide a more valid, reliable assessment of a parent's capacities in the context of child welfare and child custody cases. Such standards must require adapted naturalistic observations—for instance, in the parent's modified home setting rather than in an unfamiliar setting—instead of leaving the venue for observation open to the evaluator's discretion; must require explicit evidentiary support for statements made about a parent's capacity; and must prohibit the use of speculation and global diagnostic or disability labels as a ground for limiting custody or visitation. Professional standards must address the problem of using standardized testing to assess parenting capacity in parents with disabilities. Further, evaluators must use tools that have been developed specifically to assess the capabilities and needs of parents with disabilities, particularly intellectual and developmental disabilities, and should include existing and natural supports in the assessment.

- **States must mandate training for custody evaluators on parents with disabilities and their children.**

  NCD recommends that state legislatures mandate training for current custody evaluators to teach them the skills necessary to conduct competent disability-related custody

evaluations. Such training must include valid methods that directly evaluate parenting knowledge and skills, and must consider the role of adaptations or environmental factors that can impede or support positive outcomes.

- **CMS must expand the definition of durable medical equipment (DME) to include adaptive parenting equipment.**

  NCD recommends that CMS expand its definition of DME to include adaptive parenting equipment for parents with disabilities who receive Medicaid or Medicare.

- **States should establish adaptive parenting equipment reuse and loan programs.**

  NCD recommends that states establish adaptive parenting equipment reuse and loan programs similar to the programs states now have pursuant to the Assistive Technology Act of 2004.

FINDING 5: Prospective adoptive parents with disabilities face significant barriers to adopting children, both domestically and internationally.

Despite a growing need for adoptive parents, people with disabilities regularly encounter discriminatory practices that eliminate them solely because of their disabilities.

Recommendations

- **DOJ should issue guidance to domestic public and private adoption agencies, as well as private adoption agencies engaging in international adoption on U.S. soil, regarding their legal obligations pursuant to the ADA.**

  NCD recommends that DOJ issue guidance to domestic public and private adoption agencies, as well as private adoption agencies engaging in international adoption on U.S. soil, regarding their legal obligations pursuant to the ADA. Such guidance must address the agencies' duty to provide reasonable accommodations to prospective adoptive parents with disabilities throughout all phases of the process and state that presumptions of parental incompetence based on disability violate the ADA.

- **DOJ must investigate all reported allegations of public and private adoption agencies violating the ADA and enforce the law as appropriate.**

  NCD recommends that DOJ investigate all reported allegations of domestic public and private adoption agencies violating the ADA and enforce the law as appropriate.

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Discrimination in the adoption process against prospective parents with disabilities must be considered a violation of civil rights.

- **The Department of State should dedicate resources to expanding the rights of people with disabilities to adopt internationally.**

  NCD recommends that the Office of Children's Issues (CI), part of the Bureau of Consular Affairs at the Department of State, and the Department of State's Office of the Special Advisor for International Disability Rights work together to expand the rights of people with disabilities to adopt internationally, particularly from those nations that have ratified the Hague Convention. Such work will require educating state and private adoption agencies in other countries on the capacity of people with disabilities to parent, with or without adaptive parenting equipment, techniques, or supportive services.

- **Adoption agency staff must undergo training on how to fully assess prospective parents with disabilities.**

  NCD recommends that adoption agency staff who are responsible for evaluating prospective adoptive parents or conducting home studies to assess fitness for adoptive placement be provided with training regarding parents with disabilities, adaptive equipment, techniques, and supportive services.

FINDING 6: People with disabilities face significant barriers to receiving assisted reproductive technologies (ART), despite its importance for many people with disabilities who want to procreate.

ART can enable many people with disabilities to procreate who would otherwise be unable to do so. However, many people with disabilities face significant, and sometimes insurmountable, barriers to receiving ART. ART providers regularly engage in discriminatory practices against people with disabilities, and the growing costs of ART, combined with the limited insurance coverage for these treatments, leave many people with disabilities unable to afford the treatment.

Recommendations

- **DOJ, in collaboration with HHS, should issue guidance to ART providers on their legal obligations pursuant to the ADA and the Rehabilitation Act.**

  NCD recommends that DOJ, in collaboration with HHS, issue guidance to ART providers regarding their legal obligations pursuant to the ADA and the Rehabilitation

Act. Such guidance must address the providers' duty to provide access and reasonable accommodations throughout all phases of the process and must state that presumptions of parenting ability based on disability violate the ADA.

- **DOJ, in collaboration with HHS, must investigate all reported allegations of ART providers violating the ADA and the Rehabilitation Act, and enforce the law as appropriate.**

  NCD recommends that DOJ investigate all reported allegations of ADA and Rehabilitation Act violations by ART providers and enforce them as appropriate.

- **HHS must issue guidance to ART providers on treating patients with disabilities and make training available on parenting capacity.**

  NCD recommends that HHS—collectively the ACL, CDC, NIH, Office for Civil Rights, and the Office of the Surgeon General—issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations. ART office staff responsible for evaluating prospective parents to assess fitness should be provided with training regarding parents with diverse disabilities, adaptive parenting equipment and techniques, and supportive services.

- **ART professional organizations must issue guidance to their members on treating patients with disabilities.**

  NCD recommends that ART professional organizations, such as the Society for Reproductive Technologies and the American Society for Reproductive Medicine, issue guidance to ART providers on treating patients with disabilities and their legal obligations to provide access and reasonable accommodations.

- **Medicaid and Medicare must fund ART for people with disabilities.**

  NCD recommends that CMS identify and implement mechanisms to pay for ART for Medicaid and Medicare beneficiaries with disabilities.

FINDING 7: Personal assistance services (PAS) are a crucial support for many people with disabilities but usually may not be used to assist them with their parenting activities. PAS are a crucial support for more than 13.2 million people with disabilities. They help people with disabilities with activities of daily living (ADLs, such as eating, bathing, dressing, and toileting) and with instrumental activities of daily living (IADLs, such as grocery shopping, cooking, and cleaning). Cost is the most significant barrier for parents with disabilities who need PAS. They face significant challenges because no government program provides them with assistance in caring for their nondisabled children. PAS are considered beyond the purview

of assistance that may be provided as it does not assist the persons with disabilities themselves. Other Western nations provide this service to consumers, funding and implementing the program in a variety of ways. PAS oriented toward parenting tasks would greatly assist parents with disabilities and their families. The benefits of PAS go beyond improving quality of life—they have also been found to be cost-effective.

Recommendation

- **CMS must expand its definition of ADLs to include parenting activities.**

  NCD recommends that CMS expand its definition of ADLs to include parenting activities so that funded PAS can help consumers with their parenting responsibilities.

FINDING 8: Parents with disabilities face significant barriers to obtaining accessible, affordable, and appropriate housing for their families.

Having a home is crucial to creating and maintaining a family. However, many parents with disabilities face significant barriers in securing accessible, affordable, and appropriate housing.

Recommendations

- **HUD must require that public housing agencies (PHAs) provide at least 50 percent of their accessible units in family housing developments.**

  NCD recommends that HUD require PHAs to provide at least 50 percent of their accessible units in family housing developments. Such units must comply with all relevant federal disability access requirements and must include the same family-oriented space and appointments found in other units.

- **HUD should establish a national modification fund to pay for reasonable modifications to make private units accessible.**

  NCD recommends that HUD develop a national modification fund to pay for reasonable modifications to make private units accessible for parents with disabilities and their families.

- **HUD should develop a program for parents with disabilities who are first-time homeowners.**

  NCD recommends that HUD develop a program for parents with disabilities who are first-time homeowners. This program should include counseling and low-interest loans.

FINDING 9: Many parents with disabilities face barriers to traveling with their families using paratransit services.
Transportation affects all areas of the lives of parents with disabilities and their families—from child care to housing to participating in a child's education and meeting a child's medical needs. Nevertheless, it remains one of the most challenging areas for many parents with disabilities and their families. Paratransit services—a support used by many parents with disabilities—have many barriers related to parents traveling with their families.

Recommendation

- **The Department of Transportation must issue guidance to paratransit providers on their legal obligations to transport parents with disabilities and their families to support the successful execution of parenting and employment roles by people with disabilities.**

  NCD recommends that DOT issue guidance to paratransit providers that reflects its findings in Letter of Findings for FTA Complaint #99096 regarding their obligation to facilitate the use of the system by parents with disabilities and their children without additional charges or discriminatory conditions.

FINDING 10: Parents with disabilities have significantly less income and more frequently receive public benefits.
The financial status of parents with disabilities and their families is bleak. In fact, the most significant difference between parents with disabilities and parents without disabilities is the economic difference. Parents with disabilities are more likely to receive public benefits. A recent survey found that 52 percent of parents with disabilities receive SSI, and a substantial number of parents with disabilities and their families receive SSDI, SNAP, and TANF. Many parents with disabilities find that these programs do not adequately meet their families' needs.

Recommendations

- **SSA must explore ways to serve SSI and SSDI beneficiaries who are parents more effectively.**

  NCD recommends that SSA begin an exploratory project to determine how to serve SSI and SSDI beneficiaries more effectively, focusing on ways to increase financial assistance to parents with disabilities and their families.

(continued)

- **The HHS Administration for Children and Families (ACF) must provide additional supports to parents with disabilities who receive TANF. Such efforts will require collaboration with the Rehabilitation Services Administration (RSA) and state vocational rehabilitation agencies.**

  NCD recommends that ACF provide additional supports to parents with disabilities who receive TANF. Pursuant to the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), parents who receive TANF must work a specific number of hours (determined by the age of their children). PRWORA also imposes a five-year lifetime limit on assistance. Without appropriate family and work supports to overcome barriers to employment, parents with disabilities, especially single mothers, may be unable to comply with the PRWORA/TANF regulations, resulting in a loss of benefits to families. Specifically, work requirements do not consider disabilities as a barrier to work. Low-paying work and lack of job training programs for people with disabilities are common obstacles to employment, and people with disabilities face significant discrimination in the hiring process, further hindering their ability to comply with the work requirements. Finally, some parents with disabilities—such as those with intellectual and developmental disabilities—may need long-term employment support, such as career planning and training. ACF must provide support to parents with disabilities who receive TANF, including job training, child care, and transportation. Such efforts will require collaboration with RSA, DOL, ODEP, ETA, and state vocational rehabilitation agencies.

FINDING 11: People with disabilities, especially women, face significant barriers to receiving proper reproductive health care. Proper health care, especially reproductive health care, is crucial for people who want to create and maintain families. People with disabilities, particularly women, face significant barriers to receiving accessible, affordable, and appropriate health care.

Recommendations

- **The Agency for Healthcare Research and Quality (AHRQ), within its mandate to undertake research on priority populations, should promote research that clearly identifies the various barriers encountered by women with disabilities who are seeking reproductive health care.**

NCD recommends that AHRQ, within its mandate to undertake research on priority populations, promote research that clearly identifies the various barriers encountered by women with disabilities who are seeking reproductive health care. Such research would help disability health policy researchers and other stakeholders to paint an accurate picture of, for example, the extent to which reproductive health care technologies, facilities, and equipment remain inaccessible to women with disabilities, and would bolster efforts to effect change.

- **The Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education (LCME) should convene a workgroup charged with identifying specific disability competencies that should be required of health care professionals before they graduate from medical and residency training programs, and should translate these competencies into specific course recommendations that can be adopted by medical training programs.**

  NCD recommends that AAMC and LCME convene a workgroup charged with identifying specific disability competencies that should be required of health care professionals before they graduate from medical and residency training programs, and should translate these competencies into specific course recommendations that can be adopted by medical training programs. Competencies should include the core knowledge and skills required to provide appropriate health care to people with diverse disabilities, as well as general awareness of reproductive health care issues and concerns of women with disabilities. Such training should also address parenting with a disability.

- **DOJ, in collaboration with HHS, must increase its monitoring and enforcement of the ADA and Section 504 of the Rehabilitation Act for health care facilities and programs.**

  NCD recommends that DOJ, in collaboration with HHS, increase its monitoring and enforcement of the ADA and Section 504 of the Rehabilitation Act for health care facilities and programs. DOJ must focus additional resources on compliance monitoring and investigation of Title III complaints concerning programmatic access violations of the ADA and Section 504 by health care providers.

- **CMS must identify and implement mechanisms to pay for comprehensive preconception care for Medicaid and Medicare beneficiaries with disabilities.**

  NCD recommends that CMS identify and implement mechanisms to pay for comprehensive preconception care for Medicaid and Medicare beneficiaries with disabilities.

FINDING 12: Parents and prospective parents with disabilities face a significant lack of peer supports.

The importance of peer supports for parents and prospective parents with disabilities is significant because of the limited information that is available on parenting with a disability. Parents with disabilities often lack positive parenting role models. Moreover, social isolation is a significant issue for many parents with disabilities, particularly parents with intellectual and developmental disabilities, owing to learning difficulties, transportation challenges, and discrimination by nondisabled parents. Peer support networks can be easily developed or expanded at a minimal cost and would be supportive for many parents.

Recommendation

- **Congress should appropriate funding to establish a national parenting network for parents with disabilities.**

  NCD recommends that Congress appropriate funding to establish a national parenting network for parents with disabilities. A primary national network should include peer staffing, provide peer-to-peer links, gather information, and provide links to other networking efforts, including those in proposed state sites. The network should maintain an accessible Web site and a "warm line" (during business hours) with cross-disability, legal, and crisis intervention expertise. Proposed state sites should include peer staffing and peer-to-peer networking as well as links to the national network. State sites could also maintain an accessible Web site and warm lines with cross-disability and crisis intervention expertise and links to resources in their regions. Additionally, peer support groups could be located in independent living centers and in programs that specialize in parents with disabilities or deafness. These local parent support groups could provide the ongoing peer connections that are important to alleviate isolation in communities. Collaboration among the national, state, and local services—including training and dissemination of information—should be a priority.

FINDING 13: Social service providers regularly overlook the parenting role of their consumers.

Disability, mental health, child welfare, housing, transportation, and other service providers play a significant role in the lives of many people with disabilities. The services provided by these agencies typically overlook the parenting needs of the consumer or client. In fact, research demonstrates that the majority of providers have no idea which of their clients are parents.

Recommendations

- **Service providers must gather data on the parenting status of the people they serve.**

  NCD recommends that service providers under the authority of the Department of Education, Equal Employment Opportunity Commission, HHS, HUD, Department of the Interior, DOJ, and DOT gather and report annual data on the parenting status of the people with disabilities they serve through state and federally administered programs that include this population.

- **States must develop and implement mechanisms that support integrated, family-centered, strengths-based care for parents with disabilities and their children.**

  NCD recommends that states develop and implement mechanisms to support integrated, family-centered, strengths-based care for parents with disabilities and their children. Agencies and service providers that work with parents and their families need to communicate and coordinate with each other. Coordination across agencies should facilitate the provision of more appropriate services in a more cost-effective fashion. Further, funding for adult and child services must be family-centered and not siloed. This will require a reorganization of the administration and funding of disability services to support the system's capacity to respond to family needs whether the "identified client" is the adult or the child, and encourage a "family wraparound approach." States will have to modify interagency agreements and vendor contracts to permit the inclusion of language and expectations for integrated, family-centered, strengths-based care for parents with disabilities and their children.

FINDING 14: Formal IDEA Part C Early Intervention (EI) programs and other non-Part C early intervention and prevention model programs are an appropriate service option for many children of parents with disabilities.

Early intervention and prevention model programs have the potential to fully accommodate parents with disabilities; thus, efforts must be made to ensure that parents with disabilities and their families are considered for services.

Recommendation

- **The Department of Education and HHS must identify and implement mechanisms for Part C Early Intervention programs, other early intervention and prevention model programs, and Early Head Start to adequately serve the needs of parents with disabilities and their families.**

  NCD recommends that the Department of Education and HHS identify and implement mechanisms for early intervention and prevention programs, including Early Head Start and Head Start, to serve the needs of parents with disabilities and their families. Further, early intervention and prevention model program service providers require education about the needs of parents with disabilities and their families, including how to remediate barriers to full participation in services.

FINDING 15: Parents with disabilities involved in dependency or family law proceedings face significant barriers to retaining effective and affordable legal representation.
Parents with disabilities face significant barriers to retaining effective and affordable legal representation for dependency and family law proceedings. Many attorneys lack the skills and experience necessary to meet the needs of parents with disabilities. Parents with disabilities are often represented by court-appointed legal representatives who typically have excessive caseloads and little if any training in disability. Research demonstrates that attorneys who represent parents with disabilities in these matters often fail to represent the parents' best interests; they may harbor stereotypes about parents with disabilities that can reinforce their impression that such cases are unwinnable, and many fail to understand the implications of the ADA in these such cases.

Recommendation

- **Protection and Advocacy (P&A) agencies must establish parenting rights as a formal priority, and funding must be appropriated accordingly.**

  NCD recommends that P&A agencies establish protection of custody and parenting rights as a formal national priority. To that end, Congress should establish and authorize additional funding for P&A systems nationally to meet the legal needs of parents with disabilities and their children in child welfare and child custody cases.

FINDING 16: Centers for Independent Living (CILs), with appropriate training, can provide services to parents with disabilities.
Given the breadth and importance of CILs and the supports they provide, with training they have the potential to participate in the support of parents with disabilities, especially to advocate regarding transportation, housing, financial advocacy, and assistive technology issues, and to offer parent support groups.

Recommendation

- **CILs must make serving the needs of parents with disabilities a national priority, and funding must be appropriated accordingly.**

  NCD recommends that CILs make serving the needs of parents with disabilities a national priority. To that end, Congress and RSA must appropriate additional funding to support this unmet need.

FINDING 17: Despite limited funding and little national attention given to parents with disabilities and their families, a number of programs and support services have begun to emerge across the nation; they must be replicated nationally to provide consistent capacity to support parents with disabilities and their children.
Programs that serve the needs of parents with disabilities remain scarce. Nevertheless, despite limited funding and little national attention given to parents with disabilities and their families, a number of programs and support services have begun to emerge across the nation. Several programs show promise, long-term sustainable impact, and the potential for replication. Generally, they are small, local programs that are part of larger disability services organizations. The programs, for the most part, are specific disability focused, meaning they provide services to parents with a certain disability (e.g., intellectual disabilities or psychiatric disabilities) but not cross-disability. Despite their small size and limited focus, these programs show enormous potential for serving parents with disabilities. With greater funding, programs similar to those discussed in this report can grow and develop nationwide, and adequately serve a currently underserved segment of the United States: parents with disabilities and their families. Additional funding will enable these programs to create systems that can consistently support families proactively rather than approaching intervention through child removal and other punitive measures.

Recommendations

- **Congress, the Administration, and federal agencies should fund the development of state multidisciplinary teams (MDTs) to support parents with disabilities and their children.**

  NCD recommends that multidisciplinary programs be established in each state. Moreover, funding must be available for MDTs to train and facilitate collaboration among relevant professional communities, systems, and organizations to increase regional capacity to serve parents with disabilities and their families. Further investigation is needed into how to use a more sustained and robust version of the 360 Project funding and development model, as well as requests for proposals, to achieve this goal preliminarily in 10–12 states while working toward a national system akin to the Healthy Start system in Australia. Ultimately, these projects should reflect the best of the promising practices highlighted here, with multidisciplinary, cross-disability and infant mental health features to maximize the well-being of children with parents who have disabilities.

- **Congress, the Administration, and federal agencies should fund research to analyze existing policies, guidelines, performance standards, and data collection practices of national organizations serving parents with disabilities and their families.**

  NCD recommends that Congress, the Administration, and federal agencies fund research specifically to analyze the existing policies, guidelines, performance standards, and data collection practices of national organizations serving parents with disabilities and their families.

FINDING 18: The impact of disability on the integrity of American Indian/Alaskan Native (AI/AN) families has been utterly neglected by professionals in the fields of law, policy, and research.

This issue has been neglected despite these communities having twice the disability rate of the general population and a history of government-sponsored removal of their children so severe that it prompted the creation of the Indian Child Welfare Act (ICWA).

Recommendations

- **The Health and Human Services Administration for Native Americans, ACF Native Affairs Work Group, and Intra-Departmental Council on Native American Affairs member agencies should create a task force to investigate and secure funding for research concerning the impact of disability on familial integrity in Indian Country.**

  NCD recommends that these interrelated entities coordinate to create a task force that could investigate the impact of parental and extended family caregiver disability and its associated legal and social implications for preserving AI/AN families; identify the barriers to conducting research with this population; and procure funding for such research. In many child welfare cases involving Native children, the parents have disabilities; the inability or unwillingness of child welfare systems to meaningfully accommodate these families represents an end-run around ICWA, defeating the spirit and the power of the legislation at a time of great peril for AI/AN communities.

- **Pursuant to §805 of the Native Americans Program Act of 1975, this same task force should procure funding for pilot projects to develop supports for AI/AN parents and extended family caregivers with disabilities and thereby support family integrity in Indian Country.**

  NCD recommends that these interrelated entities coordinate to create a research task force that can investigate how best to develop the capacity to deliver the supports AI/AN parents and extended family caregivers require to care for their children and prevent entry into the child welfare system. These supports should be delivered through existing tribal and urban Indian community programs or by developing new programs. The community supports that can prevent entry into the child welfare system or can support positive outcomes in these cases are not often present in reservation or urban Indian communities. Funding should be procured for a cross-disability, multidisciplinary model program similar to the AFC 360 initiative process to allow reservation and urban Indian communities to maximize their cultural and social relevance and take advantage of their deep understanding of the functioning of their own government and social service delivery systems.

- **Grants and funding should be made available under the Indian Tribal Justice Technical and Legal Assistance Act of 2000 to support technical assistance and training for tribal courts that focuses on parents with disabilities and child welfare and custody cases.**

  NCD recommends that the Bureau of Justice Assistance, as part of DOJ's Indian Country Law Enforcement Initiative, create and administer grants to support the development and implementation of tribal legal services training and technical assistance to the court

(continued)

programs to enhance understanding in those tribal judicial systems regarding the capacity of parent and extended family caregivers with disabilities to safely and successfully care for minor children and the interplay of ADA and ICWA cases in state court proceedings involving their tribal citizens. This is important not only to support nonbiased outcomes in tribal courts, but to ensure that, where possible, they accept jurisdiction in cases where discrimination is occurring in state courts or have sufficient facility with this issue to withhold endorsement of "active efforts" by state child welfare entities where accommodation has not been provided. Existing disability and existing Native American child welfare organizations (including tribally administered organizations) should be encouraged to collaborate in submitting requests for proposals and developing projects to be funded. Existing Native American disability organizations can provide technical information and knowledge regarding parents with disabilities and how to support them in their own communities; outreach for RFPs should be directed to them. Long-standing organizations such as the Native American Independent Living Services (which serves AI/AN people in New Mexico) and the Native American Disability Law Center (which works specifically with the tribal communities in the Southwest) represent different types of Native American disability programs and are well-positioned to assist both reservation and urban Indian communities.

FINDING 19: Federal legislation, similar to the Indian Child Welfare Act, must be enacted to address the systemically disparate treatment faced by parents with disabilities throughout the country.

To fully protect the rights of parents with disabilities, federal legislation akin to the ICWA must be enacted. While the ICWA is clearly not aimed at the disability community, the impetus for the ICWA arose from circumstances similar to those surrounding families with parents who have disabilities. Both Native Americans and people with disabilities are historically oppressed minorities who have been denied civil and human rights in this country. Both groups were systemically isolated from other sectors of society until midway through the last century. Both groups suffer extreme levels of poverty, and little is understood about their cultures, leading to stereotyping and discrimination. Most important, both groups have been subjected to involuntary sterilization programs and massive removals of their children. Lack of knowledge about the culture of Native American people and how they parent is very similar to lack of knowledge about the culture, adaptive equipment, supportive services, and strengths of the disability community and how people with disabilities parent. Because of this and the other similarities between the causes of custody loss in the two communities—such as poverty, illiteracy, bias, and discrimination—portions of the ICWA that provide remedy for the Native American community should be borrowed to strengthen new legislation to protect the children of parents with disabilities.

Recommendation

- **Congress should address the disparate treatment experienced by parents with disabilities through legislation similar to the ICWA that will protect the rights of parents with disabilities and their families.**

  NCD recommends that Congress enact legislation similar to the ICWA, in accordance with the language set forth in Appendix C of this report, to protect the rights of parents with disabilities. Alternatively, legislative amendment of the ADA and other relevant federal acts governing child welfare, child custody, adoption, and assisted reproductive technologies will be necessary to advance the intention of the ADA at the national level.

FINDING 20: The United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the rights of people with disabilities to create and maintain families.

The CRPD protects the rights of people with disabilities to create and maintain families in several Articles, particularly Articles 23 and 25. Additionally, the CRPD reinforces the reproductive rights of women with disabilities.

Recommendation

- **The United States should ratify the CRPD.**

  NCD recommends that the Senate consider and expeditiously provide its advice and consent to ratification of the CRPD. U.S. ratification of the CRPD would reinforce American leadership in disability rights and support American efforts to promote the rights of parents with disabilities around the world.

Appendix A. Interviews

Iren Ahlund, FUB, the Swedish Association for People with Learning Difficulties

Adrienne Asch, PhD, Director, Center for Ethics, Yeshiva University

Dara Baldwin, MPA, Policy Analyst, National Council on Independent Living

Hanna Björg Sigurjónsdóttir, PhD, Chair of Department and Vice Director of the Center for Disability Studies, School of Social Sciences, University of Iceland

Kelly Buckland, Executive Director, National Council on Independent Living

Olegario "Ollie" D. Cantos VII, National Disability Rights Activist

Ruth Colker, JD, Professor and Heck Faust Memorial Chair in Constitutional Law, Moritz College of Law

Marc Fagan, PsyD, Associate Director, Thresholds

Diane Garreau, Director, Cheyenne River Sioux Indian Child Welfare Program Emergency Children's Shelter

Bernadette Irwin, Assistant Department Director, Kennedy Krieger Institute, Family Support Services, and Co-president of the Association for Successful Parenting

Susan Jones, Director of Positive Parenting, United Arc of Franklin and Hampshire Counties, and Co-president of the Association for Successful Parenting

Katherine Kaplan, MSEd, Assistant Director, Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities

Megan Kirshbaum, PhD, Founder and Executive Director, Through the Looking Glass, and Co-director of the National Center for Parents with Disabilities and Their Families

Traci LaLiberte, PhD, Executive Director, Center for Advanced Studies in Child Welfare, School of Social Work, University of Minnesota

Elizabeth Lightfoot, PhD, Associate Professor and Director of the Doctoral Program, School of Social Work, University of Minnesota

Jennifer Mathis, Deputy Legal Program Director, Bazelon Center for Mental Health Law

David McConnell, PhD, Professor of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta, Canada

Andrew Philips, JD, Staff Attorney, National Association of the Deaf

Mary Trimble Norris, Director, American Indian Child Resource Center

Anita Silvers, PhD, Professor and Chair of Philosophy Department, San Francisco State University

Deborah Kent Stein, Chair, Blind Parents Interest Group of the National Federation of the Blind

Susan Yuan, PhD, Associate Director, Center for Disability and Community Inclusion, University of Vermont

Appendix B. State-By-State Analysis of Dependency Statutes and Their Inclusion of Disability

Adapted from Elizabeth Lightfoot, Katharine Hill, and Traci LaLiberte, "The Inclusion of Disability as a Condition for Termination of Parental Rights," *Child Abuse and Neglect* 34 (2010): 927–934.

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Alabama	Yes	X	X	X			**Ala.Code 1975 § 12-15-319 (2009)** (a) If the juvenile court finds from clear and convincing evidence, competent, material, and relevant in nature, that the parents of a child are unable or unwilling to discharge their responsibilities to and for the child, or that the conduct or condition of the parents renders them unable to properly care for the child and that the conduct or condition is unlikely to change in the foreseeable future, it may terminate the parental rights of the parents. In determining whether or not the parents are unable or unwilling to discharge their responsibilities to and for the child and to terminate the parental rights, the juvenile court shall consider the following factors including, but not limited to, the following:

(continued)

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(2) Emotional illness, mental illness, or mental deficiency of the parent, or excessive use of alcohol or controlled substances, of a duration or nature as to render the parent unable to care for needs of the child.
Alaska	Yes	X	X	X			**AK ST § 47.10.011 (1998)** Subject to **AS 47.10.019**, the court may find a child to be a child in need of aid if it finds by a preponderance of the evidence that the child has been subjected to any of the following: (11) the parent, guardian, or custodian has a mental illness, serious emotional disturbance, or mental deficiency of a nature and duration that places the child at substantial risk of physical harm or mental injury. **AK ST § 47.10.088 (2008)** (a) Except as provided in **AS 47.10.080(o)**, the rights and responsibilities of the parent regarding the child may be terminated for purposes of freeing a child for adoption or other permanent placement if the court finds by clear and convincing evidence that (1) the child has been subjected to conduct or conditions described in **AS 47.10.011**.

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Arizona	Yes	X	X				**A.R.S. § 8-533 (2011)** B. Evidence sufficient to justify the termination of the parent-child relationship shall include any one of the following, and in considering any of the following grounds, the court shall also consider the best interests of the child: 3. That the parent is unable to discharge parental responsibilities because of mental illness, mental deficiency or a history of chronic abuse of dangerous drugs, controlled substances or alcohol and there are reasonable grounds to believe that the condition will continue for a prolonged indeterminate period.
Arkansas	Yes	X	X	X			**A.C.A. § 9-27-341 (2011)** (b)(3) An order forever terminating parental rights shall be based upon a finding by clear and convincing evidence: (B) Of one (1) or more of the following grounds: (vii)(a) That other factors or issues arose subsequent to the filing of the original petition for dependency-neglect that demonstrate that return of the juvenile to the custody of the parent is contrary to the juvenile's health, safety, or welfare and that, despite the offer of appropriate family services, the parent has manifested the incapacity or indifference to remedy the

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Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							subsequent issues or factors or rehabilitate the parent's circumstances that prevent return of the juvenile to the custody of the parent. (b) The department shall make reasonable accommodations in accordance with the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq., to parents with disabilities in order to allow them meaningful access to reunification and family preservation services. (c) For purposes of this subdivision (b)(3)(B)(vii), the inability or incapacity to remedy or rehabilitate includes, but is not limited to, mental illness, emotional illness, or mental deficiencies.
California	Yes	X	X				**Cal.Welf. & Inst.Code § 361.5 (2011)** (a) Except as provided in subdivision (b), or when the parent has voluntarily relinquished the child and the relinquishment has been filed with the State Department of Social Services, or upon the establishment of an order of guardianship pursuant to Section 360, whenever a child is removed from a parent's or guardian's custody, the juvenile court shall order the social worker to provide child welfare services to the child and the child's mother

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							and statutorily presumed father or guardians. Upon a finding and declaration of paternity by the juvenile court or proof of a prior declaration of paternity by any court of competent jurisdiction, the juvenile court may order services for the child and the biological father, if the court determines that the services will benefit the child. (b) Reunification services need not be provided to a parent or guardian described in this subdivision when the court finds, by clear and convincing evidence, any of the following: (2) That the parent or guardian is suffering from a mental disability that is described in Chapter 2 (commencing with Section 7820) of Part 4 of Division 12 of the Family Code and that renders him or her incapable of utilizing those services. **Cal.Fam.Code § 7827 (2002)** (a) "Mentally disabled" as used in this section means that a parent or parents suffer a mental incapacity or disorder that renders the parent or parents unable to care for and control the child adequately.
Colorado	Yes	X	X	X			**C.R.S.A. § 19-3-604 (2008)** (1) The court may order a termination of the parent-child legal relationship upon the finding by clear and convincing evidence of any one of the following:

(continued)

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(b) That the child is adjudicated dependent or neglected and the court finds that no appropriate treatment plan can be devised to address the unfitness of the parent or parents. In making such a determination, the court shall find one of the following as the basis for unfitness: (I) Emotional illness, mental illness, or mental deficiency of the parent of such duration or nature as to render the parent unlikely within a reasonable time to care for the ongoing physical, mental, and emotional needs and conditions of the child.
Connecticut	No						**C.G.S.A. § 17a-112 (2006)**
Delaware	Yes	X	X				**13 Del.C. § 1103 (2009)** (a) The procedure for termination of parental rights for the purpose of adoption or, if a suitable adoption plan cannot be effected, for the purpose of providing for the care of the child by some other plan which may or may not contemplate the continued possibility of eventual adoption, may be initiated whenever it appears to be in the child's best interest and that 1 or more of the following grounds exist: (3) The parent or parents of the child or any person or persons holding parental rights over such child are found by the Court to be mentally incompetent and, from evidence of 2 qualified

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							psychiatrists selected by the Court, found to be unable to discharge parental responsibilities in the foreseeable future. The Court shall appoint a licensed attorney as guardian ad litem to represent the alleged incompetent in the proceeding. **13 Del.C. § 1101 (2000)** (9) "Mentally incompetent" shall be interpreted as referring to a parent who is unable to discharge parental responsibilities by reason of mental illness, psychopathology, mental retardation or mental deficiency.
District of Columbia	Yes		X	X	X		**DC ST § 16-2353 (1999)** (a) A judge may enter an order for the termination of the parent and child relationship when the judge finds from the evidence presented, after giving due consideration to the interests of all parties, that the termination is in the best interests of the child. (b) In determining whether it is in the child's best interests that the parent and child relationship be terminated, a judge shall consider each of the following factors: (2) the physical, mental and emotional health of all individuals involved to the degree that such affects the welfare of the child, the decisive consideration being the physical, mental and emotional needs of the child.
Florida	No						**F.S.A. § 39.806 (2009)**

(continued)

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Georgia	Yes	X	X	X	X		**Ga. Code Ann., § 15-11-94 (2004)** (a) In considering the termination of parental rights, the court shall first determine whether there is present clear and convincing evidence of parental misconduct or inability as provided in subsection (b) of this Code section. If there is clear and convincing evidence of such parental misconduct or inability, the court shall then consider whether termination of parental rights is in the best interest of the child, after considering the physical, mental, emotional, and moral condition and needs of the child who is the subject of the proceeding, including the need for a secure and stable home. If the court finds clear and convincing evidence of the circumstance provided in paragraph (5) of subsection (b) of this Code section, the court shall presume that termination of parental rights is in the best interest of the child. (b) Except as provided in subsections (e) through (h) of Code Section 15-11-96, the court by order may terminate the parental rights of a parent with respect to the parent's child if:

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(4)(B) In determining whether the child is without proper parental care and control, the court shall consider, without being limited to, the following: (i) A medically verifiable deficiency of the parent's physical, mental, or emotional health of such duration or nature as to render the parent unable to provide adequately for the physical, mental, emotional, or moral condition and needs of the child; (ii) Excessive use of or history of chronic unrehabilitated abuse of intoxicating liquors or narcotic or dangerous drugs or controlled substances with the effect of rendering the parent incapable of providing adequately for the physical, mental, emotional, or moral condition and needs of the child.
Hawaii	Yes	X	X				**HRS § 571-61 (2011)** (b) Involuntary termination. (1) The family courts may terminate the parental rights in respect to any child as to any legal parent: (F) Who is found by the court to be mentally ill or intellectually disabled and incapacitated from giving consent to the adoption of or from providing now and in the foreseeable future the care necessary for the well-being of the child.

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Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Idaho	No						**I.C. § 16-2005 (2005)**
Illinois	Yes	X	X				**750 ILCS 50/1 (2011)** § 1. Definitions. When used in this Act, unless the context otherwise requires: D. "Unfit person" means any person whom the court shall find to be unfit to have a child, without regard to the likelihood that the child will be placed for adoption. The grounds of unfitness are any one or more of the following, except that a person shall not be considered an unfit person for the sole reason that the person has relinquished a child in accordance with the Abandoned Newborn Infant Protection Act: (p) Inability to discharge parental responsibilities supported by competent evidence from a psychiatrist, licensed clinical social worker, or clinical psychologist of mental impairment, mental illness or an intellectual disability as defined in Section 1-116 of the Mental Health and Developmental Disabilities Code, or developmental disability as defined in Section 1-106 of that Code, and there is sufficient justification to believe that the inability to discharge parental responsibilities shall extend beyond a reasonable time period. However, this subdivision (p) shall not be construed so as to permit a licensed clinical social worker to conduct any medical diagnosis to determine mental illness or mental impairment.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							705 ILCS 405/1-2 (1998) (1) The purpose of this Act is to secure for each minor subject hereto such care and guidance, preferably in his or her own home, as will serve the safety and moral, emotional, mental, and physical welfare of the minor and the best interests of the community; to preserve and strengthen the minor's family ties whenever possible, removing him or her from the custody of his or her parents only when his or her safety or welfare or the protection of the public cannot be adequately safeguarded without removal; if the child is removed from the custody of his or her parent, the Department of Children and Family Services immediately shall consider concurrent planning, as described in Section 5 of the Children and Family Services Act so that permanency may occur at the earliest opportunity; consideration should be given so that if reunification fails or is delayed, the placement made is the best available placement to provide permanency for the child; and, when the minor is removed from his or her own family, to secure for him or her custody, care and discipline as nearly as possible equivalent to that which should

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							be given by his or her parents, and in cases where it should and can properly be done to place the minor in a family home so that he or she may become a member of the family by legal adoption or otherwise. Provided that a ground for unfitness under the Adoption Act can be met, it may be appropriate to expedite termination of parental rights: (c) in those extreme cases in which the parent's incapacity to care for the child, combined with an extremely poor prognosis for treatment or rehabilitation, justifies expedited termination of parental rights.
Indiana	No						**IC 31-35-2-4 (2010)**
Iowa	Yes		X				**I.C.A. § 232.116 (2011)** 1. Except as provided in subsection 3, the court may order the termination of both the parental rights with respect to a child and the relationship between the parent and the child on any of the following grounds: k. The court finds that all of the following have occurred: (2) The parent has a chronic mental illness and has been repeatedly institutionalized for mental illness, and presents a danger to self or others as evidenced by prior acts.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Kansas	Yes	X	X	X	X		**K.S.A. 38-2269 (2008)** (a) When the child has been adjudicated to be a child in need of care, the court may terminate parental rights or appoint a permanent custodian when the court finds by clear and convincing evidence that the parent is unfit by reason of conduct or condition which renders
							the parent unable to care properly for a child and the conduct or condition is unlikely to change in the foreseeable future. (b) In making a determination of unfitness the court shall consider, but is not limited to, the following, if applicable: (1) Emotional illness, mental illness, mental deficiency or physical disability of the parent, of such duration or nature as to render the parent unable to care for the ongoing physical, mental and emotional needs of the child.
Kentucky	Yes	X	X				**KRS Section 625.090 (2000)** (3) In determining the best interest of the child and the existence of a ground for termination, the Circuit Court shall consider the following factors: (a) Mental illness as defined by KRS 202A.011(9), or mental retardation as defined by KRS 202B.010(9) of

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							the parent as certified by a qualified mental health professional, which renders the parent consistently unable to care for the immediate and ongoing physical or psychological needs of the child for extended periods of time. **KRS Section 202A.011 (9) (2005)** Mentally ill person means a person with substantially impaired capacity to use self-control, judgment or discretion in the conduct of the person's affairs and social relations, associated with maladaptive behavior or recognized emotional symptoms where impaired capacity, maladaptive behavior, or emotional symptoms can be related to physiological, psychological or social factors. **KRS Section 202B.010 (9) (2005)** Mentally retarded person means a person with significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.
Louisiana	No						**LSA-Ch.C. Art. 1015 (2004)** [Only mention of disability]: The grounds for termination of parental rights are: (i) abuse or neglect which is chronic, life threatening, or results in gravely disabling physical or psychological injury or disfigurement.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Maine	No					Chronic substance abuse problem	**22 M.R.S.A. § 4055 1-A (2009)** The court may presume that the parent is unwilling or unable to protect the child from jeopardy and these circumstances are unlikely to change within a time which is reasonably calculated to meet the child's needs if: (C) The child has been placed in the legal custody or care of the department, the parent has a chronic substance abuse problem, and the parent's prognosis indicates that the child will not be able to return to the custody of the parent within a reasonable period of time, considering the child's age and the need for a permanent home. The fact that a parent has been unable to provide safe care of a child for a period of 9 months due to substance abuse constitutes a chronic substance abuse problem
Maryland	Yes	X	X	X	X		**MD Code, Family Law, § 5-323 (d) (2009)** Except as provided in subsection (c) of this section, in ruling on a petition for guardianship of a child, a juvenile court shall give primary consideration to the health and safety of the child and consideration to all other factors needed to determine whether terminating a parent's rights is in the child's best interests, including: (iii) the existence of a parental disability that makes the parent consistently unable to care

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							for the child's immediate and ongoing physical or psychological needs for long periods of time; and (iv) whether additional services would be likely to bring about a lasting parental adjustment so that the child could be returned to the parent within an ascertainable time not to exceed 18 months from the date of placement unless the juvenile court makes a specific finding that it is in the child's best interests to extend the time for a specified period;
Massachusetts	Yes	X	X			Alcohol or drug addiction	**M.G.L.A. 210 § 3 (2008)** (c) In considering the fitness of the child's parent or other person named in section 2, the court shall consider, without limitation, the following factors: (xii) a condition which is reasonably likely to continue for a prolonged, indeterminate period, such as alcohol or drug addiction, mental deficiency or mental illness, and the condition makes the parent or other person named in section 2 unlikely to provide minimally acceptable care of the child;
Michigan	No						**M.C.L.A. 712A.19b (2010)**
Minnesota	No					Chemical dependency	**M.S.A. § 260C.301 (2010)** The juvenile court may upon petition, terminate all rights of a parent to a child: (b) if it finds that one or more of the following conditions exist:

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(5) that following the child's placement out of the home, reasonable efforts, under the direction of the court, have failed to correct the conditions leading to the child's placement. It is presumed that reasonable efforts under this clause have failed upon a showing that: (iv) reasonable efforts have been made by the social services agency to rehabilitate the parent and reunite the family. It is also presumed that reasonable efforts have failed under this clause upon a showing that: (A) the parent has been diagnosed as chemically dependent by a professional certified to make the diagnosis; (B) the parent has been required by a case plan to participate in a chemical dependency treatment program; (C) the treatment programs offered to the parent were culturally, linguistically, and clinically appropriate; (D) the parent has either failed two or more times to successfully complete a treatment program or has refused at two or more separate meetings with a caseworker to participate in a treatment program; and (E) the parent continues to abuse chemicals.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Mississippi	Yes	X	X		X		**Miss. Code Ann. § 93-15-103 (3) (2003)** Grounds for termination of parental rights shall be based on one or more of the following factors: (e) The parent exhibits ongoing behavior which would make it impossible to return the child to the parent's care and custody: (i) Because the parent has a diagnosable condition unlikely to change within a reasonable time such as alcohol or drug addiction, severe mental deficiencies or mental illness, or extreme physical incapacitation, which condition makes the parent unable to assume minimally, acceptable care of the child;
Missouri	Yes	X	X			Chemical dependency	**V. A. M. S. 211.477 (2003)** 5. The juvenile officer or the division may file a petition to terminate the parental rights of the child's parent when it appears that one or more of the following grounds for termination exist: (2) The child has been abused or neglected. In determining whether to terminate parental rights pursuant to this subdivision, the court shall consider and make findings on the following conditions or acts of the parent: (a) A mental condition which is shown by competent evidence either to be permanent or such that there is no reasonable likelihood

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							that the condition can be reversed and which renders the parent unable to knowingly provide the child the necessary care, custody and control; (b) **Chemical dependency** which prevents the parent from consistently providing the necessary care, custody and control of the child and which cannot be treated so as to enable the parent to consistently provide such care, custody and control; … Nothing in this subdivision shall be construed to permit discrimination on the basis of disability or disease; 10. The disability or disease of a parent shall not constitute a basis for a determination that a child is a child in need of care, for the removal of custody of a child from the parent, or for the termination of parent rights without a specific showing that there is a causal relation between the disability or disease and harm to the child.
Montana	Yes	X	X	X			**MCA 41-3-609 (1) (2005)** The court may order a termination of the parent-child legal relationship upon a finding established by clear and convincing evidence, except as provided in the federal Indian Child Welfare Act, if applicable, that any of the following circumstances exist: (f) the child is an adjudicated youth in need of care and both of the following exist:

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(i) an appropriate treatment plan that has been approved by the court has not been complied with by the parents or has not been successful; and (ii) the conduct or condition of the parents rendering them unfit is unlikely to change within a reasonable time. (2) In determining whether the conduct or condition of the parents is unlikely to change within a reasonable time, the court shall enter a finding that continuation of the parent-child legal relationship will likely result in continued abuse or neglect or that the conduct or the condition of the parents renders the parents unfit, unable, or unwilling to give the child adequate parental care. In making the determinations, the court shall consider but is not limited to the following: (a) emotional illness, mental illness, or mental deficiency of the parent of a duration or nature as to render the parent unlikely to care for the ongoing physical, mental, and emotional needs of the child within a reasonable time;
Nebraska	Yes	X	X			Habitual use of intoxicating liquor or narcotic drugs	**Neb.Rev.St. § 43-292 (2009)** The court may terminate all parental rights between the parents or the mother of a juvenile born out of wedlock and such juvenile when the court finds such action to be in the best

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							interests of the juvenile and it appears by the evidence that one or more of the following conditions exist: (4) The parents are unfit by reason of debauchery, habitual use of intoxicating liquor or narcotic drugs, or repeated lewd and lascivious behavior, which conduct is found by the court to be seriously detrimental to the health, morals, or well-being of the juvenile; (5) The parents are unable to discharge parental responsibilities because of mental illness or mental deficiency and there are reasonable grounds to believe that such condition will continue for a prolonged indeterminate period;
Nevada	Yes	X	X	X			**N.R.S. 128.105, (1999) –** [General statute on the termination of parental rights grounds—no language] **N.R.S. 128.106 (2005)-** [Specific considerations in determining neglect and unfitness] In determining neglect by or unfitness of a parent, the court shall consider, without limitation, the following conditions which may diminish suitability as a parent: 1. Emotional illness, mental illness or mental deficiency of the parent which renders the parent consistently unable to care for the immediate and continuing physical or psychological needs of the child for extended periods of time.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
New Hampshire	Yes	X	X				**N.H. Rev. Stat. § 170-C:5 (2005)** The petition may be granted where the court finds that one or more of the following conditions exist: IV. Because of mental deficiency or mental illness, the parent is and will continue to be incapable of giving the child proper parental care and protection for a longer period of time than would be wise or prudent to leave the child in an unstable or impermanent environment. Mental deficiency or mental illness shall be established by the testimony of either 2 licensed psychiatrists or clinical psychologists or one of each acting together.
New Jersey	Yes	X					**N.J.S.A. 9:2-19 (1990)** (f) If the court shall determine that custody of the child has been surrendered as provided in Article II of this act, the court may declare that the person making such surrender shall have no further right to custody of the child. If the court shall determine that a parent of the child is dead, or mentally incompetent, or has forsaken parental obligation, the court may declare that such parent shall have no further right to custody of the child.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
New Mexico	Yes	X	X		X		**N. M. S. A. 1978, § 32A-4-28 (2005)** A. In proceedings to terminate parental rights, the court shall give primary consideration to the physical, mental and emotional welfare and needs of the child, including the likelihood of the child being adopted if parental rights are terminated. B. The court shall terminate parental rights with respect to a child when: (2) the child has been a neglected or abused child as defined in the Abuse and Neglect Act and the court finds that the conditions and causes of the neglect and abuse are unlikely to change in the foreseeable future despite reasonable efforts by the department or other appropriate agency to assist the parent in adjusting the conditions that render the parent unable to properly care for the child. The court may find in some cases that efforts by the department or another agency are unnecessary, when: (a) there is a clear showing that the efforts would be futile; or (b) the parent has subjected the child to aggravated circumstances; or (3) the child has been placed in the care of others, including care by other relatives, either

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							by a court order or otherwise and the following conditions exist: (a) the child has lived in the home of others for an extended period of time; (b) the parent-child relationship has disintegrated; (c) a psychological parent-child relationship has developed between the substitute family and the child; (d) if the court deems the child of sufficient capacity to express a preference, the child no longer prefers to live with the natural parent; (e) the substitute family desires to adopt the child; and (f) a presumption of abandonment created by the conditions described in Subparagraphs (a) through (e) of this paragraph has not been rebutted. **N. M. S. A. 1978, § 32A-4-2 (2009)** As used in the Abuse and Neglect Act: E. "neglected child" means a child: (4) whose parent, guardian or custodian is unable to discharge that person's responsibilities to and for the child because of incarceration, hospitalization or physical or mental disorder or incapacity;

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							N. M. S. A. 1978, § 32A-4-29 (2009) G. When a child has been in foster care for not less than fifteen of the previous twenty-two months, the department shall file a motion to terminate parental rights, unless: (4) a parent is terminally ill, but in remission, and does not want parental rights to be terminated; provided that the parent has designated a guardian for the child;
New York	Yes	X	X				**NY SOC SERV § 384-b (2010)** 4. An order committing the guardianship and custody of a child pursuant to this section shall be granted only upon one or more of the following grounds: (c) The parent or parents, whose consent to the adoption of the child would otherwise be required in accordance with section one hundred eleven of the domestic relations law, are presently and for the foreseeable future unable, by reason of mental illness or mental retardation, to provide proper and adequate care for a child who has been in the care of an authorized agency for the period of one year immediately prior to the date on which the petition is filed in the court;

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							6. (a) For the purposes of this section, "mental illness" means an affliction with a mental disease or mental condition which is manifested by a disorder or disturbance in behavior, feeling, thinking or judgment to such an extent that if such child were placed in or returned to the custody of the parent, the child would be in danger of becoming a neglected child as defined in the family court act. (b) For the purposes of this section, "mental retardation" means sub-average intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior to such an extent that if such child were placed in or returned to the custody of the parent, the child would be in danger of becoming a neglected child as defined in the family court act. (c) The legal sufficiency of the proof in a proceeding upon the ground set forth in paragraph (c) of subdivision four of this section shall not be determined until the judge has taken the testimony of a psychologist, or psychiatrist, in accordance with paragraph (e) of this subdivision. (d) A determination or order upon a ground set forth in paragraph (c) of subdivision four shall in no way affect any other right, or constitute an adjudication of the legal status of the parent.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(e) In every proceeding upon a ground set forth in paragraph (c) of subdivision four the judge shall order the parent to be examined by, and shall take the testimony of, a qualified psychiatrist or a psychologist licensed pursuant to article one hundred fifty-three of the education law as defined in section 730.10 of the criminal procedure law in the case of a parent alleged to be mentally ill or retarded, such psychologist or psychiatrist to be appointed by the court pursuant to section thirty-five of the judiciary law. The parent and the authorized agency shall have the right to submit other psychiatric, psychological or medical evidence. If the parent refuses to submit to such court-ordered examination, or if the parent renders himself unavailable therefore whether before or after the initiation of a proceeding under this section, by departing from the state or by concealing himself therein, the appointed psychologist or psychiatrist, upon the basis of other available information, including, but not limited to, agency, hospital or clinic records, may testify without an examination of such parent, provided that such other information affords a reasonable basis for his opinion.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
North Carolina	Yes	X	X			Substance abuse	**N.C.G.S.A. § 7B-1111(2007)** (a) The court may terminate the parental rights upon a finding of one or more of the following: (6) That the parent is incapable of providing for the proper care and supervision of the juvenile, such that the juvenile is a dependent juvenile within the meaning of G.S. 7B-101, and that there is a reasonable probability that such incapability will continue for the foreseeable future. Incapability under this subdivision may be the result of substance abuse, mental retardation, mental illness, organic brain syndrome, or any other cause or condition that renders the parent unable or unavailable to parent the juvenile and the parent lacks an appropriate alternative child care arrangement.
North Dakota	Yes	X	X	X	X	Other illness or disability	**ND ST § 27-20-02** (d) [A deprived child is defined as one who] is without proper parental care, control, or education as required by law, or other care and control necessary for the child's well-being because of the physical, mental, emotional, or other illness or disability of the child's parent or parents, and that such lack of care is not due to a willful act of commission or act of omission by the child's parents, and care is requested by a parent;

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							ND ST § 27-20-44 (1) The court by order may terminate the parental rights of a parent with respect to the parent's child if: (c) The child is a deprived child…
Ohio	Yes	X	X	X	X	Chemical dependency	**OH R.C. § 2151.414** A.(2) If all of the following apply, permanent custody is in the best interest of the child…: (a) The court determines by clear and convincing evidence that one or more of the factors in division (E) of this section exist... (E) (2) Chronic mental illness, chronic emotional illness, mental retardation, physical disability, or chemical dependency of the parent that is so severe that it makes the parent unable to provide an adequate permanent home for the child…
Oklahoma	Yes	X	X	X	X		**10A Okl.St.Ann. § 1-4-90413** A finding that all of the following exist: (a) the parent has a diagnosed cognitive disorder, an extreme physical incapacity, or a medical condition, including behavioral health which renders the parent incapable of adequately and appropriately exercising parental rights, duties, and responsibilities within a reasonable time considering the age of the child, and (b) allowing the parent to have custody would cause the child actual harm or harm in the near future.

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							A parent's refusal or pattern of noncompliance with treatment, therapy, medication, or assistance from outside the home can be used as evidence that the parent is incapable of adequately and appropriately exercising parental rights, duties, and responsibilities. A finding that a parent has a diagnosed cognitive disorder, an extreme physical incapacity, or a medical condition, including behavioral health or substance dependency shall not in and of itself deprive the parent of parental rights.
Oregon	No						
Pennsylvania	No						
Rhode Island	No						
South Carolina	Yes	X	X		X	Alcohol or drug addiction	**Code 1976 § 63-7-2570** The family court may order the termination of parental rights upon a finding of one or more of the following grounds and a finding that termination is in the best interest of the child: (6) The parent has a diagnosable condition unlikely to change within a reasonable time including, but not limited to, alcohol or drug addiction, mental deficiency, mental illness, or extreme physical incapacity, and the condition makes the parent unable or unlikely to

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							provide minimally acceptable care of the child. It is presumed that the parent's condition is unlikely to change within a reasonable time upon proof that the parent has been required by the department or the family court to participate in a treatment program for alcohol or drug addiction, and the parent has failed two or more times to complete the program successfully or has refused at two or more separate meetings with the department to participate in a treatment program.
South Dakota	No						
Tennessee	Yes	X	X	X			**T.C.A. § 36-1-113** (8)(A) The chancery and circuit courts shall have jurisdiction in an adoption proceeding, and the chancery, circuit, and juvenile courts shall have jurisdiction in a separate, independent proceeding conducted prior to an adoption proceeding to determine if the parent or guardian is mentally incompetent to provide for the further care and supervision of the child, and to terminate that parent's or guardian's rights to the child; (B) The court may terminate the parental or guardianship rights of that person if it determines on the basis of clear and convincing evidence that:

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(i) The parent or guardian of the child is incompetent to adequately provide for the further care and supervision of the child because the parent's or guardian's mental condition is presently so impaired and is so likely to remain so that it is unlikely that the parent or guardian will be able to assume or resume the care of and responsibility for the child in the near future; and (ii) That termination of parental or guardian rights is in the best interest of the child; (C) In the circumstances described under subdivisions (8)(A) and (B), no willfulness in the failure of the parent or guardian to establish the parent's or guardian's ability to care for the child need be shown to establish that the parental or guardianship rights should be terminated;
Texas	Yes	X	X	X			**V.T.C.A., Family Code § 161.003** (a) The court may order termination of the parent-child relationship in a suit filed by the Department of Protective and Regulatory Services if the court finds that: (1) the parent has a mental or emotional illness or a mental deficiency that renders the parent unable to provide for the physical, emotional, and mental needs of the child;

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State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							(2) the illness or deficiency, in all reasonable probability, proved by clear and convincing evidence, will continue to render the parent unable to provide for the child's needs until the 18th birthday of the child;
Utah	Yes*						**U.C.A. 1953 § 78A-6-507** (1) The court may terminate all parental rights with respect to a parent if the court finds any one of the following: (c) that the parent is unfit or incompetent [The language is so vague it could mean any disability, but none is stated directly.]
Vermont	No						
Virginia	Yes	X	X	X			**VA Code Ann § 16.1-283** (A) The residual parental rights of a parent or parents may be terminated by the court as hereinafter provided in a separate proceeding if the petition specifically requests such relief… (a) The parent or parents are suffering from a mental or emotional illness or mental deficiency of such severity that there is no reasonable expectation that such parent will be able to undertake responsibility for the care needed by the child in accordance with his age and stage of development;

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Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
Washington	Yes	X	X				**West's RCWA § 13.34.180** (1) A petition seeking termination of a parent and child relationship may be filed in juvenile court by any party to the dependency proceedings concerning that child. (e) That there is little likelihood that conditions will be remedied so that the child can be returned to the parent in the near future…In determining whether the conditions will be remedied the court may consider, but is not limited to, the following factors: (ii) Psychological incapacity or mental deficiency of the parent that is so severe and chronic as to render the parent incapable of providing proper care for the child for extended periods of time or for periods of time that present a risk of imminent harm to the child, and documented unwillingness of the parent to receive and complete treatment or documentation that there is no treatment that can render the parent capable of providing proper care for the child in the near future….
West Virginia	Yes	X	X	X			**W. VA. Code § 49-6-5** (a) Following a determination pursuant to section two of this article wherein the court finds a child to be abused or neglected, the department shall file with the court a copy

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							of the child's case plan, including the permanency plan for the child.... The court shall give precedence to dispositions in the following sequence:...(6) Upon a finding that there is no reasonable likelihood that the conditions of neglect or abuse can be substantially corrected in the near future and, when necessary for the welfare of the child, terminate the parental, custodial and guardianship rights and responsibilities of the abusing parent...(b) As used in this section, "no reasonable likelihood that conditions of neglect or abuse can be substantially corrected" shall mean that...(6) The abusing parent or parents have incurred emotional illness, mental illness or mental deficiency of such duration or nature as to render such parent or parents incapable of exercising proper parenting skills or sufficiently improving the adequacy of such skills.
Wisconsin	Yes	X	X	X			**W.S.A. § 48.415** (3) Continuing parental disability. Continuing parental disability, which shall be established by proving that: (a) The parent is presently, and for a cumulative total period of at least 2 years within the 5 years immediately prior to the filing of the petition has been, an inpatient at

(continued)

Appendix B. (continued)

State	Disability as Grounds for Termination of Parental Rights	Intellectual or Developmental Disability	Mental Illness	Emotional Disability	Physical Disability	Other	Citation and Language
							one or more hospitals... (c) licensed treatment facilities …or state treatment facilities…on account of mental illness…or…developmental disability…or other like incapacities…; (b) The condition of the parent is likely to continue indefinitely; and (c) The child is not being provided with adequate care by a relative who has legal custody of the child, or by a parent or a guardian.
Wyoming	No						-

Appendix C. Model Legislation (State or Federal)

AN ACT TO PRESERVE FAMILIES THAT INCLUDE A PARENT WITH A DISABILITY

(a) Findings

Congress finds that—

(1) a primary motivation in enactment of the Americans with Disabilities Act (ADA) was to end the subjection of people with disabilities to eugenics-inspired policies during the 20th century that deprived them of their fundamental right to procreate and raise their children;

(2) in enacting the ADA, Congress sought to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities";

(3) while Congress expected that the Americans with Disabilities Act, and the regulations promulgated thereunder, would protect the 14th Amendment rights of individuals with disabilities to procreate and raise children, and the right of those children to be free from discrimination based on their association with a person with a disability (their parent), that expectation has not been fulfilled;

(4) 37 of the 50 states have promulgated child welfare statutes codifying parental disability as a separate and distinct basis upon which the state may seize and detain children and terminate parental rights; and child custody laws, using the best interest of the child standard, regularly deny parents' custody of a child on the basis of parental disability, with little or no evidence of a nexus between disability and detriment to the child;

(5) the holding in *In re Christina A.*, 261 Cal. Rptr. 903 (Cal. Ct. App. 1989) that disability-based exceptions to the due process requirements for reunification services in child welfare cases are constitutional and do not violate due process or equal protection and are not vague;

(6) the holding in *In re Doe*, 100 Haw. 335 (2002) that the Americans with Disabilities Act is never a defense to termination of parental rights;

(7) the holding in *Adams v. Monroe County Dept. of Social Services*, 21 F.Supp.2d 235 (W.D.N.Y. 1998) that totally unregulated discretion is vested with adoption agencies to determine whether a prospective parent's disability is a legitimate barrier to adoption;

(8) that the states, exercising their recognized jurisdiction over child custody proceedings through administrative and judicial bodies, have often failed to provide accommodation as required pursuant to the ADA, while implementing and upholding invidious classification;

(9) as a result, an alarming number of families are unnecessarily broken up by the loss of custody or parental rights, and many prospective parents with disabilities are unable to build families through assisted reproductive

technologies or adoption, based largely on the disability of the parent or prospective parent;

(b) Purposes

The purpose of this act is—

(1) to protect the best interests of children parented by people with disabilities by preserving their families, and to protect the rights of people with disabilities to procreate and raise children, through the establishment of minimum standards requiring adherence to the ADA and respect for the due process and equal protection rights of this population of parents in the context of child welfare, family law, adoption, and probate guardianship cases.

§ _____. Definitions

As used in this chapter:

(1) "adaptive parenting equipment" includes any piece of equipment or any item that is used to increase, maintain, or improve the parenting capabilities of a parent with a disability.

(A) acquisition or modification of such equipment or devices.

(2) "adaptive techniques" are defined as strategies for accomplishing child care tasks that enable parents with disabilities to execute the task safely for themselves and their children. Adaptive techniques can be useful alone or in conjunction with equipment.

(3) "adoption" refers to the legal process by which a minor child and each adoptive parent gain the legal relationship of parent and child and have all the rights and duties of that relationship under law.

(4) "assisted reproductive technologies" include a wide range of medical technologies designed to treat infertility or otherwise assist with conception, such as drug or hormone therapy, artificial insemination by husband (AIH), artificial insemination by donor (AID), in vitro fertilization (IVF), or surrogacy.

(5) "child custody proceedings" includes any action in which a third party is seeking to take custody of a child from its parent where the parent cannot have the child returned upon demand, up to and including the termination of the parent's custody or visitation rights in either family court child custody or probate court guardianship or adoption cases.

(6) "child welfare proceeding" includes any action in which the state is removing a child from his or her parent pursuant to the *parens patriae* power of the state where the parent cannot have the child returned upon demand, up to and including the termination of the parent's parental rights occurring in a juvenile court.

(7) "disability" means a physical or mental impairment that substantially limits one or more of the major life activities of an individual, a record of such impairment, or being regarded as having such an impairment. This definition must be broadly interpreted, consistent with the ADA Amendments Act of 2008.

(8) "preventive services" include services designed to address the specific needs of a parent, including any needs that may be related to the parent's disability, in order to prevent the removal of the child from the parent.

(9) "reunification services" include services designed to address the specific needs of a parent whose child has been removed from the home as a result of abuse or neglect, including any needs that may be related to the parent's disability, and to make it possible for the child to return safely to the parent.

(10) "supportive parenting services" include services that help parents with a disability compensate for those aspects of the disability

that affect their ability to care for their children and that will enable them to discharge their parental responsibilities. The term includes specialized or adapted training, evaluations, and assistance with effective use of adaptive equipment, as well as accommodations that allow a parent with a disability to benefit from other services, such as braille text or sign language interpreters.

(A) other similar services and actions.

(1) State

The term "state" means each of the several states, the District of Columbia, the Commonwealth of Puerto Rico, Guam, American Samoa, the Virgin Islands of the United States, the Trust Territory of the Pacific Islands, and the Commonwealth of the Northern Mariana Islands. [RELEVANT FOR FEDERAL, NOT FOR STATE]

§_____. Discrimination in Access to Assisted Reproductive Technologies, Child-Rearing, and Adoption

(a) General Rule

No covered entity shall deny a person access to assisted reproductive technologies, adoption services, or the right to custody and control of their child solely on the basis of the person's disability or the disability of the child in the latter case, and the states shall render appropriate assistance to parents with disabilities in the performance of their child-rearing responsibilities.

(b) Construction

As used in subsection (a) of this section, the phrase "solely on the basis of the person's disability" includes—

(1) promulgating, implementing, or enforcing state child welfare, family, or probate guardianship statutes that create special grounds or policies for the removal and detention of children from a parent owing to the parent's disability, or the termination of the parental rights of, or the denial of custody or visitation to, a parent with a disability, solely on the basis of the parent's disability;

(2) refusal to accommodate parents with disabilities in the child welfare system, family law, or probate courts, as required by 42 U.S.C. §12131, et seq.; or

(3) engaging in policies that have the effect of denying people with disabilities access to assisted reproductive technologies or adoption solely on the basis of their disability;

(4) participating in a contractual or other arrangement or relationship that has the effect of subjecting a parent with a disability or a child of such a parent to the discrimination prohibited by this subchapter;

(5) using standards, criteria, or methods of administration—

(A) that have the effect of discrimination on the basis of disability; or

(B) that perpetuate the discrimination of others who are subject to common administrative control.

(c) Access to Assisted Reproductive Technologies

(1) Providers of assisted reproductive technologies (ART) shall not deny prospective parents with disabilities access to their services solely on the basis of a disability, or on speculation that the disability will render them unfit, without consideration of whether adaptive parenting equipment and/or supportive services could enable them to adequately parent, and providers should secure consultation where they lack expertise on adaptive parenting equipment and/or supportive services;

(2) a provider who chooses to deny ART to a prospective parent with a disability based in

whole or in part on the belief that the disability renders the person unfit to parent must provide the prospective parent with a written statement to that effect.

(d) Medical/Psychological Assessment and Evaluation

(1) Psychiatrists and psychologists performing assessments or evaluations in the context of child welfare, family, or probate guardianship cases shall ensure that the measures they administer are intended for use with the disability population of which the parent is a member; and

(2) shall include as part of any evaluation or assessment of parental capacity or fitness observation of the parent and child, so long as this will not affect the physical or psychological safety of the child;

(3) shall include as part of any evaluation or assessment of parental capacity or fitness an inquiry into how adaptive parenting equipment and/or supportive services for parents with disabilities might affect the capacity or fitness of the parent; and

(4) shall be familiar with adaptive parenting equipment, supportive services, and/or the assessment and evaluation of people with disabilities, or secure consultation or assistance if they lack such familiarity.

(e) Court Proceedings Generally

(1) In family law, child welfare, or probate guardianship proceedings in which a parent with a disability may lose custody or visitation of a child, a parent with an intellectual or psychiatric disability that renders him or her unable to meaningfully participate in court proceedings shall be provided with appointed counsel from the time of the initial court hearing;

(2) Evidence regarding the role that adaptive parenting equipment and/or supportive parenting services can play in improving the parental fitness and/or capacity of parents with disabilities is relevant and admissible;

(3) Where parental disability is alleged to have a detrimental impact on the child, the party raising the allegation bears the burden of proving a causal relationship and the detriment by clear and convincing evidence;

(4) Should a court decide that disability is a relevant factor in a custody or visitation determination in child welfare, family, or probate guardianship proceedings, the court shall provide a written decision as to that issue.

(f) Parents with Disabilities in Child Welfare Cases Specifically

To ensure compliance with the ADA and protect the 14th Amendment rights of parents with disabilities and their families, a covered entity—

(1) shall make inquiries into and document the disability status of the parent when a child is detained, to ensure that the parent is provided with appropriate accommodations during the child welfare process;

(2) shall not order foster care placement in the absence of a determination, supported by clear and convincing evidence that includes testimony of qualified expert witnesses, that the continued custody of the child by the parent or custodian with a disability is likely to result in serious emotional or physical damage to the child;

(3) shall not order termination of parental rights in the absence of a determination, supported by evidence beyond a reasonable doubt that includes testimony of qualified expert witnesses, that the continued custody of the child by the parent or custodian with a disability is likely to result in serious emotional or physical damage to the child;

(4) shall provide reasonable accommodations to parents with disabilities with regard to placement and visitation decisions; preventive, maintenance, and reunification services; and evaluation or assessment of parenting capacity, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the entity;

(5) shall include a comprehensive array of preventive, maintenance, and reunification services that may be necessary to address a parent's disability, such as supportive housing, assertive community treatment, crisis services, peer supports, household management training, homemaker services, substance abuse services, occupational therapy and parenting skills training, adaptive parenting equipment, and adaptive parenting technique training that is tailored to address the parent's specific needs, and other supportive parenting services;

(6) shall not deny parents with disabilities reunification services solely on the basis of their disability or speculation regarding the impact of their disability on their capacity or fitness to parent, or require them to submit to additional testing to qualify for reunification services provided to nondisabled parents without additional testing;

(7) a covered entity must provide evidence of active efforts to prevent the removal of a child or termination of parental rights of a parent with a disability where the parental disability is alleged to have a detrimental effect on the well-being of the child; and

(8) where there has been a finding of a failure by the covered entity to accommodate a parent with a disability during the pendency of proceedings, the Americans with Disabilities Act is a defense to termination of parental rights.

(g) Prospective Adoptive Parents with Disabilities

(1) Providers of adoption services shall not deny prospective parents with disabilities access to their services solely on the basis of disability or on speculation that the disability will render them unfit, without consideration of whether adaptive parenting equipment and/or supportive services could enable them to adequately parent, and providers should secure consultation where they lack expertise on adaptive parenting equipment and/or supportive services;

(2) where it is alleged that the prospective adoptive parent's disability will have a detrimental impact on the child, the party raising the allegation bears the burden of proving that causal relationship and the detriment by clear and convincing evidence;

(3) an adoption services provider who chooses to deny a prospective parent with a disability the opportunity to adopt based in whole or in part on their belief that the disability renders the person unfit to parent must provide the prospective parent with a written statement to that effect.

(h) Access to Child-Centered Facilities and Programs

(1) Parents with disabilities must be afforded meaningful access, and accommodations to facilitate that access, to daycare and school facilities, including preschool.

Appendix D. Proposed ADA Amendment

Title 42. The Public Health and Welfare

Chapter 126. Equal Opportunity for Individuals with Disabilities

Subchapter V. Respect for Home and Family

§§12214. Discrimination Against People with Disabilities in Parenting

§12214. Findings and Purpose.

(a) Findings.

Congress finds that—

(1) a primary motivation in enactment of the ADA was to address the subjection of people with disabilities to eugenics-inspired policies during the 20th century that deprived them of their fundamental right to procreate and raise their children;

(2) in enacting the ADA, Congress sought to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities";

(3) while Congress expected that 42 USC §12132, and the regulations promulgated thereunder, would protect the 14th Amendment rights of people with disabilities to procreate and raise children, and the right of those children to be free from discrimination based on their association with a person with a disability (their parent), that expectation has not been fulfilled;

(4) 37 of the 50 states have promulgated child welfare or child custody statutes codifying parental disability as a separate and distinct basis upon which the state may seize and detain children, terminate parental rights, or deny custody of a child, with little or no requirement that the state prove a nexus between disability and detriment to the child;

(5) the holding in *In re Christina A.*, 261 Cal. Rptr. 903 (Cal. Ct. App. 1989) that disability-based exceptions to the due process requirements for reunification services in child welfare cases are constitutional and do not violate due process or equal protection and are not vague;

(6) the holding in *In re Doe*, 100 Haw. 335 (2002) that the Americans with Disabilities Act is never a defense to termination of parental rights;

(7) the holding in *Adams v. Monroe County Dept. of Social Services*, 21 F.Supp.2d 235 (W.D.N.Y.1998) that totally unregulated discretion is vested with adoption agencies to determine whether a prospective parent with a disability can ever adopt;

(8) that the states, exercising their recognized jurisdiction over child custody proceedings through administrative and judicial bodies, have often failed to provide accommodation as required pursuant to the ADA, while implementing and upholding invidious classification;

(9) as a result, an alarming number of families are broken up by the loss of custody or parental

rights, often unwarranted, largely on the basis of the disability of the parent;

(b) Purpose.

The purpose of this act is—

(1) to protect the best interests of children parented by a person with a disability by preserving the family and to protect the rights of people with disabilities to procreate and raise children through the establishment of minimum standards requiring adherence to the ADA and respect for the due process and equal protection rights of this population of parents in the context of child welfare, family law, and probate guardianship cases.

§12215. Definitions.

As used in this chapter:

(1) "adaptive parenting equipment" includes any piece of equipment or any item that is used to increase, maintain, or improve the parenting capabilities of a parent with a disability.

(A) acquisition or modification of such equipment or devices.

(2) "adaptive techniques" are defined as strategies for accomplishing child care tasks that enable parents with disabilities to execute the task safely for themselves and their child. Adaptive techniques can be useful alone or in conjunction with equipment.

(3) "adoption" refers to the legal process by which a minor child and each adoptive parent gain the legal relationship of parent and child and have all the rights and duties of that relationship under law.

(4) "assisted reproductive technologies" include a wide range of medical technologies designed to treat infertility or otherwise assist with conception, such as drug or hormone therapy, artificial insemination by husband (AIH), artificial insemination by donor (AID), in vitro fertilization (IVF), or surrogacy.

(5) "child custody proceedings" includes any action where a third party is seeking to take custody of a child from its parent where the parent cannot have the child returned upon demand, up to and including the termination of the parent's custody or visitation rights in either family court child custody, or probate court guardianship or adoption cases.

(6) "child welfare proceeding" includes any action where the state is removing a child from its parent pursuant to the *parens patriae* power of the state where the parent cannot have the child returned upon demand, up to and including the termination of the parent's parental rights occurring in a juvenile court.

(7) "disability" means a physical or mental impairment that substantially limits one or more of the major life activities of an individual, a record of such impairment or being regarded as having such an impairment. This definition must be broadly interpreted, consistent with the ADA Amendments Act of 2008.

(8) "preventive services" include services designed to address the specific needs of a parent, including any needs that may be related to the parent's disability, in order to prevent the removal of the child from the parent.

(9) "reunification services" include services designed to address the specific needs of a parent whose child has been removed from the home as a result of abuse or neglect, including any needs that may be related to the parent's disability, and to make it possible for the child to return safely to the parent.

(10) "supportive parenting services" include services that help parents with a disability compensate for those aspects of the disability

that affect their ability to care for their children and that will enable them to discharge their parental responsibilities. The term includes specialized or adapted training, evaluations, and assistance with effective use of adaptive equipment, as well as accommodations that allow a parent with a disability to benefit from other services, such as braille text or sign language interpreters.

(A) other similar services and actions.

§12216. Discrimination.

(a) General rule.

No covered entity shall deny a person access to assisted reproductive technologies, adoption, or the right to custody and control of their child solely on the basis of the person's disability or the disability of the child in the latter case, and the states shall render appropriate assistance to parents with disabilities in the performance of their child-rearing responsibilities.

(b) Construction.

As used in subsection (a) of this section, the term "solely on the basis of the person's disability" includes –

(1) promulgating, implementing, or enforcing state child welfare, family, or probate guardianship statutes that create special grounds or policies for the removal and detention of children from a parent owing to the parent's disability, or the termination of the parental rights of, or the denial of custody or visitation to, a parent with a disability, solely on the basis of the parent's disability;

(2) refusal to accommodate parents with disabilities in the child welfare system, family law, or probate courts, as required by 42 U.S.C. §12131, et seq.; or

(3) engaging in policies that have the effect of denying people with disabilities access to assisted reproductive technologies solely on the basis of their disability;

(4) participating in a contractual or other arrangement or relationship that has the effect of subjecting a parent with a disability or a child of such a parent to the discrimination prohibited by this subchapter;

(5) using standards, criteria, or methods of administration--

(A) that have the effect of discrimination on the basis of disability; or

(B) that perpetuate the discrimination of others who are subject to common administrative control.

§12217. Access to Assisted Reproductive Technologies

(a) Providers of assisted reproductive technologies (ART) shall not deny prospective parents with disabilities access to their services solely on the basis of a disability, or on speculation that the disability will render them unfit, without consideration of whether adaptive parenting equipment and/or supportive services could enable them to adequately parent, and providers should secure consultation where they lack expertise on adaptive parenting equipment and/or supportive services;

(b) a provider who chooses to deny ART to a prospective parent with a disability based in whole or in part on their belief that the disability renders the person unfit to parent must provide the prospective parent with a written statement to that effect.

§12218. Medical and Psychological Assessment and Evaluation.

(a) Psychiatrists and psychologists performing assessments or evaluations in the context of child welfare, family, or probate guardianship cases shall ensure that the measures they

administer are intended for use with the disability population of which the parent is a member; and

(b) shall include as part of any evaluation or assessment of parental capacity or fitness observation of the parent and child, so long as this will not affect the physical or psychological safety of the child;

(c) shall include as part of any evaluation or assessment of parental capacity or fitness an inquiry into how adaptive parenting equipment and/or supportive services for parents with disabilities might affect the capacity or fitness of the parent; and

(d) shall be familiar with adaptive parenting equipment, supportive services, and/or the assessment and evaluation of people with disabilities, or secure consultation or assistance if they lack such familiarity.

§12219. Court Proceedings.

(a) In family law, child welfare, or probate guardianship proceedings in which a parent with a disability may lose custody or visitation of a child, a parent with an intellectual or psychiatric disability that renders him or her unable to meaningfully participate in court proceedings shall be provided with appointed counsel from the time of the initial court hearing;

(b) Evidence regarding the role that adaptive parenting equipment and/or supportive parenting services can play in improving the parental fitness and/or capacity of parents with disabilities is relevant and admissible;

(c) Where parental disability is alleged to have a detrimental impact on the child, the party raising the allegation bears the burden of proving a causal relationship and the detriment by clear and convincing evidence;

(d) Should a court decide that disability is a relevant factor in a custody or visitation determination in child welfare, family, or probate guardianship proceedings, the court shall provide a written decision as to that issue;

§12220. Parents with Disabilities in Child Welfare Cases Specifically.

To ensure compliance with the ADA and protect the 14th Amendment rights of parents with disabilities and their families, a covered entity—

(1) shall make inquiries into and document the disability status of the parent when a child is detained, to ensure that the parent is provided with appropriate accommodations during the child welfare process;

(2) shall not order foster care placement in the absence of a determination, supported by clear and convincing evidence that includes testimony of qualified expert witnesses, that the continued custody of the child by the parent or custodian with a disability is likely to result in serious emotional or physical damage to the child;

(3) shall not order termination of parental rights in the absence of a determination, supported by evidence beyond a reasonable doubt that includes testimony of qualified expert witnesses, that the continued custody of the child by the parent or custodian with a disability is likely to result in serious emotional or physical damage to the child.

(4) shall provide reasonable accommodations to parents with disabilities with regard to placement and visitation decisions; preventive, maintenance, and reunification services; and evaluation or assessment of parenting capacity, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the entity;

(5) shall include a comprehensive array of preventive, maintenance, and reunification

services that may be necessary to address a parent's disability, such as supportive housing, assertive community treatment, crisis services, peer supports, household management training, homemaker services, substance abuse services, occupational therapy and parenting skills training, adaptive parenting equipment and adaptive parenting technique training that is tailored to address the parent's specific needs, and other supportive parenting services.

(6) shall not deny parents with disabilities reunification services solely on the basis of their disability or speculation regarding the impact of their disability on their capacity or fitness to parent, or require them to submit to additional testing to qualify for reunification services provided to nondisabled parents without additional testing;

(7) a covered entity must provide evidence of active efforts to prevent the removal of a child or termination of parental rights of a parent with a disability where the parental disability is alleged to have a detrimental effect on the well-being of the child; and

(8) where there has been a finding of a failure by the covered entity to accommodate a parent with a disability during the pendency of proceedings, the Americans with Disabilities Act is a defense to termination of parental rights.

§12221. Adoption.

(a) Providers of adoption services shall not deny prospective parents with disabilities access to their services solely on the basis of disability or on speculation that the disability will render them unfit, without consideration of whether adaptive parenting equipment and/or supportive services could enable them to adequately parent, and providers should secure consultation where they lack expertise on adaptive parenting equipment and/or supportive services;

(b) where it is alleged that the prospective adoptive parent's disability will have a detrimental impact on the child, the party raising the allegation bears the burden of proving that causal relationship and the detriment by clear and convincing evidence;

(c) an adoption services provider who chooses to deny a prospective parent with a disability the opportunity to adopt based in whole or in part on their belief that the disability renders the person unfit to parent must provide the prospective parent with a written statement to that effect.

§12222. Access to Facilities and Programs

(a) Parents with disabilities must be afforded meaningful access, and accommodations to facilitate that access, to daycare and school facilities, including preschool.

§12223. Regulations.

(a) Generally.

Not later than 1 year after _____, the Attorney General shall issue regulations in an accessible format to carry out this section.

(b) Relationship to Other Regulations

Regulations under subsection (a) of this section shall be consistent with this chapter and with the coordination regulations under part 41 of title 28, Code of Federal Regulations

(c) Standards.

Regulations under subsection (a) of this section shall include standards applicable to public and private entities covered by Titles II and III of the Americans with Disabilities Act.

§12224. Severability.

Should any provision in this chapter be found to be unconstitutional by a court of law, such provision shall be severed from the remainder of this chapter and such action shall not affect the enforceability of the remaining provisions of this chapter.

Endnotes

1 Jennifer Thomas, mother of seven-year-old twins Abigail and Noah. Jennifer is a wheelchair user with cerebral palsy.
2 Carl H. Coleman, "Conceiving Harm: Disability Discrimination in Assisted Reproductive Technologies," *UCLA Law Review* 50 (2002): 24.
3 Michael G. Silver, "Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History," *George Washington Law Review* 72 (2004): 862, 864.
4 Paul A. Lombardo, "Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom," *Journal of Contemporary Health and Policy* 13 (1996): 1, 3.
5 Paul A. Lombardo, *Three Generations, No Imbeciles: Eugenics, the Supreme Court, and Buck v. Bell* (Baltimore, MD: John Hopkins University Press, 2008).
6 *Buck v. Bell*, 274 U.S. 200 (1927).
7 *Id.* at 205.
8 *Id.*
9 *Id.* at 206.
10 *Id.* at 208.
11 *Estate of C.W.*, 640 A.2d 427 (Pa. Super. Ct. 1994), cert. denied, 115 S. Ct. 1175 (1995).
12 *Vaughn v. Ruoff*, 253 F.3d 1124 (8th Cir. 2001).
13 *Id.* at 1129.
14 The following states retain dangerous and offensive statutory language that authorizes a court to order the involuntary sterilization of a person with a disability: Arkansas (Ark. Code Ann. §20-49-101); Colorado (Colo. Rev. Stat. §27-10.5-130); Delaware (16 Del.C. §5712); Georgia (Ga. Code. Ann. §31-20-3); Maine (34-B M.R.S.A. §7010); North Carolina (N.C.G.S.A. §35A-1245); Oregon (O.R.S. §436.205); Utah (U.C.A. 1953 §62A-6-102); Vermont (18 V.S.A. §8705 et seq.); Virginia (Va. Code Ann. §54.1-2975 et seq.); West Virginia (W.Va. Code, §27-16-1 et seq. (uses especially offensive language regarding the best interests of society).
15 Ed Pikington and Karen McVeigh, "'Ashley Treatment' on the Rise Amid Concerns from Disability Rights Groups," *The Guardian*, March 15, 2012, http://www.guardian.co.uk/society/2012/mar/15/ashley-treatment-rise-amid-concerns/print.
16 *Guardianship of Mary Moe*, 960 N.E.2d 350 (Mass. App. Ct. 2012).
17 Craig Hemmens et al., "The Consequences of Official Labels: An Examination of the Rights Lost by the Mentally Ill and Mentally Incompetent Ten Years Later," *Community Mental Health Journal* 38(2) (2002): 136.
18 *Id.*
19 Law Students for Reproductive Justice, "Women with Disabilities," accessed November 15, 2011, http://lsrj.org/documents/11_Women with Disabilities.pdf.
20 Michael Ashley Stein, "Mommy Had a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities," *Brooklyn Law Review* 60 (1994): 1073.
21 *Id.* at 1074.
22 *Id.* at 1075.

23 Elizabeth Lightfoot, Katharine Hill, and Traci LaLiberte, "The Inclusion of Disability as a Condition for Termination of Parental Rights," *Child Abuse and Neglect* 34 (2010): 928.
24 Corbett Joan O'Toole and Tanis Doe, "Sexuality and Disabled Parents with Disabled Children," *Sexuality and Disability* 20 (2002): 90.
25 Pseudonym used to protect confidentiality. E-mail, February 28, 2012.
26 Carrie Killoran, "Women with Disabilities Having Children: It's Our Right Too," *Sexuality and Disability* 12 (1994): 122.
27 O'Toole and Doe, *Supra* note 24, 90.
28 Pseudonym used to protect confidentiality. Telephone conversation, January 20, 2012.
29 Pseudonym used to protect confidentiality. Telephone conversation, October 12, 2011.
30 Kara Ayers, "Anything for Baby," *New Mobility*, February 2011, accessed November 30, 2011, http://www.newmobility.com/articleView.cfm?id=11807.
31 *Id.*
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1313 *See Cleburne v. Cleburne Living Center*, 473 U.S. at 439.

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1315 Americans with Disabilities Act 42 U.S.C.A. §12131 et seq.; Rehabilitation Act of 1973, as amended, 29 U.S.C.A. §794; Regulations for the Rehabilitation Act of 1973, as amended, 45 C.F.R. §84.4 et seq.; Regulations for the Americans with Disabilities Act, 28 C.F.R. §35.130 et seq.

1316 *Egelhoff v. Egelhoff ex rel. Breiner*, 532 U.S. 141, 151–152 (2001); *Hisquierdo v. Hisquierdo*, 439 U.S. 572, 581, 99 S.Ct. 802, 59 L.Ed.2d 1 (1979); *Boggs v. Boggs*, 520 U.S. 833, 117 S.Ct. 1754, 138 L.Ed.2d 45 (1997) (holding that ERISA preempts a state community property law permitting the testamentary transfer of an interest in a spouse's pension plan benefits).

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