

**FIRST DISTRICT APPELLATE PROJECT
TRAINING SERIES**

February 23, 2022

February 25, 2022

March 3, 2022

March 4, 2022



**REPRESENTING PARENTS WITH DISABILITIES IN
DEPENDENCY PROCEEDINGS: AN OVERVIEW OF RELEVANT
CASE LAW AND FEDERAL AND STATE DISABILITY
PROTECTIONS**

A Joint Presentation:

**AYESHA E. LEWIS, STAFF ATTORNEY
DISABILITY RIGHTS & EDUCATION DEFENSE FUND**

**LOUISE E. COLLARI, STAFF ATTORNEY
FIRST DISTRICT APPELLATE PROJECT**

March 3, 2022

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Representing Parents with Disabilities in Dependency Proceedings: An Overview of Relevant Case Law and Federal and State Disability Protections

Overview: Parents with Disabilities

Greater risks for parents with disabilities

There are more than 4 million parents with disabilities in the U.S. (National Council on Disability, 2012). (Parents with Disabilities in Child Welfare Agencies and Courts. www.adata.org.)

Parents with disabilities are at higher risk of being referred to child welfare services than parents without disabilities. (Parents with Disabilities in Child Welfare Agencies and Courts. www.adata.org.)

Bias pervades the child welfare system, and “at any step in the process, societal prejudices, myths, and misconceptions may rear their heads.”

(Susan Kerr, “The Application of the Americans with Disabilities Act to the Termination of the Parental Rights of Individuals with Mental Disabilities,” *Journal of Contemporary Health Law and Policy* 16 (2000): 402.)

<https://scholarship.law.edu/cgi/viewcontent.cgi?article=1269&context=jchlp>

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.

(<https://www.ncd.gov/publications/2012/Sep272012/Ch5>.)

“Persons with disabilities who are also members of minorities face double discrimination and a double disadvantage in our society.” (National Council on Disability, *Meeting the Unique Needs of Minorities with Disabilities*, (Washington, DC: 1993),

<http://www.ncd.gov/NCD/publications/1993/April261993>.)

Children in families with a parent with a disability face higher removal rate: 70-80% when the parent has a psychiatric disability and 40-80% when the parent has an intellectual disability. ((National Council On Disability, *Rocking the Cradle: Ensuring the Rights of Parents With Disabilities and Their Children* 78 (2012),

https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf [<https://perma.cc/B2B3-CY2G>]).

Impact of ASFA on parent with disabilities

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

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 (the time frames are even shorter if the child is an infant). While the goal of permanency is praiseworthy, research shows that many parents with disabilities find it difficult to comply within the strict timelines.

<https://www.ncd.gov/publications/2012/Sep272012/Ch5>

“Reasonable efforts” are required but the term has not been defined in federal regulations. In addition, services that have not been adapted are often provided to parents with disabilities.

Legal Framework for Parents with Disabilities

Disability discrimination prohibited

Mandates of state and federal laws prohibits disability discrimination in government programs, services, and activities. These laws cover child welfare agencies, service providers, and state courts, and require appropriate reasonable modifications for parents with disabilities.

Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132

“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.”
(42 U.S.C. § 12132.)

Section 504 of the Rehabilitation Act, 42 U.S.C. § 794

Cal. Gov. Code § 11135(b) [incorporating the standards of the ADA and its implementing regulations]

28 C.F.R. § 35.101 et seq.

Cal. Code Regs. tit. 2, § 11140 et seq. (formerly Cal. Code Regs. tit. 22, § 98000 et seq.)

U.S. Dep't of Health and Human Services and U.S. Department of Justice, Protecting the Rights of Parents and Prospective Parents with Disabilities: Technical Assistance for State and Local Child Welfare Agencies and Courts under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act (August 2015), available at <https://www.hhs.gov/sites/default/files/disability.pdf>.)["Like child welfare agencies, courts must also make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination on the basis of disability."]

Case law: *Tennessee v. Lane* (2004) 541 U.S. 509, 531-32 [124 S.Ct. 1978, 158 L.Ed.2d 820] [Title II of the ADA requires state courts to make "reasonable modifications" to individuals with disabilities, and this obligation is "perfectly consistent" with the well-established due process principle that individuals must have a meaningful opportunity to be heard in state courts];

In re Marriage of James & Christine C. (2008) 158 Cal.App.4th 1261, 1265 [reversing and remanding where trial court should have accommodated disabled litigant under ADA and court rule by granting continuance]; see also *Fry v. Saenz* (2002) 98 Cal.App.4th 256, 261 [applying ADA, Rehabilitation Act, and state analogs to CalWORKS program and finding that rule cutting off benefits when children reach age 18 discriminated against disabled children].)

Cal. Rules of Court, rule 1.100; Cal. Rules of Court, rule 989.3 (1996), Drafter's Notes [The (predecessor) rule was "enacted "to help implement the Americans with Disabilities Act, which requires public entities, including the courts, to make reasonable modifications in policies, practices, or procedures to avoid discrimination against persons with disabilities."]

These anti-discrimination mandates can apply to

- Investigations
- Witness interviews
- Assessments
- Provisions of in-home services
- Removal of children from their homes
- Case planning and service planning
- Visitation
- Guardianship
- Adoption
- Foster care
- Reunification services
- Child welfare hearings
- Custody hearings
- Proceedings to terminate parental rights

ADA is not a defense in CA dependency proceedings (but violations may be relevant)

California Courts have held that the ADA does not directly apply in dependency proceedings and cannot be used as a defense in them. (*In re Anthony P.* (2000) 84 Cal.App.4th 1112, 1115-1116; *In re Diamond H.* (2000) 82 Cal.App.4th 1127, disapproved on other ground to the extent inconsistent, *Renee J. v. Superior Court* (2001) 26 Cal.4th 735, 748, n.6.)

ADA creates a separate, private, federal cause of action that can be instituted in federal court separate and apart from any challenge raised under state law. (Seiser & Kumli, *Cal.Juv.Dep.Prac.* (2020) §2.129[11].)

Using disability nondiscrimination standards

The nondiscrimination standards provided by these laws can and should be considered when determining whether an agency has provided reasonable parental reunification services as required by the Welfare & Institutions Code. (See *In re Hicks/Brown* (2017) 500 Mich. 79, 86-87 [893 N.W.2d 637, 640] “[E]fforts at reunification cannot be reasonable under the Probate Code if the Department has failed to modify its standard procedures in ways that are reasonably necessary to accommodate a disability under the ADA.”) As New York’s highest state court reasoned in *Lacey L.*, “Family Court should not blind itself to the ADA’s requirements placed on ACS and like agencies. The courts may look at the accommodations that have been ordered in ADA cases to provide

guidance as to what courts have determined in other contexts to be feasible or appropriate with respect to a given disability.” (*Matter of Lacey L.* (N.Y. 2018) 32 N.Y.3d 219, 231; 114 N.E.3d 123, 129.)

Bypass of Reunification Services Pursuant to WIC 361.5, subd. (b)(2) [parents has mental disability that makes them unable to use reunification services]

Section 361.5(b)(2): Reunification services need not be provided to a parent or guardian when the court finds, by clear and convincing evidence, that the parent is suffering from a mental disability described in Chapter 2 of Part 4 of Division 12 of the Family Code and that renders [the parent] incapable of utilizing those services

Family Code 7827(a) defines “mentally disabled” as a mental incapacity or disorder that renders parent unable to care for and control child adequately.

Family Code 7827 (c) requires two experts to support a finding for bypass. However, one Court held that section 7827(a) does not require both experts to agree that the parent is unlikely to benefit from services in order for it to deny reunification services. Instead, evidence from two experts is required “from which the court then can make inferences and base its findings.” (*Curtis F. v. Superior Court* (2000) 80 Cal.App.4th 470, 474.)

The court may deny reunification services under 361.5(b)(2) if parent refuses to submit to a psychological evaluation required to make determination. (*In re C.C.* (2003) 111 Cal.App.4th 76.)

**Other bypass provisions can be problematic for parents with disabilities. For instance, bypass based on prior termination of services and/or parental rights. (§ 361.5, subdivision (b)(7), (10), and (11). Anecdotal evidence suggests that bypass based on termination of parental rights to a sibling 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.

<https://web.archive.org/web/20150716014729/http://www.ncd.gov/publications/2012/Sep272012/Ch5#end364>

Juvenile Dependency Court Orders Reunification Services to be Provided to the Parent

Possible framework for juvenile court to use when a parent has a mental health disability

Steps the juvenile court should take if the “reasonable efforts mandate is to be meaningful in cases involving mentally ill parents.” (Edwards, *Mental Health Issues in Dependency Court* (Fall 2014) *The Bench: The Official Journal of the California Judges Association*, at p. 21-22; <http://www.judgeleonardedwards.com/docs/Bench2014-4-Mental-Health-Juv-ct.pdf> .)

These steps include:

1. Determine whether the mental illness or disability has a negative impact on the care of the child such that state intervention is necessary,
2. Determine the nature of the mental illness,
3. Determine whether it is treatable,
4. Determine how the agency’s proposed case plan will address the parent’s rehabilitation and whether the proposed services are specially designed to address the parent’s disability.
5. What should the court expect from the Agency in order to prevent removal or assist in rehabilitation of parent.
6. Can the parent be rehabilitated in foreseeable future? Rehabilitation does not mean that the disability has disappeared – only that the behavior no longer creates harm to the child.
7. Are there support persons who will enable the parent to safely care for the child.

Mental disability as starting point

When services are provided to parents with mental health issues, the mental illness must be the starting point so that the reunification plan and the services to be provided “accommodate the family’s unique hardship.” (*In re Elizabeth R.* (1995) 35 Cal.App.4th 1774, 1790.)

An assessment may be required: What is the nature of the parent’s disability?

Proper assessments are crucial for the provision of appropriately tailored services. A parent’s disability should be identified accurately and with

enough specificity to enable the determination of appropriate adaptations in practice. (*Rocking the Cradle, supra*, at p. 135.) An appropriate assessment is particularly critical for parents with psychiatric disabilities, as these parents lose custody of their children at the highest rate of any disability group. (*Id.* at p. 210.)

After a finding that the child is at risk and jurisdiction over the child has been taken, “where the aim is to reunify parent and child, expert opinion on the cause and extent of mental illness may be required to ascertain which services will eliminate the conditions leading to dependency.” (*Laurie S. v. Superior Court* (1994) 26 Cal.App.4th 195, 202-203.)

When considering the appropriateness of an assessment, the American Psychological Association’s Guidelines for Psychological Evaluations in Child Protection Matters (<https://www.apa.org/practice/guidelines/child-protection>) and Guidelines for Assessment of and Intervention With Persons With Disabilities (<https://www.apa.org/pi/disability/resources/assessment-disabilities>) may be instructive.

Problems with vague and inconsistent diagnosis:

“Mother’s mental illness appears in this case to be so vaguely and inconsistently diagnosed, it appears she herself was the most well informed of anyone. The petition alleged she “suffers from bipolar with persistent delusions along with command auditory hallucinations.” The detention report said the hospital at one point had “narrowed down her diagnosis to Mood Disorder but they are not sure which one.” According to the disposition report, mother reported that she had “OCD, bipolar, anxiety, depression, and schizophrenia.” Mother testified she wasn’t bipolar but schizophrenic, and told that to the hospital upon her discharge at the beginning of the case. Whatever her precise medical condition, there is no dispute mother suffered homicidal hallucinations.” (*Patricia W. v. Superior Court* (2016) 244 Cal.App.4th 397, 423-424.)

The *Patricia W.* Court noted, “we fail to see how the Agency could discharge its obligation to try to reunify mother with her son, and provide reunification services appropriately tailored to her needs, without a clear diagnosis of her mental illness secured through an evaluation as part of a case plan.” (*Id.* at pp. 423-424.) There was not a “careful evaluation” of her mental illness or even an effort to “secure a psychological evaluation as part of a case plan.” (*Id.* at p. 422.)

The “problem with drawing inferences from the diagnosis of ‘schizophrenic’ is that schizophrenia is not a well-defined or well-understood condition.” (*In re Jamie M.* (1982) 134 Cal.App.3d 530, 537.)

The *Jamie M.* Court examined the “complex, often ill-defined and poorly understood nature of schizophrenia, which is a category that encompasses a wide group of disorders and defies generalization (or even professional consensus) as to its causes, diagnosis, treatment and a patient’s prospects for relapse, since every case is unique. (*In re Jamie M., supra*, 134 Cal.App.3d at pp. 537–538.)” “Because it may represent a collection of parts from several types of emotional disturbances rather than a single ‘disease,’ labeling some patients as schizophrenic may be equivalent to saying an accident victim with a concussion, fractured spine, broken ribs and a collapsed lung is ‘severely ill.’ ” (*Id.* at p. 538.) “Schizophrenia has so diverse a patterning from patient to patient that it is hard to see how one universal physiological or biological cause can be applied to it.” (footnote omitted.) (*Id.* at p. 539.)

The *Jamie M.* Court noted the mere fact the mother was labeled a schizophrenic “really tells us very little about her behavior and its affect [sic] on her children” and asked, “How then is a court to use this crucial and yet nebulous diagnosis in ruling on the proper disposition to be made of her children?” (*In re Jamie M., supra*, 134 Cal.App.3d at p. 540.)

Designing a Case Plan and Reasonable Services

Case Plan requirements

Section 16051.1 mandates “that services are provided to the child and parents or other caretakers ... in order to improve the conditions in the parent’s home, to facilitate the safe return of the child to a safe home or the permanent placement of the child, and to address the needs of the child while in foster care.” (§ 16501.1, subds. (a)(2) [goals] & (e) [written].)

The case plan has three main goals: (1) identify the reasons for the dependency, (2) set forth specific goals and describe why the planned services are appropriate to meet those goals, and (3) describe the services to be provided to assist in reunification. (§ 16501.1, subds. (g)(2), (3), (10).) The case plan is generally written within 60 days of removing the child and must be updated as the service needs of the family dictate. (§ 16501.1, subd. (e).) The case plan must be updated with each status

review hearing. (*Ibid.*) Between review hearings, the casework supervisor may modify the case plan in furtherance of its goals without court approval. (§ 16501.1, subd. (g)(14).)

The program must be “designed to eliminate those conditions that led to the court’s finding that the child is a person described by Section 300.” (§ 362, subd. (d); *In re M.R.* (2020) 48 Cal.App.5th 412, 424.)

Reunification services, generally

Disposition, where reunification services are ordered, has been considered the “meat and potatoes” of juvenile law “because it is during disposition that the family’s future is charted.” (Cal. Juv. Dep. Pract. (2021) Disposition, §5.1, p. 341.)

The purpose of reunification services is to remedy the problems that led to the child’s removal. (*In re Ronell A.* (1996) 44 Cal.App.4th 1352, 1362.)

A “mechanical approach” to a reunification plan is not acceptable. Reunification services must be “tailored to the particular needs of the family arising out of the unique circumstances of the situation.” (*In re J.E.* (2016) 3 Cal.App.5th 557, 559; *In re M.F.* (2019) 32 Cal.App.5th 1, 15.)

Services must not only be appropriately tailored; they must be accessible. (*T.J. v. Superior Court* (2018) 21 Cal.App.5th 1229, 1242.)

The adequacy of the plan and the agency’s services are judged according to the specific circumstances of each case, and “ ‘the effort must be made to provide reasonable reunification services in spite of the difficulties in doing so or the prospects of success.’ ” (*In re K.C.* (2012) 212 Cal.App.4th 323, 329; see also *In re Riva M.* (1991) 235 Cal.App.3d 403, 414.)

The parent is “not required to complain about the lack of reunification services as a prerequisite to the [Agency] fulfilling its statutory obligation.” (*Mark N. v. Superior Court* (1998) 60 Cal.App.4th 996, 1014, superseded by statute on another ground as stated in *Earl L. v. Superior Court* (2011) 199 Cal.App.4th 1490, 1503-1504.)

But, “In almost all cases it will be true that more services could have been provided more frequently and that the services provided were imperfect.” (*In re Misako R.* (1991) 2 Cal.App.4th 538, 547.)

Standard of review: When a parent challenges the adequacy of reunification services, the appellate court reviews it for substantial evidence. (*In re Alvin R.* (2003) 108 Cal.App.4th 962, 971.)

Reunification services for parents with mental health disabilities-

The “juvenile dependency system is mandated by law to accommodate the special needs of disabled and incarcerated parents, including those disabled by mental illness.” (*In re K.C.* (2012) 212 Cal.App.4th 323, 331; See *Tracy J. v. Superior Court* (2012) 202 Cal.App.4th 1415, 1425-1426.)

Even when a parent’s disability is serious enough that the parent “may never be able to properly care for [the child],” the agency cannot simply “[give] up without really trying.” (*In re Daniel G.* (1994) 25 Cal.App.4th 1205, 1216.)

An agency does not provide appropriate tailoring when it identifies the mental health challenges that give rise to the loss of custody without taking appropriate steps to actually address them. (See *In re K.C.* (2012) 212 Cal.App.4th 323, 330.)

A social services agency cannot force a parent to participate in services. (*In re Nolan W.* (2009) 45 Cal.4th 1217, 1233; *In re Ronell A.* (1996) 44 Cal.App.4th 1352, 1365.) Parents with mental health disabilities are often described as unwilling or non-compliant, but the court can look beyond a case worker’s opinion on whether a parent was willing to engage in services. (See *T.J. v. Superior Court* (2018) 21 Cal.App.5th 1229, 1249-1250.)

Once the plan is appropriately tailored to the needs of the disabled parent, the parent is not excused from participating in the plan because of his or her disability. (*In re Christina L.* (1992) 3 Cal.App.4th 404, 415.)

Cases where Courts have found lack of reasonable services

Developmentally disabled parent not referred to regional center or similar provider. (*In re Victoria M.* (1989) 207 Cal.App.3d 1317.) Mother’s “disabilities were not considered in determining what services would best suit her needs.” (*Id.* at p. 1329.)

Services were not reasonable because they did not address mother’s compliance in taking medication for mental illness, which was what led to child’s detention. (*Patricia W. v. Superior Court* (2016) 244 Cal.App.4th 397

Agency failed to provide reasonable services designed to address special needs of intellectually disabled mother. (*T.J. v. Superior Court* (2018) 21 Cal. App.5th 1229, 1248.)

A parent's resistance to psychotropic medical evaluation was itself a product of his mental illness and department's failure to secure the evaluation could not be reconciled with the reasonable services requirement. (*In re K.C.* (2012) 212 Cal.App.4th 232, 331.)

Reunification plans must accommodate parents with disabilities. The juvenile court could exercise its discretion under section 352 to continue services where parent's hospitalization for mental illness compromised her ability to participate in reunification services. (*In re Elizabeth R.* (1995) 35 Cal.App.4th 1774.)

Visitation as Part of the Reunification Plan

Visitation, generally

Visitation is an essential component of a reunification plan. (*In re Mark L.* (2001) 94 Cal.App.4th 573, 580; *In re M.F.* (2019) 32 Cal.App.5th 1, 16.)

To promote reunification, visitation must be as frequent as possible, consistent with the well-being of the child. (§ 362.1, subd. (a)(1)(A); *In re Alvin R.* (2003) 108 Cal.App.4th 962, 972.)

To maintain ties between the parent and child, and to provide information relevant to deciding if and when to return a child to the custody of his or her parent, every order placing a child in foster care and ordering reunification services must provide for visitation between the parent and child. (§362.1.) "No visitation order shall jeopardize the safety of the child." (§362.1, subd. (a)(2).)

Visitation for parents can serve as a mean of maintaining a relationship between a parent and child when reunification is not possible or is not accomplished. (*In re Nicholas B.* (2001) 88 Cal.App.4th 1088, 1093.)

Visitation for parents with disabilities

Parents with developmental disabilities may require particular services to expand visitation. (*Tracy J. v. Superior Court* (2012) 202 Cal.App.4th 1415 [Agency did not demonstrate reasonable services to disabled parents where parents received only limited and supervised visitation and were not instructed on how to recognize the child's asthma symptoms].)

In the absence of evidence showing the parent's behavior has jeopardized the child's safety, the agency cannot limit and impede the progression of

visitation services based solely on concerns about the parent's mental health status. (*Tracy J. v. Superior Court* (2012) 202 Cal.App.4th 1415, 1419.)

Resources

Disability Rights Education and Defense Fund www.dredf.org

National Council on Disability www.ncd.org

Judge Leonard Edwards www.judgeleonardedwards.com

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 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

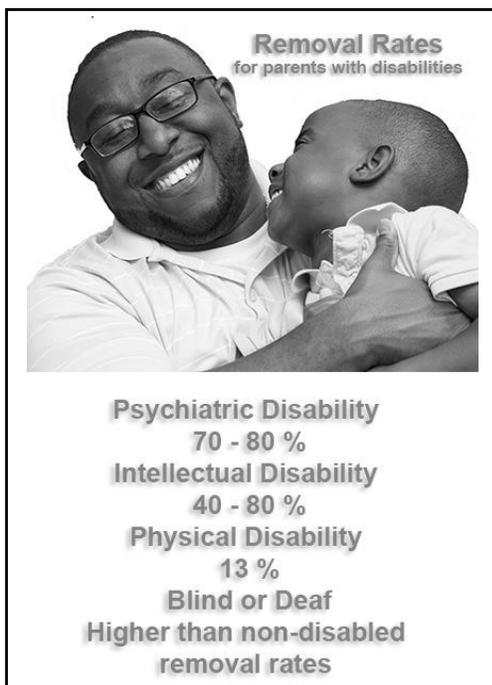
Beginning with the investigation into a report of child maltreatment, bias pervades the child welfare system, and "at any step in the process, societal prejudices, myths, and misconceptions may rear their heads."²⁵² Systematic discrimination by state courts, child welfare agencies, and legislatures against 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 caregivers²⁵³ with disabilities.²⁵⁴ To complete this study, TLG analyzed data from 19 states²⁵⁵ 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.

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

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.

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

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.

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

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.

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

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.

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

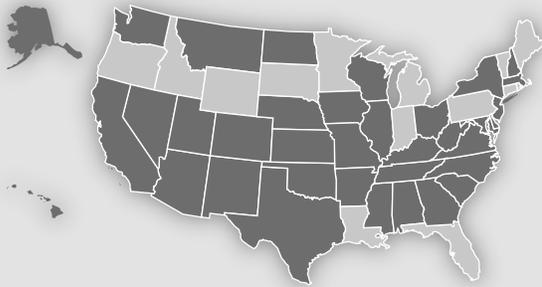
All the states that include disability in their grounds for termination specify explicit types of disabilities for courts to consider. Currently, 36 states list psychiatric disabilities, 32 list intellectual or developmental disability, 18 list "emotional illness," and 7 list physical disabilities as 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

37 of 50 states

and the District of Columbia allow disability as a grounds for termination of parental rights.



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

[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.

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

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

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.

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.

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

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

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

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;
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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

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

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,

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

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

"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."

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

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

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.

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 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

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.

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

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.

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

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.

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

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

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

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



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

and family court and assessment in these systems.

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

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 disabilities⁶⁵⁶ concluded that “one cannot discern the full

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

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

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

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.

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

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

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

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 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

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

Correlation and causation are often confused in the research, resulting in an impression that children’s problems are caused by parents’ disabilities.

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

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

[S]tudies have indicated that it is impossible to predict parenting outcomes on the basis of the results of intelligence testing.

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.

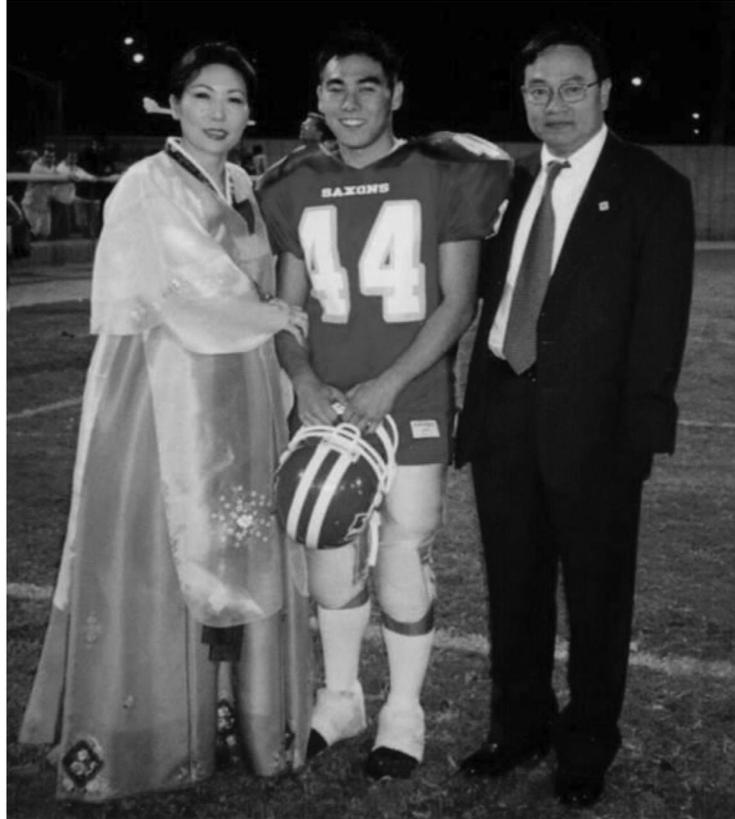
Lisa, who has cerebral palsy and is a mother of two daughters, says, “When parenting with a disability, I think it’s important to embrace the fact that we are all interdependent and we each have different skills to contribute in raising happy, healthy children.... It’s that interdependence with other 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 eligible 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. Jessica¹⁰¹³ 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

For parents with disabilities, the lack of affordable accessible housing frequently affects child custody.

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

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 to 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.

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

[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.

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

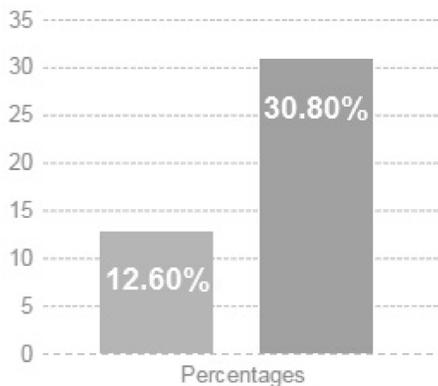
Parents with disabilities use a variety of modes of transportation. Interestingly, the survey found that parents whose primary disability is physical are more likely to use their own car or van than parents whose primary disability is not physical (85 percent versus 64 percent).¹⁰⁴¹ Surveyors speculate 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

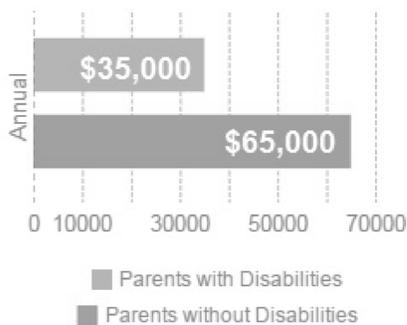
Education of Parents with Disabilities

Percentage of College Degrees



Income of Parents with Disabilities

Median Income of Parents with Disabilities



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 hysterectomy[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

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’s¹⁰⁸⁶ 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

[W]omen 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.

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.

“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.’”

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.

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 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.

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

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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

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-

[T]he behavioral health systems and the child protective systems are gateways into each other's services.

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

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.

Bill of Rights Act.¹¹³² An extensive 12-section chapter titled "Family Supports" contains not one mention of parents with intellectual disabilities.¹¹³³

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 need for 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’s¹¹⁶¹ 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.



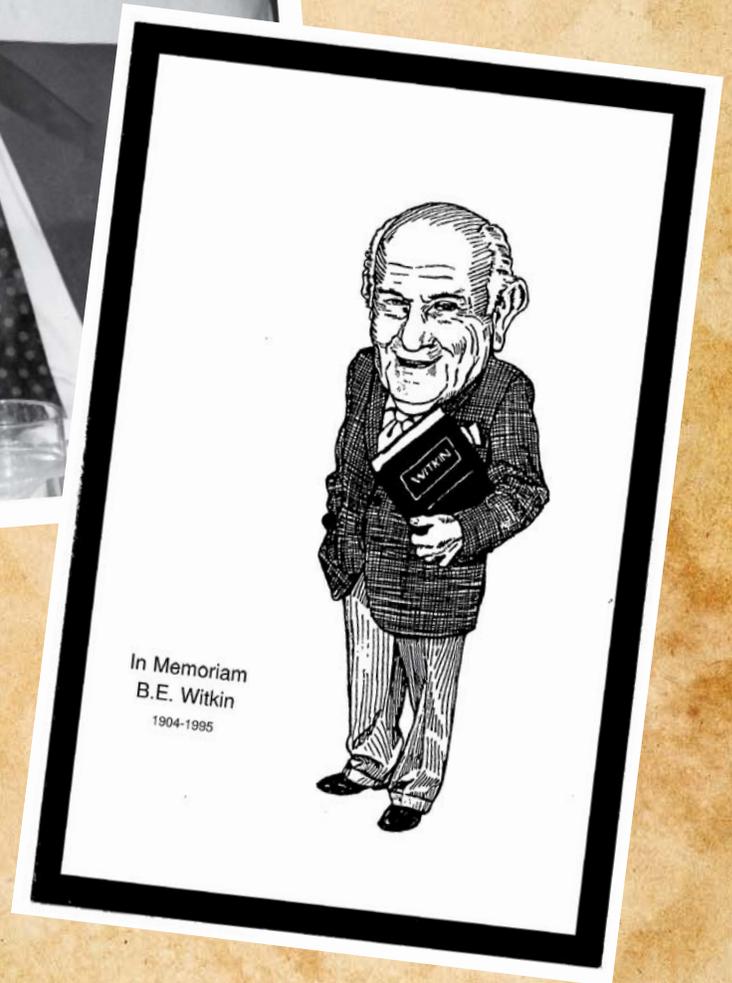
THE BENCH

THE OFFICIAL JOURNAL OF THE CALIFORNIA JUDGES ASSOCIATION

Fall 2014



The Traynor/Witkin Legacy *Reflections by Justice Ming Chin*



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Mental Health Issues in Dependency Court

All child welfare service providers have to work with mentally challenged parents struggling to rear their children, and all juvenile court judges must make decisions about the ability of these parents safely to parent their children.¹ Some parents have mental health problems so severe that the state will intervene and remove the child from their care. States vary widely in their response to parents with these problems. California has created an exception permitting reunification services to be bypassed in cases of chronic mental illness.² If two experts with specified qualifications conclude that the parent has a mental incapacity or disorder that renders the parent unable to care for and control the child adequately and is likely to remain so in the foreseeable future, family reunification services need not be offered.³

Some California courts have resisted the trend to bypass services and have ordered reunification services where the parent has mental illness.⁴ Their decisions to provide services start from the proposition that just because a parent has mental health problems, it does not mean that he or she is unfit to parent or that the child should be removed permanently. As

several appellate decisions have held, there must be a nexus between the parent's mental illness and child endangerment before the children can be removed.⁵

California's appellate courts have also required that the social services agency provide reasonable efforts to prevent removal and to facilitate reunification in these cases. For example, one appellate court held that a failure to provide a case plan for a mentally ill mother did not meet the reasonable efforts requirement and reversed the trial court's termination of parental rights decision.⁶ Another found the agency did not provide reasonable efforts when it failed to arrange for counseling for a child, thus preventing the father and child to participate in conjoint counseling.⁷ In another case the appellate court reversed a termination of parental rights decision, because the agency failed to give the developmentally disabled parents an opportunity to demonstrate that they were able to parent their child.⁸ However, frequently the state court will determine that the agency has provided reasonable efforts when the parent is uncooperative⁹ or when the

time for reunification has run out.¹⁰

On several occasions the appellate courts have demanded that appropriate services be provided to mentally ill parents and have reversed termination of parental rights decisions because the state failed to provide reasonable efforts. One appellate court found that the agency had not provided tailored services to meet the needs of a developmentally disabled parent.¹¹ In this case the agency removed the children from a developmentally delayed adult living in filthy surroundings. The court ordered her to find housing and demonstrate suitable parenting skills. The appellate court reversed the termination of parental rights holding that clear and convincing evidence must show that services specially designed to meet the needs of the parent were explored, and, despite the availability of such services, it is in the best interest of the children to be declared free for adoption. The court pointed out the mother was given no assistance to find housing and was not referred to a regional center which could have assisted her. The court noted that the agency had failed to help the mother deal

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with the health and cleanliness issues plaguing her children. The only “help” the agency provided the mother to find housing was to tell her to keep her eyes open for a house. The court stated the record was “clear that no accommodation was made for [the mother’s] special needs in providing reunification services.”¹² One can conclude from this ruling that mental illness, standing alone, is not a sufficient basis to justify legal proceedings removing a child.¹³

The reasoning in *In re Victoria M.* resembles that in *In re Venita L.*,¹⁴ where the child had been removed and dependency proceedings commenced when the mother was confined to a psychiatric hospital. When services were terminated, the parents appealed the decision, and the appellate court reversed the trial court finding of reasonable efforts. The appellate court noted that the agency had amended the service plan five times in a little over a year and that the mother had been successful in her rehabilitation from mental illness. The father was told to be involved with Alcoholics Anonymous, but the court of appeals pointed out that that was not the reason for the dependency and that the mother had completed her case plan. Changing the focus from the conduct that brought the child to the attention of the court to new problems occurs somewhat frequently in child protection cases.¹⁵

When the appellate court concludes that the agency has not provided reasonable efforts or when the evidence reveals that a parent is recovering from mental illness, the court has frequently ordered additional family reunification

services. In one case, the appellate court reversed a termination of parental rights decision by the trial court, holding that the mentally ill parent was hospitalized most of the reunification period, presently she was making great improvements, and that the trial court had discretion to extend the time for reunification given the unique circumstance of the case.¹⁶ In the case of *In re David D.*¹⁷ the mother voluntarily placed her children in foster care to escape an abusive environment with her husband. Her accompanying depression resulted in a suicide attempt during the reunification period, prompting the system to cease all efforts to help her reunify. The appellate court found the system reacted with “appalling lack of compassion” and ordered six more months of services, during which the mother was to receive a chance to reestablish regular visits with her children.

While the court may order reunification in these cases, the parent must demonstrate some interest in reunification. In one case it was discovered during the reunification period that mother was developmentally disabled and that it was difficult for her to comply with the case plan. Services were terminated and the court terminated parental rights.¹⁸ On appeal the termination was affirmed. The court found that there was substantial evidence to support the trial court’s finding that it was unlikely that the mother would develop an adequate parental relationship with her daughter. Reasonable efforts were offered, but mother had no motivation and no participation in the case plan. A similar result occurred in the case of *In re Walter P.*

where the court noted that the mother’s problem was less a function of lack of mental ability than a poor attitude and a lack of motivation to parent a fragile child with special health needs.¹⁹ As the court noted, reunification services are voluntary, and an unwilling or indifferent parent cannot be forced to comply with them.²⁰

Some critics assert that welfare agencies do not tailor reunification services to the needs of disabled parents. They point out that without individualized services that address the special needs of these parents, a termination of parental rights will occur.²¹ Moreover, the Americans with Disabilities Act (ADA) does not provide any support for disabled parents facing termination of parental rights proceedings. State appellate decisions including those in California have concluded that termination of parental rights proceedings do not constitute ‘services, programs, or activities’ within the meaning of 42 U.S.C. 12132 [the ADA].²² Whether the ADA applies to the family reunification period remains an open question, and at least one out-of-state appellate decision found that it did.²³

Our juvenile and family courts will always have to face difficult issues regarding mentally ill and developmentally delayed parents and their children. Judges should insist that they receive high quality information about each parent’s capabilities. The information may come from psychological or psychiatric evaluations or from sources such as California’s Regional Centers. Judges should also consider what supports the parent has including relatives and close friends. Often the

parent can remain a part of the child’s life if others are present in the daily family life.²⁴ Most importantly, the courts should not give up on these parents without making an effort to see if the parent is capable of parenting.

As one critic concluded:

*It is not that Mary Ann (and others like her) is reasonably likely to become a fit parent; rather, it is that she ought to be provided the opportunity to achieve fitness, and that her children should be provided the opportunity to remain with their biological mother. The state cannot be held liable for failing to perform miracles, but the state can be expected to make the minimum ‘reasonable effort’ that might afford some chance of change for these parents.*²⁵

The research collected in preparing this paper included hundreds of appellate cases across the country involving reasonable efforts in child protection cases.²⁶ A review of those cases reveals that most appellate decisions involving mentally ill parents affirm trial court orders terminating parental rights. If the reasonable efforts mandate is to be meaningful in cases involving mentally ill parents, the court should take the following steps:

- (1) Determine whether the mental illness or disability has a negative impact on the care of the child such that state intervention is necessary.
- (2) If so, determine the nature of the mental illness.

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(3) Determine whether it is treatable.

(4) Determine how the agency's proposed case plan will address the parent's rehabilitation and whether the proposed services are specially designed to address the parent's disability. In this regard determine whether there was consultation with an agency that has expertise in working with parents with mental health challenges/disabilities.

(5) Determine what the court should expect from the agency in order to prevent removal of the child or assist in rehabilitating the parent.

(6) Determine whether the parent can be rehabilitated in the foreseeable future such that she or he can safely care for the child. Rehabilitation does not mean that the disability has disappeared – only that the parent's behavior no longer creates harm to the child.

(7) Find out whether there are support persons such as a spouse, relatives, or good friends who will enable the parent safely to care for the child.

By addressing these questions and making appropriate orders, the court will be offering the parent a fair opportunity to parent their child. ☺

Endnotes:

1 See generally “Zimmerman, S., “Parents’ Mental Illness or Mental Deficiency as Ground for Termination of Parental Rights – Issues Concerning Rehabilitative and Reunification Services,” 12 A.L.R.6th 417; Spreng, J., “The Private World of Juvenile Court: Mothers, Mental Illness and the Relentless Machinery of the State,” *Duke J. Gender L. & Pol’y*, Vol. 117 (2010) at pp. 189-218.

2 California (Welfare and Institutions Code section 361.5(b)(2). Refer also to Family Code §§ 7826 and 7827.

3 *Id.*

4 For a comprehensive review of cases involving mentally ill parents involved in the child protections system see Zimmerman, S., “Parents’ Mental Illness or Mental Deficiency as Ground for Termination of Parental Rights,” *op.cit.*, footnote 1.

5 *In re Jamie M.*, 134 Cal.App.3d 530 (1982). See also *In re Kimberly F.*, 56 Cal.App.4th 519 (1997) where the appellate court held that a “narcissistic personality” is an insufficient basis for removal of children. A similar result occurred in the case of *In re Elizabeth R.*, 42 Cal. Rptr.2d 200 (1995).

6 *In re T.M.*, 175 Cal. App. 4th 1166 (2009).

7 *In re Alvin R.*, 108 Cal. App. 4th 962 (2003).

8 *Tracy J. v. Superior Court*, 202 Cal. App. 4th 1415 (2012)

9 *In re Misako R.*, 1 Cal. App. 4th 538 (1991).

10 *In re Daniel G.*, 25 Cal. App. 4th 1205, 31 Cal. Rptr. 2d 75 (1994)

11 *In re Victoria M.*, 207 Cal.App. 3d 1317, 255 Cal.Rptr.498 (1989).

12 *Id.* at 504.

13 *In re Victoria M.*, 207 Cal.App.3d 1317 (1989). *In re Jamie M.*, 134 Cal.App.3d 530 (1982) held that there must be some nexus between the mother's mental illness and child endangerment before her children could be removed. Also see the cases cited in footnote 5.

14 191 Cal. App. 3d 1229, 236 Cal. Rptr. 859 (1987)

15 Although the juvenile court can consider “new” problems, such “new” problems cannot be the basis for findings continuing the dependency unless those problems would sustain a jurisdictional finding. (*In re Venita L.*, 191 Cal.App.3d 1229, 1242-1243.) “Dependency proceedings should not be allowed to drift from major problem-solving circumstances to prolonged attempts to resolve shortcomings in the parental home which would

not cause dependency in the first place.” *In re Kristin W.* 222 Cal. App. 3d 234. “A review of the literature concerning reunification services for such parents reveals that the efforts typically made by state child welfare agencies are frequently both unsuitable and ineffective.” Kaiser, J., “Victimized Twice: The Reasonable Efforts Requirement in Child Protection Cases When Parents Have a Mental Illness,” *Western New England University School of Law Legal Studies Research Paper Series*, No. 12-8, available at <http://ssrn.com/abstract=2056387> at pp 25.

16 *In re Elizabeth R.*, 35 Cal. App. 4th 1774; 42 Cal. Rptr. 2d 200 (1995)

17 28 Cal. App. 4th 941, 952, 956 (1994)

18 *In re Christina L.*, 3 Cal. App. 4th 404 (1990).

19 228 C.A.3d 113 (1991). *Accord In re Misako R.*, 1 Cal.App. 4th 538 (1991), *Katie V. Superior Court*, 130 Cal. App. 4th 586 (2005), *In re Mario C.*, 226 Cal. App. 3d 599 (1990), and *In re Christina L.*, 3 Cal.App. 4th 404 (1992).

20 *In re Jonathan R.* (1989) 211 Cal. App.3d 1214, 1220 [259 Cal. Rptr. 863]; *In re Lynna B.* (1979) 92 Cal.App.3d 682, 702 [155 Cal. Rptr. 256].

21 Kaiser, J., “Victimized Twice: The Reasonable Efforts Requirement in Child Protection Cases When Parent Have a Mental Illness,” *Western New England University School of Law, Legal Studies Research Paper Series*, No. 12-8; *Whittier Journal of Child and Family Advocacy*, Vol. 11-1; Kaiser, J. “Finding a Reasonable Way to Enforce the Reasonable Efforts Requirement in Child Protection Cases,” *op.cit.*, footnote 16.

22 *In re Anthony P.*, 84 Cal.App.4th 1112, 101 Cal. Rptr. 2d 423 (4th Dist. 2000); *In re Terry*, 240 Mich. App. 14, 610 N.W.2d 563 (2000); Zimmerman, S., “Parents’ Mental Illness or Mental Deficiency as Ground for Termination of Parental Rights – Applicability of the Americans With Disabilities Act,” 119 A.L.R. 5th 35; Margolin, D., “No Chance to Prove Themselves: The Rights of Mentally Disabled Parents Under the Americans with Disabilities Act and State Law,” *Va. J. Soc. Pol’y & L.*, Vol. 15, (2007) at p. 112.

23 “Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children, National Council on Disability, www.ncd.org at pp. 107-113.

24 The author has noted that some psychological reports focus exclusively on the parent and make no mention of the parent's support system or those persons who might live with the parent and assist in parenting duties.

25 DeVault, E., “Reasonable Efforts Not So Reasonable: The Termination of the Parental Rights of a Developmentally Disabled Mother,” *Roger Williams U. L. Rev.*, Vol.10, Spring, 2005, 763 at p. 787.

26 These cases are collected in Appendix A of a forthcoming book, *Reasonable Efforts: A Judge's Perspective*. Check with my website (judgeleonardedwards.com) to see when it appears and how to obtain a copy.



U.S. Department of Health And Human Services

Office for Civil Rights Administration for Children and Families

U.S. Department of Justice

*Civil Rights Division
Disability Rights Section*



**Protecting the Rights of Parents and Prospective Parents with Disabilities:
Technical Assistance for State and Local Child Welfare Agencies and Courts under
Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act**

The United States Department of Health and Human Services (HHS) and the United States Department of Justice (DOJ) are issuing this technical assistance to assist state and local child welfare agencies and courts to ensure that the welfare of children and families is protected in a manner that also protects the civil rights of parents and prospective parents¹ with disabilities. This guidance provides an overview of the issues and application of civil rights laws, answers to specific questions and implementation examples for child welfare agencies and courts, and resources to consult for additional information.

Section 504 of the Rehabilitation Act of 1973 (Section 504)² and Title II of the Americans with Disabilities Act of 1990 (ADA)³ protect parents and prospective parents with disabilities from unlawful discrimination in the administration of child welfare programs, activities, and services.⁴ At the same time, child welfare agencies and courts have the responsibility to protect children from abuse and neglect. The goals of child welfare and disability non-discrimination are mutually attainable and complementary. For example, ensuring that parents and prospective parents with disabilities have equal access to parenting opportunities increases the opportunities for children to be placed in safe and caring homes.

Need for This Technical Assistance

Both the HHS Office for Civil Rights (OCR) and DOJ Civil Rights Division have received numerous complaints of discrimination from individuals with disabilities involved with the child welfare system, and the frequency of such complaints is rising. In the course of their civil rights enforcement activities, OCR and DOJ have found that child welfare agencies and courts vary in the extent to which they have implemented policies, practices, and procedures to prevent discrimination against parents and prospective parents with disabilities in the child welfare system.

For example, in a recent joint investigation by OCR and DOJ of practices of a State child welfare agency, OCR and DOJ determined that the State agency engaged in discrimination against a parent with a disability.⁵ The investigation arose from a complaint that a mother with a developmental disability was subject to discrimination on the basis of her disability because the State did not provide her with supports and services following the removal of her two-day-old infant. The supports and services provided and made

available to nondisabled parents were not provided to this parent, and she was denied reasonable modifications to accommodate her disability. As a result, this family was separated for more than two years.

These issues are long-standing and widespread. According to a comprehensive 2012 report from the National Council on Disability (NCD), parents with disabilities are overly, and often inappropriately, referred to child welfare services, and once involved, are permanently separated at disproportionately high rates.⁶ In a review of research studies and other data, NCD concluded that among parents with disabilities, parents with intellectual disabilities and parents with psychiatric disabilities face the most discrimination based on stereotypes, lack of individualized assessments, and failure to provide needed services.⁷ Parents who are blind or deaf also report significant discrimination in the custody process, as do parents with other physical disabilities.⁸ Individuals with disabilities seeking to become foster or adoptive parents also encounter bias and unnecessary barriers to foster care and adoption placements based on speculation and stereotypes about their parenting abilities.⁹

Discriminatory separation of parents from their children can result in long-term negative consequences to both parents and their children. In addition to the OCR and DOJ case where a mother and daughter were deprived of the opportunity for maternal/child bonding for two years, the National Council on Disability report is replete with case studies with similar consequences. For example, a child welfare agency removed a newborn for 57 days from a couple because of assumptions and stereotypes about their blindness, undermining precious moments for the baby and parents that can never be replaced.¹⁰ Similarly, after a child welfare agency removed a three-year-old from his grandmother because she had arthritis and a mobility disability, the toddler developed behavioral issues and progressively detached from his grandmother, though he had had no such experiences before this separation.¹¹ Any case of discrimination against parents and caregivers due to their disability is not acceptable.

Role of HHS and DOJ

The Children's Bureau in the HHS Administration for Children and Families administers funding for child welfare agencies and courts and provides guidance and technical assistance to child welfare agencies regarding child welfare law. HHS OCR is responsible for ensuring that entities receiving Federal financial assistance from HHS, including child welfare agencies and state courts, comply with their legal obligation under Section 504 to provide equal access to child welfare services and activities in a nondiscriminatory manner. In addition, both DOJ and HHS OCR enforce Title II of the ADA against public entities, including child welfare agencies and state courts.

Overview of Legal Requirements

Title II of the ADA

Title II of the ADA provides that 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 such entity.¹² Title II of the ADA applies to the services, programs, and activities of all state and local governments throughout the United States, including child welfare agencies and court systems.¹³ The “services, programs, and activities” provided by public entities include, but are not limited to, investigations, assessments, provision of in-home services, removal of children from their homes, case planning and service planning, visitation, guardianship, adoption, foster care, and reunification services. “Services, programs, and activities” also extend to child welfare hearings, custody hearings, and proceedings to terminate parental rights.

Section 504 of the Rehabilitation Act

Section 504 provides that 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 any entity that receives Federal financial assistance, or be subjected to discrimination by such entity.¹⁴ Federal financial assistance includes grants, loans, and reimbursements from Federal agencies, including assistance provided to child welfare agencies and the courts.¹⁵ An entity can be a recipient of Federal financial assistance either directly or as a sub-recipient.¹⁶ Section 504 applies to all of the operations of agencies and sub-agencies of state and local governments, even if Federal financial assistance is directed to one component of the agency or for one purpose of the agency.¹⁷ Recipients of Federal financial assistance must agree to comply with Section 504, and generally other civil rights laws, as a condition of receiving Federal financial assistance.¹⁸

Application

A child welfare agency or court may not, directly or through contract or other arrangements, engage in practices or methods of administration that have the effect of discriminating on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the child welfare agency’s or court’s program for persons with disabilities.¹⁹ Under these prohibitions, a child welfare agency could be responsible for the discriminatory actions of a private foster care or adoption agency with which it contracts when those actions are taken in fulfillment of the private entity’s contractual obligations with the child welfare agency. For example, if the private foster care or adoption agency imposed discriminatory eligibility requirements for foster or adoptive parents that screened out prospective parents with HIV, the state child welfare agency would most likely be responsible for the contractor’s practice of discriminating on the basis of disability.

Two principles that are fundamental to Title II of the ADA and Section 504 are:

(1) individualized treatment; and (2) full and equal opportunity. Both of these principles are of particular

importance to the administration of child welfare programs.

Individualized treatment. Individuals with disabilities must be treated on a case-by-case basis consistent with facts and objective evidence.²⁰ Persons with disabilities may not be treated on the basis of generalizations or stereotypes.²¹ For example, prohibited treatment would include the removal of a child from a parent with a disability based on the stereotypical belief, unsupported by an individual assessment, that people with disabilities are unable to safely parent their children. Another example would be denying a person with a disability the opportunity to become a foster or adoptive parent based on stereotypical beliefs about how the disability may affect the individual's ability to provide appropriate care for a child.

Full and equal opportunity. Individuals with disabilities must be provided opportunities to benefit from or participate in child welfare programs, services, and activities that are equal to those extended to individuals without disabilities.²² This principle can require the provision of aids, benefits, and services different from those provided to other parents and prospective parents where necessary to ensure an equal opportunity to obtain the same result or gain the same benefit, such as family reunification.²³

This does not mean lowering standards for individuals with disabilities; rather, in keeping with the requirements of individualized treatment, services must be adapted to meet the needs of a parent or prospective parent who has a disability to provide meaningful and equal access to the benefit.²⁴ In some cases, it may mean ensuring physical or programmatic accessibility or providing auxiliary aids and services to ensure adequate communication and participation, unless doing so would result in a fundamental alteration to the nature of the program or undue financial and administrative burden.²⁵ For example, a child welfare agency must provide an interpreter for a father who is deaf when necessary to ensure that he can participate in all aspects of the child welfare interaction. In other instances, this may mean making reasonable modifications to policies, procedures, or practices, unless doing so would result in a fundamental alteration to the nature of the program.²⁶ For example, if a child welfare agency provides classes on feeding and bathing children and a mother with an intellectual disability needs a different method of instruction to learn the techniques, the agency should provide the mother with the method of teaching that she needs.

Under Title II of the ADA or Section 504, in some cases, a parent or prospective parent with a disability may not be appropriate for child placement because he or she poses a significant risk to the health or safety of the child that cannot be eliminated by a reasonable modification.²⁷ This exception is consistent with the obligations of child welfare agencies and courts to ensure the safety of children. However, both the ADA and Section 504 require that decisions about child safety and whether a parent or prospective parent represents a threat to safety must be based on an individualized assessment and objective facts, including the nature, duration, and severity of the risk to the child, and the probability that the potential injury to the child will actually occur.²⁸ In addition, if the risk can be eliminated by a reasonable modification of policies, practices,

or procedures, or by the provision of auxiliary aids or services, the child welfare agency must take such mitigating actions.²⁹ A public entity may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities, but they may not be based on stereotypes or generalizations about persons with disabilities.³⁰

By applying these principles consistently in the child welfare system, child welfare agencies and courts can ensure that parents and prospective parents with disabilities have equal access to parenting opportunities while ensuring children safely remain in or are placed in safe and caring homes. The attached Questions and Answers provide more detailed information and specific implementation examples for child welfare agencies and courts.

QUESTIONS AND ANSWERS

1. *What are the basic requirements of ADA Title II and Section 504?*

Answer: Title II of the ADA provides that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination in, the services, programs, or activities of state and local government entities.³¹ Section 504 similarly prohibits discrimination on the basis of disability against qualified individuals with a disability in programs, services, and activities receiving Federal financial assistance.³²

Under the ADA and Section 504, programs cannot deny people with disabilities an opportunity to participate,³³ and must provide people with disabilities with meaningful and equal access to programs, services, and activities.³⁴ Programs and services must be accessible to and usable by people with disabilities.³⁵ In addition, programs must provide people with disabilities with an equal opportunity to participate in and benefit from the programs, services and activities of the entity;³⁶ they are also prohibited from using methods of program administration, which includes written rules as well as agency practices, that have a discriminatory effect on individuals with disabilities.³⁷ Moreover, programs must provide reasonable modifications in policies, practices, and procedures when necessary to avoid discrimination;³⁸ and must take appropriate steps to ensure that communications with applicants, participants, members of the public, and companions with disabilities are as effective as communications with others through the provision of auxiliary aids and services.³⁹

Who is protected by disability nondiscrimination laws?

2. *Who is considered a person with a disability under Title II of the ADA and Section 504?*

Answer: The ADA and Section 504 protect the rights of individuals with disabilities.⁴⁰ A

“disability” is defined as a physical or mental impairment that substantially limits a major life activity, such as caring for oneself, performing manual tasks, breathing, standing, lifting, bending, speaking, walking, reading, thinking, learning, concentrating, seeing, hearing, eating, sleeping, or working.⁴¹ Major life activities also include the operation of major bodily functions, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, or bladder, neurological, brain, and respiratory, circulatory, endocrine, and reproductive functions.⁴²

Congress has made clear that the definition of disability in the ADA and Section 504 is to be interpreted broadly.⁴³ Even if an individual’s substantially limiting impairment can be mitigated through the use of medication; medical supplies, equipment, and devices; learned behavioral or adaptive neurological modifications; assistive technology (e.g. a person with a hearing disability who uses hearing aids that substantially restores the sense of hearing); or reasonable modifications to policies, practices, or procedures, the individual is still protected by the ADA and Section 504.⁴⁴ The ADA and Section 504 also apply to people who have a record of having a substantial impairment (e.g., medical, military, or employment records denoting such an impairment), or are regarded as having such an impairment, regardless of actually having an impairment.⁴⁵

An “individual with a disability” under the ADA and Section 504 does not include an individual who is currently engaged in the illegal use of drugs, when the state or local government program or program receiving Federal financial assistance acts on the basis of the illegal drug use.⁴⁶ However, an individual is not excluded from the definition of disability on the basis of the illegal use of drugs if he or she (1) has successfully completed a drug rehabilitation program or has otherwise been successfully rehabilitated and is no longer engaging in drug use, or (2) is participating in a supervised rehabilitation program and is no longer engaging in drug use.⁴⁷

To be eligible, an individual with a disability must be “qualified.” An individual with a disability is qualified if he or she meets the essential eligibility requirements of a service, program, or activity, with or without the provision of reasonable modifications, the provision of appropriate auxiliary aids and services, or the removal of architectural and communication barriers.⁴⁸

3. Who do Title II of the ADA and Section 504 protect in child welfare programs?

Answer: Title II of the ADA and Section 504 protect qualified individuals with disabilities, which can include children, parents, legal guardians, relatives, other caretakers, foster and adoptive parents, and individuals seeking to become foster or adoptive parents, from discrimination by child welfare agencies and courts.⁴⁹ Title II also protects individuals or entities from being denied or excluded from child welfare services, programs or activities because of association with an

individual with a disability.⁵⁰ For example, Title II prohibits a child welfare agency from refusing to place a child with a prospective foster or adoptive parent because the parent has a friend or relative with HIV.

Title II and Section 504 also protect “companions” of individuals involved in the child welfare system when the companion is an appropriate person with whom the child welfare agency or court should communicate. A companion may include any family member, friend, or associate of a person seeking or receiving child welfare services.⁵¹ For instance, when a child welfare agency communicates with an individual’s family member who is deaf, appropriate auxiliary aids and services to the family member must be provided by the agency to ensure effective communication.⁵²

Finally, the ADA and Section 504 protect individuals from any retaliation or coercion for exercising their right not to experience discrimination on the basis of disability. Individuals enjoy this protection whether or not they have a disability.⁵³

Who is required to comply with the disability nondiscrimination laws?

4. What types of child welfare programs and activities are covered by these laws?

Answer: Title II covers *all* of the programs, services, and activities of state and local governments, their agencies, and departments.⁵⁴ Similarly, Section 504 applies to all of the activities of agencies that receive Federal financial assistance.⁵⁵ Therefore, all child welfare-related activities and programs of child welfare agencies and courts are covered, including, but not

All activities of child welfare agencies are covered by Title II and Section 504, including removal proceedings and agencies’ programs and activities must not discriminate on the basis of disability.

limited to, investigations, witness interviews, assessments, removal of children from their homes, case planning and service planning, visitation, guardianship, adoption, foster care, reunification services, and family court proceedings. Title II and Section 504 also make child welfare agencies responsible for the programs and activities of private and non-profit agencies that provide services to children and families on behalf of the state or municipality.⁵⁶

5. Do Title II and Section 504 apply to the programs, services, and activities of family courts?

Answer: Yes. State court proceedings, such as termination of parental rights proceedings, are state activities and services for purposes of Title II.⁵⁷ Section 504 also applies to state court proceedings to the extent that court systems receive Federal financial assistance.⁵⁸

Title II and Section 504 require court proceedings to be accessible to persons with disabilities, and persons with disabilities must have an equal opportunity to participate in proceedings.⁵⁹ For example, if a conference or hearing is scheduled in a location that is inaccessible to wheelchair users, it should be moved to an accessible location in order to ensure a wheelchair user can participate fully in the conference or hearing.

Courts are required to provide auxiliary aids and services when necessary to ensure effective communication, unless an undue burden or fundamental alteration would result.⁶⁰ For example, courts should provide appropriate auxiliary aids and services to a parent who is deaf so that he or she can access court proceedings as fully and effectively as those who are not deaf.

Like child welfare agencies, courts must also make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination on the basis of disability.⁶¹ For example, it may be necessary to adjust hearing schedules to accommodate the needs of persons with disabilities, if the need for the adjustment is related to the individual's disability. Or it may be necessary to provide an aide or other assistive services in order for a person with a disability to participate fully in a court event.⁶² Such assistance should be provided unless doing so would result in a fundamental alteration.⁶³

6. Do Title II and Section 504 apply to private contractors of child welfare agencies and courts?

Answer: Yes. Title II prohibits discrimination in child welfare programs and services when those services are provided by contractors.⁶⁴ Section 504 prohibits discrimination in child welfare programs receiving federal financial assistance, including programs receiving federal financial assistance operated by private entities under contract with child welfare agencies.⁶⁵ Accordingly, to the extent that courts and agencies contract with private agencies and providers to conduct child welfare activities, the agencies should ensure that in the performance of their contractual duties contractors comply with the prohibition of discrimination in Title II and Section 504.⁶⁶

What do the disability nondiscrimination laws require of child welfare agencies and courts?

7. What is a reasonable modification?

Answer: Under Title II of the ADA and Section 504, child welfare agencies and courts must make changes in policies, practices, and procedures to accommodate the individual needs of a qualified person with a disability, unless the change would result in a fundamental alteration to the nature of the program.⁶⁷ Parenting skills do not come naturally to many parents, with or without disabilities. To provide assistance to parents with disabilities that is equal to that offered to parents without disabilities, child welfare agencies may be required to provide enhanced or supplemental training,

to increase frequency of training opportunities, or to provide such training in familiar environments conducive to learning. For example, child welfare agencies may have a parenting skills class once per week. For a parent with a disability who requires individualized assistance in learning new skills because of her or his disability, child welfare agencies may need to modify this training to allow more frequent, longer, or more meaningful training.

8. What are auxiliary aids and services? What does it mean to provide effective communication?

Answer: Child welfare agencies and courts are required to take appropriate steps – including the provision of appropriate auxiliary aids and services – where necessary to ensure that individuals with communication disabilities understand what is said or written and can communicate as effectively as individuals without disabilities.⁶⁸ Examples of auxiliary aids and services include, among others, qualified interpreters, note takers, computer-aided transcription services, accessible electronic and information technology, written materials, telephone handset amplifiers, assistive listening devices, assistive listening systems, telephones compatible with hearing aids, closed caption decoders, open and closed captioning, telecommunications devices for deaf persons (TDD's), videotext displays, qualified readers, taped texts, audio recordings, braille materials, large print materials, and modifications to existing devices.⁶⁹

Child welfare agencies and courts should consider whether they are taking appropriate steps to ensure that effective communication is provided in different settings and as cases develop. For example, a qualified interpreter may be necessary for smaller settings involving only a few people, such as home visits or assessments, whereas the use of real-time captioning may be appropriate during larger group meetings, such as family team meetings or in court, where numerous people are present or where the layout of the room makes it difficult to view an interpreter and obtain visual cues from the speaker.

The type of auxiliary aid or service necessary to ensure effective communication will vary in accordance with the method of communication used by the individual with a disability; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place.⁷⁰ For example, a local child welfare agency may be required to provide qualified interpreters to ensure effective communication with individuals with disabilities during agency meetings to discuss service planning. However, to communicate a simple message such as an appointment date or address, handwritten notes may be sufficient.

State and local child welfare agencies and courts must give primary consideration to the auxiliary aid or service requested by the individual.⁷¹ This means, for

Child welfare agencies must refrain from using minor children as

example, that if a parent with a disability requests a qualified interpreter who is an oral transliterator (a type of interpreter who facilitates spoken communication between individuals who are deaf or hard of hearing and individuals who are not), the agency must provide a qualified oral transliterator, unless the agency can

interpreters except in limited exigent circumstances. Adult companions may be used as interpreters only in emergencies and only when other factors are met.

demonstrate that it would pose a fundamental alteration or an undue administrative or financial burden and an alternative auxiliary aid or service provides communication to the individual that is as effective as communication provided to others.⁷² If provision of a particular auxiliary aid or service would result in a fundamental alteration in the nature of a service, program, or activity, or if it would result in undue financial and administrative burdens, a child welfare agency or court need not provide it.⁷³ These entities must nonetheless provide auxiliary aids or services that do not result in a fundamental alteration or undue burdens that place the individual with a disability on equal footing with individuals without disabilities to the maximum extent possible.

In order to be effective, auxiliary aids and services must be provided in a timely manner and in such a way as to protect the privacy and independence of the individual with a disability.⁷⁴

Child welfare agencies and courts are prohibited from requiring individuals with disabilities to supply their own interpreters or other auxiliary aids and services.⁷⁵ Child welfare agencies and courts may not rely on minor children accompanying individuals with disabilities to interpret, except in emergencies involving imminent threats to the safety or welfare of an individual or the public where no interpreter is available.⁷⁶

Child welfare agencies should consult with and include organizations that support and advocate for the rights of individuals with disabilities in their policy-making and training efforts.

Child welfare agencies and courts may rely on adults accompanying individuals with disabilities to interpret, but only in emergencies or where the individual with a disability specifically makes such a request, the accompanying adult agrees to provide such assistance, and reliance on that adult for such assistance is appropriate under the circumstances.⁷⁷

State and local child welfare agencies and courts are also prohibited from placing a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the costs of the provision of auxiliary aids or other services that are required to provide that individual or group with nondiscriminatory treatment.⁷⁸

9. What steps are child welfare agencies required to take to ensure that parents and prospective

parents with disabilities involved with the child welfare system have an equal opportunity to participate in and benefit from their programs and activities?

Answer: Child welfare agencies are required to ensure that parents and prospective parents with disabilities involved in the child welfare system are afforded an opportunity to preserve their families and/or to become parents that is equal to the opportunity that the entities offer to individuals without disabilities.⁷⁹

Title II and Section 504 require that agency staff refrain from basing assessments, services, or decisions on assumptions, generalizations, or stereotypes about disability.

Agencies should take steps to ensure, for example, that investigators, social workers, supervisors, and others base their assessments of and decisions regarding individuals with disabilities on actual facts that pertain to the individual person, and not on assumptions, generalizations, fears, or stereotypes about disabilities and how they might manifest. The child welfare agency's obligation to ensure individualized assessments applies at the outset and throughout any involvement that an individual with a disability has with the child welfare system.

Child welfare agencies should take steps to ensure that their obligations under Title II and Section 504 are met by reviewing the following:

- existing policies, practices, and procedures;
- how the agency actually processes cases;
- the agency's licensing and eligibility requirements for foster parents and guardians; and
- whether there are staff training or professional development needs.

Service plans for parents and prospective parents should address the individual's disability-related needs and the auxiliary aids and services the agency will provide to ensure equal opportunities. At the same time, service plans should not rely on fears or stereotypes to require parents with disabilities to accept unnecessary services or complete unnecessary tasks to prove their fitness to parent when nondisabled parents would not be required to do so.

Agencies also have an obligation to ensure that the aids, benefits, and services provided to parents and prospective parents in support of appropriate service plan activities and goals – such as visitation, parenting skills training, transportation assistance, counseling, respite, and other “family preservation services” and “family support services” – are appropriately tailored to be useful to the

individual.⁸⁰ For example, if a child welfare agency provides transportation to visits for individuals without disabilities, it should provide accessible transportation to individuals with disabilities to ensure equal opportunity.

To ensure that persons with disabilities have equal opportunity to retain or reunify with their children, it may be necessary for the agency to reasonably modify policies, practices, and procedures in child welfare proceedings. In general, agencies should consider whether their existing policies, practices, and procedures; their actual processing of cases; and their training materials comply with the nondiscrimination requirements of Title II and Section 504 for individuals with disabilities. Agencies should also take appropriate steps to ensure that components of child welfare processing, such as “fast-track” and concurrent planning, are not applied to persons with disabilities in a manner that has a discriminatory effect and that denies parents with disabilities the opportunity to participate fully and meaningfully in family reunification efforts.

In some instances, providing appropriate supports for persons with disabilities means selecting an appropriate alternative already provided in the Federal child welfare statutes. For instance, section 475 of the Social Security Act provides that the child welfare agency is required to file a petition to terminate parental rights when the child is in foster care for the preceding 15 out of 22 months. However, the law provides exceptions to this requirement and gives child welfare agencies the flexibility to work with parents who have a child in foster care beyond the 15 month period, including parents with disabilities.⁸¹ Exceptions to the termination of parental rights requirement include situations where: (1) at the state’s discretion, the child is being cared for by a relative; (2) there is a compelling reason for determining that filing the petition would not be in the best interests of the child; or (3) the state, when reasonable efforts are to be made, has failed to provide such services deemed necessary for the safe return of the child to his or her home.⁸² As to number (3), a child welfare agency should provide the family of the child with the services necessary for the safe return of the child to the child’s home in a manner that meets the unique needs of the family. Failure to provide services, including services to address family members’ disability-related needs, could qualify as an exception to the termination of parental rights requirement. Decisions about whether this exception applies to a situation in which the supports necessary for a person with a disability to access services were not provided should be made on a case-by-case basis.

Given the responsibilities of agencies discussed above, we also recommend that courts consider whether parents and prospective parents with disabilities have been afforded an equal opportunity to attain reunification, including whether they have been provided with appropriate services and supports and other reasonable modifications to enable them to participate fully and meaningfully in family preservation efforts. Additionally, we suggest that courts consider whether any reasonable

modifications are necessary and should be made for parents with disabilities. We also recommend that courts consider evidence concerning the manner in which the use of adaptive equipment or supportive services may enable a parent with disabilities to carry out the responsibilities of parenting.

Foster care and adoption agencies must also ensure that qualified foster parents and prospective parents with disabilities are provided opportunities to participate in foster care and adoption programs equal to opportunities that agencies provide to individuals without disabilities.⁸³ This may require foster care and adoption agencies to reasonably modify policies, practices, and procedures, where necessary to avoid discrimination on the basis of disability. For example, an adoption agency may be required to provide large print and electronically accessible adoption materials to accommodate the known needs of a visually impaired adoption program applicant.

10. When a child welfare agency or court provides or requires an assessment of a parent during the processing of the child welfare case, what do Title II and Section 504 require regarding the assessment?

Answer: Title II and Section 504 require that assessments be individualized.⁸⁴ An individualized assessment is a fact-specific inquiry that evaluates the strengths, needs, and capabilities of a particular person with disabilities based on objective evidence, personal circumstances, demonstrated competencies, and other factors that are divorced from generalizations and stereotypes regarding people with disabilities. Child welfare agencies and courts may also be required to provide reasonable modifications to their policies, practices, or procedures and/or appropriate auxiliary aids and services during assessments to ensure equal opportunities for individuals with disabilities. For example, a child welfare agency or court may be required to provide a qualified sign language interpreter to accommodate an individual with a communication disability during an evaluation to ensure an accurate assessment.

11. How does the equal opportunity requirement apply to case planning activities of child welfare agencies?

Answer: The equal opportunity requirement applies throughout the continuum of a child welfare case, including case planning activities. In many instances, providing the same services and resources to an individual with a disability that are provided to individuals without disabilities will not be sufficient to provide an equal opportunity to an individual with a disability. Where this is the case, Title II and Section 504 may require agencies to provide additional, individually tailored services and resources to meet the requirement to provide an equal opportunity to participate in and benefit from the program. For example, when providing training to parents, agencies should

consider the individual learning techniques of persons with disabilities and may need to incorporate the use of visual modeling or other individualized techniques to ensure equal opportunity to participate in and benefit from the training.

Staff should consider whether the agency is appropriately assisting family members in meeting service plan tasks and case goals, and whether modifications must be made. For example, if parenting training is not working, staff should evaluate whether there are any unnecessary barriers to the training that could be removed or reasonably modified, such as increased opportunities for modeling behavior. Agencies should also ensure that staff members develop appropriate service plan tasks and goals that address the individualized needs of all affected family members with disabilities, recognizing that allowing parents with disabilities to use family members as part of their support network may be appropriate.

12. Is an agency required to arrange for services to parents and prospective parents with disabilities that are necessary to avoid discrimination but are not available within the agency's programs?

Child welfare agencies may be required to modify their own services, or, when necessary, to arrange for services outside of the agency, in order to ensure equal opportunity for parents and prospective parents with disabilities under Title II and Section 504.

Answer: In addition to providing to parents with disabilities all reunification services that it provides to parents without disabilities, a child welfare agency may be required, under Title II and Section 504, to arrange for available services from sources outside of the agency as a reasonable modification of its procedures and practices for parents with disabilities so long as doing so would not constitute a fundamental alteration. Arranging for such services

from outside sources may be necessary to provide an

equal opportunity to participate in and benefit from the agency's programs. Many specialized services to support persons with disabilities are often available from other social service agencies, as well as disability organizations. For example, for a person with a mental health disability, mental health services and supports, such as supportive housing, peer supports, assertive community treatment, and other community-based supports are often available from mental health service agencies. Child welfare agencies should coordinate with such agencies and organizations to ensure that parents and prospective parents with disabilities receive the most complete set of support services possible, and also to ensure that reunification and other services are specifically tailored to their needs.⁸⁵ This requirement does not change an entity's responsibility to make available those reunification services provided to parents without disabilities or to reasonably modify them to provide equal opportunity.

13. Are child welfare agencies and courts permitted to impose a surcharge on persons with disabilities for the provision of reasonable modifications or auxiliary aids and services?

Answer: No. Title II prohibits the imposition of surcharges to cover the costs of measures required to provide an individual with nondiscriminatory treatment.⁸⁶ For example, child welfare agencies and courts may not charge persons with disabilities for any costs associated with providing effective communication during visitation, meetings, and court hearings, and may be required to provide transportation to accessible facilities when needed to fulfill their program access obligations.

14. Child welfare agencies have an obligation to ensure the health and safety of children. How can agencies comply with the ADA and Section 504 while also ensuring health and safety?

Answer: Under child welfare law, child welfare agencies must make decisions to protect the safety of children. The ADA and Section 504 are consistent with the principle of child safety. For example, the ADA explicitly makes an exception where an individual with a disability represents a "direct threat."⁸⁷ Section 504 incorporates a similar principle.⁸⁸

Under the ADA and Section 504, a direct threat is a 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.⁸⁹ In determining whether an individual poses a direct threat to the health or safety of a child or others, child welfare agencies and courts 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 to the child; the probability that the potential injury to the child will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk.⁹⁰

As such, in some cases an individual with a disability may not be a qualified individual with a disability for child placement purposes. What both the ADA and Section 504 require, however, is that decisions about child safety and whether a parent, prospective parent, or foster parent represents a direct threat to the safety of the child must be based on an individualized assessment and objective facts and may not be based on stereotypes or generalizations about persons with disabilities.⁹¹

15. What are some other best practices for child welfare agencies and courts?

Answer: We recommend that child welfare agencies and courts review and update their policies and procedures on a regular basis to ensure that they comply with the ADA and Section 504. We recommend that child welfare agencies and courts also ensure that their employees and

contractors are sufficiently trained in ADA and Section 504 compliance. In addition, we recommend that they look for ways to coordinate with disability organizations and agencies to assist in service planning and to support them in their efforts to ensure equal opportunity for parents and prospective parents with disabilities.

How can aggrieved persons file a complaint?

16. What can individuals do when they believe they have been subjected to discrimination in violation of Title II or Section 504?

Answer: An aggrieved person may raise a Title II or Section 504 claim in child welfare proceedings. Additionally, subject to certain limitations, an aggrieved person may pursue a complaint regarding discrimination in child welfare services, programs, or activities under Title II or Section 504 in federal court.⁹²

Aggrieved individuals may also file complaints with HHS and DOJ. HHS and DOJ also have authority to initiate compliance review investigations of child welfare agencies and courts with or without receiving a complaint. If an investigation of a complaint or a compliance review reveals a violation, HHS or DOJ may issue letters of findings and initiate resolution efforts.⁹³ DOJ may initiate litigation when it finds that a child welfare agency or court is not in compliance with Title II. HHS may also refer cases to DOJ for litigation where a violation is found and is not voluntarily resolved.⁹⁴

Title II and Section 504 allow for declaratory and injunctive relief, such as an order from a court finding a violation and requiring the provision of reasonable modifications. Title II and Section 504 also allow for compensatory damages for aggrieved individuals. Individuals who prevail as parties in litigation may also obtain reasonable attorney's fees, costs, and litigation expenses.⁹⁵

Under Section 504, remedies also include suspension and termination of Federal financial assistance, the use of cautionary language or attachment of special conditions when awarding Federal financial assistance, and bypassing recalcitrant agencies and providing Federal financial assistance directly to sub-recipients.⁹⁶

Additional Resources

For more information about the ADA and Section 504, you may call the DOJ's toll-free ADA information line at 800-514-0301 or 800-514-0383 (TDD), or access its ADA website at www.ada.gov. For more information about the responsibilities of child welfare agencies under the ADA and Rehabilitation Act, see "DOJ/HHS Joint Letter to Massachusetts Department of Children

and Families,” at www.ada.gov/new.htm. For more information about Title II of the ADA, including the Title II Technical Assistance Manual and Revised ADA Requirements: Effective Communication, see www.ada.gov/ta-pubs-pg2.htm.

Information about filing an ADA or Section 504 complaint with DOJ can be found at www.ada.gov/filing_complaint.htm. Individuals who believe they have been aggrieved under Title II or Section 504 should file complaints at the earliest opportunity.

You can also file a Section 504 or Title II ADA complaint with OCR at <http://www.hhs.gov/ocr/civilrights/complaints/index.html>.

General information about civil rights and child welfare issues can be found at: <http://www.hhs.gov/ocr/civilrights/resources/specialtopics/adoption/index.html>.

For information about ACF's Children Bureau, please visit: <http://www.acf.hhs.gov/programs/cb>.

For ACF and OCR regional offices, please visit:

- <http://www.acf.hhs.gov/programs/oro>
- <http://www.hhs.gov/ocr/office/about/rgn-hqaddresses.html>

Duplication of this document is encouraged.

August 2015

¹ The term “parents” includes biological, foster, and adoptive parents. It also includes caretakers such as legal guardians or relatives.

Prospective parents include individuals who are seeking to become foster or adoptive parents.

² 29 U.S.C. § 794.

³ 42 U.S.C. §§ 12131-12134.

⁴ Children with disabilities also have nondiscrimination protections under Section 504 and Title II of the ADA, but the focus of this technical assistance is on parents and prospective parents with disabilities.

⁵ Letter from the U.S. Department of Justice, Civil Rights Division and U.S. Department of Health and Human Services, Office for Civil Rights to

the Massachusetts Department of Children and Families (Jan. 29, 2015), at www.ada.gov/ma_docf_lof.pdf and www.hhs.gov/ocr/civilrights/activities/examples/Disability/mass_lof.pdf (Massachusetts Department of Children and Families).

⁶ National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* at 14, 18 (2012), at www.ncd.gov/publications/2012/Sep272012/.

⁷ *Id.* at 114, 122-26.

⁸ *Id.* at 92-93.

⁹ *Id.* at 194-199.

¹⁰ *Id.* at 114.

¹¹ *Id.* at 125-26.

¹² 42 U.S.C. § 12132.

¹³ 42 U.S.C. § 12131(1)(A), (B); *see also, e.g.*, 28 C.F.R. § 35.130(b)(1) (prohibiting disability discrimination directly or through contractual, licensing, or other arrangements), 35.130(b)(3) (prohibiting methods of administration that have a discriminatory effect). Private entities involved in the child welfare system may also be independently covered by Title III of the ADA, 42 U.S.C. §§ 12181-12189.

¹⁴ 29 U.S.C. § 794(a).

¹⁵ *See, e.g.*, 28 C.F.R. § 42.105; 45 C.F.R. § 84.5.

¹⁶ *See Grove City College v. Bell*, 465 U.S. 555, 564 (1984).

¹⁷ 29 U.S.C. § 794(b).

¹⁸ *See, e.g.*, 45 C.F.R. § 84.5.

¹⁹ *See* 28 C.F.R. § 35.130(b)(3); 45 C.F.R. § 84.4(b)(4); *see also* 28 C.F.R. § 42.503(b)(3).

²⁰ *See, e.g.*, 28 C.F.R. § 35.130(b); *see also* 28 C.F.R. pt. 35, App. B (explaining in the 1991 Section-by-Section guidance to the Title II regulation that, “[t]aken together, the[] provisions [in 28 C.F.R. § 35.130(b)] are intended to prohibit exclusion . . . of individuals with

disabilities and the denial of equal opportunities enjoyed by others, based on, among other things, presumptions, patronizing attitudes, fears, and stereotypes about individuals with disabilities. Consistent with these standards, public entities are required to ensure that their actions are based on facts applicable to individuals and not presumptions as to what a class of individuals with disabilities can or cannot do.”); *School Bd. of Nassau County v. Arline*, 480 U.S. 273, 285 (1987).

²¹ See, e.g., *id.*

²² See 28 C.F.R. §§ 35.130(b)(1)(ii)-(iv), (vii), (b)(7); 45 C.F.R. § 84.4(b)(1)(ii)-(iii); see also 28 C.F.R. § 42.503(b)(1)(ii), (iii).

²³ See, e.g., 28 C.F.R. § 35.130(b)(1)(ii)-(iv).

²⁴ *Id.*; see also *Alexander v. Choate*, 469 U.S. 287 (1985).

²⁵ 28 C.F.R. §§ 35.149-151, 160-164; 45 C.F.R. §§ 84.21-23, 84.52(d); see also 28 C.F.R. §§ 42.503(e), (f), 42.520-522.

²⁶ See 45 C.F.R. §§ 84.12(a), 84.22(a) and (f), and 84.52(d); and 28 C.F.R. § 35.130(b)(7).

²⁷ 28 C.F.R. § 35.139(a)-(b); *Arline*, 273 U.S. at 287.

²⁸ 28 C.F.R. § 35.139(b); *Arline*, 273 U.S. at 288.

²⁹ 28 C.F.R. § 35.139(b); *Arline*, 273 U.S. at 288.

³⁰ See 28 C.F.R. § 35.130(h).

³¹ 42 U.S.C. § 12132.

³² 29 U.S.C. § 794(a).

³³ 42 U.S.C. § 12132; 29 U.S.C. § 794(a); 28 C.F.R. § 35.130(a); 45 C.F.R. § 84.4(a).

³⁴ *Choate*, 469 U.S. 287.

³⁵ 28 C.F.R. § 35.150(a); 45 C.F.R. § 84.22(a).

³⁶ 28 C.F.R. § 35.130(b)(1)(ii); 45 C.F.R. § 84.4(b)(1)(ii);

³⁷ 28 C.F.R. § 35.130(b)(3); 45 C.F.R. § 84.4(b)(4).

³⁸ 28 C.F.R. § 35.130(b)(7); *Choate*, 469 U.S. at 301.

[39](#) 28 C.F.R. § 35.160(a)(1); *see also* 45 C.F.R. § 84.52(d) (requiring health and social services entities to provide appropriate auxiliary aids to persons with impaired sensory, manual, or speaking skills, where necessary to afford such persons an equal opportunity to benefit from the service in question).

[40](#) 42 U.S.C. § 12132; 29 U.S.C. § 794(a).

[41](#) 42 U.S.C. § 12102(1), (2)(A); 29 U.S.C. § 705(9)(B).

[42](#) 42 U.S.C. § 12102(2)(B).

[43](#) 42 U.S.C. § 12102(4)(A); 29 U.S.C. § 705(9)(B).

[44](#) 42 U.S.C. § 12102(4)(E)(i); 29 U.S.C. § 705(9)(B); *see also* Equal Employment Opportunity Commission, Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008, at www.eeoc.gov/laws/regulations/ada_qa_final_rule.cfm.

[45](#) 42 U.S.C. § 12102(2)(1)(B)-(C); 29 U.S.C. § 705(9)(B). The ADA Amendments Act of 2008 amended the definition of disability for Titles I, II, and III of the ADA as well as Section 504. Pub. L. No. 110 - 325, 122 Stat. 3553 (2008). For a discussion of the United States Department of Justice's (DOJ's) interpretation of the changes to the definition, *see* DOJ's Notice of Proposed Rulemaking to Implement ADA Amendments Act of 2008, 79 Fed. Reg. 4839 (January 30, 2014). *See also* Equal Employment Opportunity Commission, Questions and Answers on the Final Rule Implementing the ADA Amendments Act of 2008, at www.eeoc.gov/laws/regulations/ada_qa_final_rule.cfm.

[46](#) 42 U.S.C. § 12210(a); 29 U.S.C. § 794(d).

[47](#) 42 U.S.C. § 12210(b)(1)-(2); 29 U.S.C. § 794(d).

[48](#) 42 U.S.C. § 12131(1); 28 C.F.R. § 35.104; *see also* 45 C.F.R. § 84.3(l)(4) (defining "qualified handicapped person" under HHS' Section 504 regulation).

[49](#) For a discussion of a "qualified individual with a disability," *see* discussion *supra* at Q&A 2.

[50](#) 28 C.F.R. § 35.130(g); 28 C.F.R. pt. 35, App. B.

[51](#) 28 C.F.R. § 35.160(a)(2).

[52](#) 28 C.F.R. § 35.160(a)(1); 28 C.F.R. pt. 35, App. A., Subpt. E (2010).

[53](#) 42 U.S.C. § 12203; 28 C.F.R. § 35.134; 45 C.F.R. § 84.61; 45 C.F.R. § 80.7(e).

[54](#) See *Pa. Dep't. of Corrs. v. Yeskey*, 524 U.S. 206, 209-12 (1998) (discussing the breadth of Title II's coverage).

[55](#) See 29 U.S.C. § 794(b)(1)(A), (B).

[56](#) See 28 C.F.R. §§ 35.130(b)(1), (3), 42.503(b)(1), (3); 45 C.F.R. § 84.4(b)(1), (4).

[57](#) See *Yeskey*, 524 U.S. at 209-12 (discussing the breadth of Title II's coverage); cf. *Shelley v. Kraemer*, 334 U.S. 1 (1948) (finding judicial enforcement of racially discriminatory restrictive covenants state action in violation of the Fourteenth Amendment). See also 28 C.F.R. § 35.190(b)(6) (designating to the DOJ responsibility for investigation of complaints and compliance reviews of “[a]ll programs, services, and regulatory activities relating to . . . the administration of justice, including courts.”).

[58](#) 29 U.S.C. § 794; see *U.S. Dep't of Transp. v. Paralyzed Veterans of America*, 477 U.S. 597, 600 n.4 (1986). We also remind judges and court personnel of their obligations under the [American Bar Association, Model Code of Judicial Conduct, Rule 2.3 \(b\)](#) that states: “A judge shall not, in the performance of judicial duties, by words or conduct manifest bias or prejudice, or engage in harassment, including but not limited to bias, prejudice, or harassment based upon race, sex, gender, religion, national origin, ethnicity, disability, . . . and shall not permit court staff, court officials, or others subject to the judge’s direction and control to do so.”

[59](#) See 28 C.F.R. § 35.130; 45 C.F.R. § 84.4; see also 28 C.F.R. § 42.503.

[60](#) 28 C.F.R. § 35.160-.164; 45 C.F.R. § 84.52(d); see also 28 C.F.R. § 42.503(f).

[61](#) 28 C.F.R. § 35.130(b)(7); see also *Choate*, 469 U.S. at 304-06.

⁶² In addition, advocacy organizations, such as those within the Protection and Advocacy system, may provide assistance to individuals with disabilities when they become involved with the child welfare system.

⁶³ See 28 C.F.R. § 35.130(b)(7), 35.160-.164; *see also Choate*, 469 U.S. at 300-309.

⁶⁴ See 28 C.F.R. § 35.130(b)(1), (3).

⁶⁵ 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.3(h); 84.4(b)(1), (4).

⁶⁶ Private entities involved in child welfare activities may also be public accommodations with their own nondiscrimination obligations under Title III of the ADA. See 42 U.S.C. §§ 12181-12189 (Title III of the ADA).

⁶⁷ See 28 C.F.R. § 35.130(b)(7); 45 C.F.R. § 84.22(a). A fundamental alteration can be a change that is so significant that it alters the essential nature of the public entity's service, program, or activity. *Id.*; *cf.* U.S. Dep't of Justice, ADA Title III Technical Assistance Manual Covering Public Accommodations and Commercial Facilities § III-4.3600 (discussing a fundamental alteration as a modification that is so significant it alters the essential nature of services, privileges, and accommodations). A fundamental alteration is necessarily highly fact-specific. Child welfare entities have the burden of establishing that a proposed action would fundamentally alter the service, program, or activity or would result in undue financial and administrative burdens. A public entity still must take any other action that would not result in such an alteration or such burdens but would nevertheless ensure that, to the maximum extent possible, individuals with disabilities receive the benefits or services provided by the public entity.

⁶⁸ 28 C.F.R. § 35.160; 45 C.F.R. § 84.52(d).

⁶⁹ 42 U.S.C. § 12103(1); 28 C.F.R. § 35.104.

⁷⁰ 28 C.F.R. § 35.160(b)(2). For further information on ensuring effective communication, see U.S. Dep't of Justice, ADA Requirements: Effective Communication (Jan. 31, 2014), at www.ada.gov/effective-comm.htm; *see also* U.S. Dep't of Justice and U.S. Dep't of Educ.,

Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools (2015), at www.ada.gov/doe_doj_eff_comm/doe_doj_eff_comm_faqs.pdf.

⁷¹ 28 C.F.R. § 35.160(b)(2).

⁷² 28 C.F.R. §§ 35.160(b)(2); 35.164.

⁷³ See *supra* footnote 70.

⁷⁴ 28 C.F.R. § 35.160(b)(2).

⁷⁵ 28 C.F.R. § 35.160(c)(1).

⁷⁶ 28 C.F.R. § 35.160(c)(2)(i), (3).

⁷⁷ 28 C.F.R. § 35.160(c)(2)(ii).

⁷⁸ See 28 C.F.R. § 35.130(f).

⁷⁹ 28 C.F.R. § 35.130(b)(1)(ii); 45 C.F.R. §§ 84.4(b)(1)(ii), 84.52(a)(2).

⁸⁰ "Family preservation services" are services for children and families to protect children from harm and to help families at risk or in crisis. 42 U.S.C. § 629a(a)(1); 45 C.F.R. § 1357.10(c). "Family support services" are community-based services to promote the safety and well-being of children and families, to increase the strength and stability of families in various ways, and to enhance child development. 42 U.S.C. § 629a(a)(2); 45 C.F.R. § 1357.10(c).

⁸¹ 42 U.S.C. § 675(5)(E); 45 C.F.R. § 1356.21(i).

⁸² 42 U.S.C. § 675(5)(E)(i)-(iii); 45 C.F.R. § 1356.21(i)(2)(i)-(iii).

⁸³ 42 U.S.C. § 12132; 29 U.S.C. § 794(a); 28 C.F.R. pt. 35 (Title II); 28 C.F.R. pt. 42, subpt. G (DOJ Section 504 regulation); 45 C.F.R. pt. 84 (HHS Section 504 regulation).

⁸⁴ See 28 C.F.R. pt. 35, App. B; *cf. PGA Tour, Inc. v. Martin*, 532 U.S. 661, 690 (2001) (explaining that an individualized inquiry is among the ADA's most "basic requirement[s]").

⁸⁵ See 28 C.F.R. § 35.130(b)(1)(i)-(iv), (b)(7).

[86](#) See 28 C.F.R. § 35.130(f).

[87](#) 28 C.F.R. § 35.139.

[88](#) See *Arline*, 480 U.S. 273.

[89](#) 28 C.F.R. § 35.139(b).

[90](#) *Id.*

[91](#) See 28 C.F.R. § 35.139.

[92](#) See 28 C.F.R. §§ 35.170-172; 45 C.F.R. § 84.61; see also 28 C.F.R. § 42.530. In addition, child welfare agencies and courts that employ 50 or more persons are required to have grievance procedures for prompt and equitable resolution of complaints alleging actions prohibited by Title II and Section 504. 28 C.F.R. § 35.107; 45 C.F.R. § 84.6; see also 28 C.F.R. § 42.505.

[93](#) 28 C.F.R. §§ 35.172(c), 35.173; 45 C.F.R. § 84.61; see also 28 C.F.R. § 42.530.

[94](#) 28 C.F.R. § 35.174; 45 C.F.R. § 84.61.

[95](#) 42 U.S.C. § 12205; 29 U.S.C. § 794a(b); 28 C.F.R. § 35.175.

[96](#) See 42 U.S.C. § 2000d-1.

The Americans with Disabilities Act authorizes the Department of Justice (the Department) to provide technical assistance to individuals and entities that have rights or responsibilities under the Act. This document provides informal guidance to assist you in understanding the ADA and the Department's regulations.

This guidance document is not intended to be a final agency action, has no legally binding effect, and may be rescinded or modified in the Department's complete discretion, in accordance with applicable laws. The Department's guidance documents, including this guidance, do not establish legally enforceable responsibilities beyond what is required by the terms of the applicable statutes, regulations, or binding judicial precedent.

AGREEMENT BETWEEN
UNITED STATES DEPARTMENT OF JUSTICE,
UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES,
AND
MASSACHUSETTS DEPARTMENT OF CHILDREN AND FAMILIES

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I. BACKGROUND

A. Introduction

1. This Agreement is entered by and between the U.S. Department of Justice (“DOJ”) and the U.S. Department of Health and Human Services (“HHS”) (collectively, the “Departments”) and the Massachusetts Department of Children and Families (“DCF”) to resolve the Departments’ findings that DCF discriminated by reason of disability in violation of Title II of the Americans with Disabilities Act (“ADA”), 42 U.S.C. §§ 12131-12134, and its implementing regulation, 28 C.F.R. Part 35, and Section 504 of the Rehabilitation Act of 1973 (“Section 504”), as amended, 29 U.S.C. § 794, and its implementing regulation, 45 C.F.R. Part 84. DOJ, HHS, and DCF are referred to collectively in this Agreement as the “Parties.”

B. Federal Investigation & Letter of Findings

2. Following an investigation of DCF (DJ # 204-36-216 and HHS # 14-182176), DOJ and HHS issued a joint Letter of Findings to DCF on January 29, 2015. As stated therein, DOJ and HHS determined that DCF discriminated against a mother with a developmental disability in violation of Title II of the ADA and Section 504. *See* Joint Letter of Findings, https://www.ada.gov/ma_docf_lof.doc. DCF disputes these findings and denies any and all allegations of discrimination and any and all allegations that DCF violated the law.
3. DOJ thereafter substantiated the allegations in numerous additional complaints from parents with physical, hearing, developmental, and other disabilities alleging that DCF failed to provide them with needed reasonable modifications, effective communication, and an equal opportunity to benefit from DCF’s programs and services. DOJ further substantiated allegations that DCF’s methods of administering its programs and services have the effect of subjecting parents with disabilities to discrimination, and of defeating or substantially impairing accomplishment of the objectives of DCF’s programs with respect to parents with disabilities. DCF denies DOJ’s allegations of discrimination and any and all allegations that DCF violated the law.
4. This Agreement does not amount to any admission of wrongdoing by DCF. This Agreement does not affect DCF’s continuing responsibility to comply with the ADA and Section 504. This Agreement does not constitute a finding by the Departments about whether DCF is in full compliance with the ADA or Section 504.
5. Subject to the provisions set forth herein, this Agreement resolves the Departments’ findings in their joint Letter of Findings dated January 29, 2015, as well as all Disability-Related Complaints against DCF received by the Departments up to and including the Effective Date of this Agreement, except as set forth in Part VI of this Agreement.

C. Parties & Jurisdiction

6. DOJ is responsible for administering and enforcing Title II of the ADA and its implementing regulation. DOJ is authorized, under 28 C.F.R. Part 35, Subpart F, to investigate alleged violations of Title II of the ADA, to issue findings, and, where appropriate, to negotiate and secure voluntary compliance agreements or take other enforcement actions authorized by law.
7. HHS is authorized under 28 C.F.R. Part 35, Subpart G, to conduct compliance reviews and investigate alleged violations of Title II of the ADA by a public entity relating to the provision of health care and social services. HHS is also responsible for investigating complaints and conducting compliance reviews to determine if recipients of HHS funding operate their programs and activities in compliance with Section 504, and, where appropriate, take enforcement actions authorized by law.
8. DCF is an agency of the Commonwealth of Massachusetts, under the authority of the Executive Office of Health and Human Services, that administers and provides, through its Central, Regional, and Area Offices, *inter alia*, a child welfare program for children and families in the Commonwealth.
9. DCF is a “public entity” within the meaning of Title II of the ADA. 42 U.S.C. § 12131(1); 28 C.F.R. § 35.104.
10. DCF is a recipient of financial assistance from HHS, including grants under Titles IV-B and IV-E of the Social Security Act, within the meaning of Section 504, 29 U.S.C. § 794 and 45 C.F.R. § 84.3, and is therefore subject to the requirements of Section 504.
11. DCF provides services, programs, and activities within, *inter alia*, the meaning of Title II of the ADA and Section 504, including assessment and action/service planning, family support services, parent aides, in-home parenting supports, providing parent-child visitation, and other contact with children placed in substitute care. *See* 29 U.S.C. § 794; 42 U.S.C. § 12132; 28 C.F.R. § 35.130; 45 C.F.R. § 84.3.

D. Definitions

12. “Action Plan” (formerly referred to in DCF policies as “Service Plan”) is a written document describing the goals and objectives that DCF-involved parents must meet, the tasks that must be undertaken by DCF-involved parents, and the services to be provided to achieve the goal of strengthening and preserving the family unit, reunifying a family unit for a child who has been removed, or providing an alternative permanent home for a child who has been removed from his or her home. An Action Plan, to the maximum extent possible, is jointly developed between DCF and the family receiving services from DCF. An Action Plan is reviewed during each case review or every six (6) months. For purposes of this Agreement, the term “Action Plan” also encompasses “Action Planning.”

13. “Auxiliary Aids and Services” are defined in the regulation implementing Title II of the ADA, 28 C.F.R. § 35.104.
14. “Disability” is defined pursuant to Title II of the ADA, 42 U.S.C. § 12102, and its implementing regulation, 28 C.F.R. § 35.108.
15. “Disability discrimination,” as used in this Agreement, refers to violations of Title II of the ADA and Section 504 and their implementing regulations.
16. “Disability-Related Complaints,” as used in this Agreement, refers to both complaints of disability discrimination as defined herein, as well as violations of DCF’s Parents with Disabilities Policy established pursuant to Part IV.B and Appendix A *infra*. This includes any and all complaints subject to Part VI *infra*.
17. “Offices,” as used in this Agreement, refer to the current organizational structure of DCF, which includes one “Central Office” in Boston, five “Regional Offices,” and twenty-nine “Area Offices” across the Commonwealth, as well as any future office-based child welfare services provided by DCF that are organized by geographic regions and areas consistent with those established by the Massachusetts Secretary of Health and Human Services under section 16 of chapter 6A of the General Laws of Massachusetts.
18. “DCF-Involved Parent,” for purposes of this Agreement, means a child’s mother, father, or legal guardian who is being investigated by DCF or who has an open clinical case with DCF, regardless of whether the case is opened due to court involvement or receiving in-home services.
19. For purposes of this Agreement, the term “reasonable modification” from the Title II regulation, 28 C.F.R. § 35.130(b)(7), is used interchangeably with the term “reasonable accommodation” under Section 504. The term “reasonable accommodation,” for purposes of this Agreement, reflects its meaning under Section 504 and does not reflect the meaning of this term under Title I of the ADA.
20. “Regional Disability Liaison” is defined *infra* in Part III.B.
21. The Parties agree that it is in their mutual interest and the public interest to resolve this matter on mutually agreeable terms and without litigation. Accordingly, the Parties have voluntarily entered into this Agreement, as follows:

II. GENERAL NONDISCRIMINATION PROVISIONS

22. With respect to a DCF-involved parent with a disability, DCF agrees to comply, and through the Commonwealth of Massachusetts’ standard terms and conditions for contracts requires signatories thereto to comply, with Title II of the ADA, Section 504, and their implementing regulations, including the following requirements:

- a. DCF will not exclude from or otherwise deny the benefits of its services, programs, or activities to a DCF-involved parent with a disability on the basis of disability. DCF will also not exclude or otherwise deny equal services, programs, or activities to a parent or other individual because of their relationship or association with a DCF-involved parent with a disability. *See* 42 U.S.C. § 12132; 29 U.S.C. § 794(a); 28 C.F.R. § 35.130(a), (g); 45 C.F.R. §§ 84.4(a), 84.52(a).
- b. DCF will ensure that DCF-involved parents with disabilities are afforded an opportunity to preserve their families that is equal to the opportunity that DCF offers to individuals without disabilities. 28 C.F.R. § 35.130(b) & (g); 45 C.F.R. §§ 84.4(b)(1)(ii), 84.52(a)(2).
- c. DCF may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities. DCF will ensure that its safety requirements are based on actual risks that pertain to the individual parent and child(ren) and not on mere speculation, generalizations, or stereotypes about individuals with disabilities. *See* 28 C.F.R. § 35.130(h); 45 C.F.R. §§ 84.4(b), 84.52(a)(2)-(a)(5).
- d. DCF will make reasonable modifications in policies, practices, and procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless DCF can demonstrate that making a modification would fundamentally alter the nature of the service, program, or activity or be an undue financial or administrative burden. Reasonable modifications should be appropriately tailored to the needs of the DCF-involved parent with a disability. *See* 28 C.F.R. § 35.130(b)(7); 45 C.F.R. § 84.4(a), (b)(vii).
- e. DCF will take appropriate steps to ensure that communications with DCF-involved parents with disabilities and their companions are as effective as communications with others and that DCF-involved parents with disabilities receive appropriate auxiliary aids and services when necessary to afford them an equal opportunity to participate in and enjoy the benefits of DCF's services, programs, and activities, unless DCF can demonstrate that doing so would result in a fundamental alteration in the nature of the service program or activity or in an undue financial and administrative burden. 28 C.F.R. §§ 35.160(a)-(b), 35.164; 45 C.F.R. § 84.52(d).
- f. DCF will adopt and publish grievance procedures providing for prompt and equitable resolution of complaints alleging disability discrimination, and will designate at least one employee to coordinate its efforts to comply with and carry out its responsibilities under the ADA and Section 504, including investigation of any complaint alleging disability discrimination. 28 C.F.R. § 35.107; 45 C.F.R. § 84.7.
- g. DCF will ensure that no surcharge will be placed on a particular DCF-involved parent with a disability or any group of DCF-involved parents with disabilities to

cover the costs of measures, such as the provision of auxiliary aids or program accessibility, that are required for DCF to provide such parent(s) with nondiscriminatory treatment. 28 C.F.R. § 35.130(f); 45 C.F.R. §§ 84.4(a), 84.52(d).

- h. DCF also will not utilize criteria or methods of administration that have the effect of discriminating on the basis of disability. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(b)(3); 45 C.F.R. § 84.4(b)(4); *see also* 28 C.F.R. pt. 35, App. B (discussing 28 C.F.R. § 35.130(b)(3)).
23. Nothing in this agreement prohibits DCF from removing, or initiating or implementing actions to remove, a child from a parent with a disability if DCF determines that the child is at imminent risk of abuse and/or neglect. However, DCF will not base decisions about removal of a child on stereotypes or generalizations about persons with disabilities, or on a parent's disability, diagnosis, or intelligence measures (e.g., IQ scores) alone. Rather, DCF will base such decisions on an individualized assessment of the parent with a disability and objective facts. Even if DCF determines that a child must be removed from the home, DCF may be required to permit the parent to participate in and benefit from DCF's services, programs, and activities, unless the parent poses a direct threat to the health or safety of others when participating in such services, programs, and activities. In determining whether an individual poses a direct threat to the health or safety of others, DCF 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. 28 C.F.R. § 35.139; 45 C.F.R. §§ 84.4(a), (b)(1), (b)(4).
24. DCF will not coerce, intimidate, threaten, interfere, or engage in other discriminatory or retaliatory conduct against anyone because he or she has either taken action or participated in an action to secure rights protected by the ADA and Section 504, including making a request for reasonable accommodations or auxiliary aids and services or filing a disability discrimination complaint with DCF, DOJ, or HHS. *See* 42 U.S.C. § 12203; 45 C.F.R. § 80.7(e).

III. DISABILITY COORDINATOR AND REGIONAL DISABILITY LIAISONS

25. Within one (1) month of the Effective Date of this Agreement, DCF will appoint or otherwise designate a Statewide Disability Coordinator ("Disability Coordinator") to carry out the day-to-day responsibility for compliance with Title II of the ADA and Section 504, their implementing regulations, and the provisions of this Agreement, and will notify the Departments when they have done so. The Disability Coordinator will

have professional experience with Title II of the ADA and Section 504 and their implementing regulations.

26. Within one (1) month of the Effective Date of this Agreement, DCF will appoint or otherwise designate at least one DCF Deputy Regional Counsel as a Regional Disability Liaison for each of its Regional Offices, and will notify the Departments when they have done so. DCF reserves the right to change who fills each Regional Disability Liaison position if necessary, depending, for example, on the volume of cases under review by the Regional Disability Liaison or if DCF determines over time that the role would be better served by a member of the clinical staff. DCF will promptly notify the Departments by e-mail of any change to who fills each Regional Disability Liaison position during the term of this Agreement.
27. The Disability Coordinator and Regional Disability Liaisons will be responsible for the following, and for reporting such information to DCF's policy and training units and General Counsel's Office on a regular basis:
 - a. Reviewing DCF's policies, practices, procedures, and regulations pursuant to Part IV *infra*;
 - b. Identifying emerging and best practices in assisting DCF-involved parents with disabilities involved with child welfare programs;
 - c. Identifying and, where possible, fostering the development of disability resources and supports;
 - d. Meeting on a regular basis with individuals, agencies, and organizations external to DCF that are involved with the Massachusetts child welfare program and/or have expertise working with DCF-involved parents with disabilities; and
 - e. Providing input to DCF on the development of training and professional development opportunities for investigators, social workers, supervisors, and other DCF staff.
28. The Disability Coordinator will work with the Regional Disability Liaisons to review, resolve, and record Disability-Related Complaints, as defined herein.
29. The Disability Coordinator and Regional Disability Liaisons will be responsible for reviewing, resolving, and recording requests for reasonable accommodations and auxiliary aids and services; assisting Area Office staff, as needed, regarding the handling of such requests; and for ensuring that, when necessary to avoid discrimination on the basis of disability, any reasonable accommodations or auxiliary aids and services requested are provided in an appropriate and timely manner in accordance with the ADA, Section 504, and the Parents with Disabilities Policy, established pursuant to Part IV.B and Appendix A *infra*.

30. The Disability Coordinator will be responsible for maintaining a centralized, electronic, searchable database or log that tracks the information required in Part VII *infra*, and reporting it to the Departments.
31. The mailing address, email address, and telephone number (including TTY number and toll-free number) for the Disability Coordinator will be posted prominently on the homepage of DCF's website, currently located at <http://www.mass.gov/eohhs/gov/departments/DCF/>.
32. Within two (2) months of the Effective Date of this Agreement, DCF will provide notice to all DCF staff and administrators regarding the appointment of the Disability Coordinator and Regional Disability Liaisons, which will include a description of the positions' responsibilities contained in this Part. DCF will provide a copy of the notice to the Departments upon completion.

IV. WRITTEN POLICIES, PRACTICES, AND PROCEDURES

A. Review and Revise DCF Policies

33. Within three (3) months of the Effective Date of this Agreement, the Departments will review and propose amendments to, as necessary, DCF's Permanency Planning Policy # 2013-01 (effective 7/1/2013), Protective Intake Policy # 86-015 (revised 6/22/2020), Family Assessment & Action Planning Policy # 2017-01 (effective 2/6/2017), Family Resource Policy # 2006-01 (revised 7/8/2008), and any other DCF policies (including appendices and implementation tools and protocols) that cite disability or any specific disability, impairment, medical condition, intelligence measure (e.g., IQ score), or diagnosis to remove the mere fact of such disability, impairment, condition, intelligence measure, or diagnosis as a basis for removal of custody (legal, physical, or otherwise) and to reflect the requirements under the ADA and Section 504 that individuals with disabilities must be treated on a case-by-case basis consistent with facts and objective evidence, and may not be treated on the basis of generalizations or stereotypes. For example, prohibited treatment would include the removal of a child from a parent with a developmental or intellectual disability based on the stereotypical belief, unsupported by individual facts and objective evidence, that people with developmental or intellectual disabilities (or with an IQ score below a certain number) are unable to safely parent their children.
34. Within three (3) months of receiving proposed revisions from the Departments, DCF will make good faith efforts, including working with the relevant Unions, to implement the revised policies and will distribute them to all employees and contractors. If DCF disagrees with any of the Departments' comments, the Parties will work together, within that three-month period, to discuss DCF's concerns and to try to reach agreement on the proposed revisions. If the Parties cannot agree on the revisions, then the Parties may utilize the dispute resolution procedure set out in paragraph 58. If DCF is unable to implement within three (3) months, DCF will provide a detailed monthly progress report until implementation has been accomplished. Implementation will be

accomplished no later than nine (9) months after the Departments have provided proposed revisions. Any further extensions may be requested pursuant to the process set forth in Paragraph 66.

35. DCF will ensure that all new and existing DCF policies, regulations, and procedures are fully compliant with the requirements of this Agreement and the Parents with Disabilities Policy, as described below.

B. Parents with Disabilities Policy

36. Within eight (8) months of the Effective Date of this Agreement DCF will develop and provide to the Departments a draft “Parents with Disabilities Policy” to ensure that DCF-involved parents with disabilities are provided an equal opportunity to benefit from and participate in DCF’s services, programs, and activities consistent with the requirements of the ADA, Section 504, and their implementing regulations. This policy must address and comply with all of the requirements of Appendix A to this Agreement, including development and implementation of a Disability-Related Complaints Process.
37. Upon receipt of the draft Parents with Disabilities Policy from DCF, the Departments may review and provide DCF with comments and suggestions to ensure compliance with this Agreement, Title II of the ADA, and Section 504, which DCF will incorporate. Within three (3) months of receiving any revisions from the Departments, DCF will make good faith efforts, including working with the relevant Unions, to implement the revised Parents with Disabilities Policy and will distribute it to all employees and contractors, and, when implemented, will maintain its implementation for, at minimum, the term of this Agreement. If DCF disagrees with any of the Departments’ comments, the Parties will work together, within that three-month period, to discuss DCF’s concerns and to try to reach agreement on the proposed revisions. If the Parties cannot agree on the revisions, then the Parties may utilize the dispute resolution procedure set out in paragraph 58. If DCF is unable to implement within three (3) months, DCF will provide a detailed monthly progress report until implementation has been accomplished. Implementation will be accomplished no later than nine (9) months after the Departments have provided comments. Any further extensions may be requested pursuant to the process set forth in Paragraph 66.
38. Any proposed revisions to the policy during the term of the Agreement may be timely reviewed and commented upon by the Departments before being implemented by DCF. Once any revisions to the policy are implemented, DCF will update its training materials for the trainings required by Part V *infra* to reflect the revised policy and highlight substantive changes to the policy in any subsequent trainings.

C. Notice of Parents with Disabilities Policy

39. Within two (2) months of DCF’s issuance of the Parents with Disabilities Policy under Subsection B of this Part, DCF will develop a short, plain language document (at an

appropriate literacy level) to notify individuals involved with the Massachusetts child welfare program (including DCF-involved parents, foster parents, pre-adoptive parents, advocates, and attorneys) of DCF's Parents with Disabilities Policy, including the process to make a request for reasonable accommodations and auxiliary aids and services and the process to initiate Disability-Related Complaints, including disability discrimination complaints ("Nondiscrimination Notice"). The Nondiscrimination Notice must prominently display the contact information (including a mailing address, email address, phone number, TTY number, and toll-free number) for the Disability Coordinator.

40. DCF will share the Nondiscrimination Notice with the Departments within one (1) month of its development for the Departments' comments and suggestions. Within one (1) month of receiving the Departments' comments and suggestions, and upon agreement by the Parties on the suggested revisions, DCF will incorporate those comments and make the Nondiscrimination Notice publicly available.
41. DCF will provide the Nondiscrimination Notice to every DCF-involved parent during the term of this Agreement. DCF will post the approved Nondiscrimination Notice in an accessible manner (*e.g.*, conforming to the voluntary Web Content Accessibility Guidelines (WCAG) 2.0 AA standards) and in a conspicuous location on its homepage, currently located at <http://www.mass.gov/eohhs/gov/departments/dcf/>.

D. Accessible Format

42. DCF will take appropriate steps to ensure that all policies, practices, and procedures, as well as the Nondiscrimination Notice, are provided in appropriate alternate formats, as determined by DCF, to ensure effective communication with individuals with disabilities.

V. TRAINING

43. DCF agrees to provide annually at least two hours of interactive training(s) for the (a) General Counsel, (b) Disability Coordinator, (c) Regional Disability Liaisons, (d) social workers, (e) investigators, (f) family resource workers, and (g) supervisors. This training will cover the Parents with Disabilities Policy upon implementation (including all content listed in Appendix A) and the application of Title II of the ADA and Section 504 to child welfare, including the requirements of Part II of this Agreement. The first annual training will be completed within eleven (11) months of the Effective Date of this Agreement, and subsequent trainings conducted every twelve (12) months thereafter.
44. DCF also specifically agrees to the following:
 - a. The General Counsel, Disability Coordinator, Regional Disability Liaisons, and all DCF attorneys will be required to receive training addressing the requirements of this Agreement and the application of Title II of the ADA and Section 504 to

child welfare, within six (6) months of the Effective Date of this Agreement. The General Counsel, Disability Coordinator, and Regional Disability Liaisons will also be required to receive training on the Parents with Disability Policy within two (2) months of implementation.

- b. DCF will include at least one hour of training on the subject matter listed in paragraph 43 in its mandatory new employee training.
 - c. DCF will provide training on the subject matter listed in paragraph 43 annually at an area manager meeting that all Area Clinical Managers and Area Program Managers are required to attend, barring extenuating circumstances.
 - d. Pursuant to DCF's standard practice, upon issuance of the Parents with Disabilities Policy, DCF will notify all DCF staff and administrators of the Policy and provide at least one hour of training on the requirements of the Policy, including the subject matter listed in Appendix A, to all DCF staff and administrators.
 - e. In addition to the above, DCF will strongly encourage all staff to attend the trainings made available to them pursuant to this Part. DCF will also include a training module relating to reasonable accommodation requests in the annual trainings required by this Part to assist staff in meeting annual professional development requirements and will ensure other trainings required by this Part similarly satisfy staff professional development requirements whenever possible.
45. The trainer(s) must have proficiency with the application of the ADA and Section 504 to the child welfare context.
46. DCF will take appropriate steps to ensure that the training curricula, written materials, and format for the trainings required by this Part are provided in appropriate alternate formats if needed to ensure effective communication with individuals with disabilities.
47. Upon request from DCF, the Departments will provide technical assistance to DCF concerning the development and implementation of the trainings required by this Part. DCF may also consult with the Disability Coordinator, Regional Disability Liaisons, DCF social workers, outside experts on conducting parental capacity evaluations and assessments of DCF-involved parents with disabilities, and representatives of non-profit or private organizations that provide services to DCF-involved parents.
48. During the term of the Agreement, the Departments may attend any of the trainings required by this Part and may provide comments and suggestions on the training to DCF, which DCF will consider for future trainings.
49. DCF will obtain from the trainer(s) attendance lists for all attendees at any of the trainings conducted pursuant to this Part. These attendance lists will be forwarded to the Departments upon request.

VI. DISABILITY-RELATED COMPLAINTS FILED WITH DOJ & HHS

50. Pursuant to Part IV.B and Appendix A of this Agreement, DCF has established a Disability-Related Complaints Process (“Complaints Process”). That process, which must comply with the requirements of Appendix A, is outlined in the flowchart in Appendix B. DCF will submit any Disability-Related Complaints (as defined herein) received from the Departments, DCF-involved parents, or their representatives to that process. As provided by Appendix B, this process will include:
- a. Within two (2) weeks of receipt of any complaint subject to paragraph 51, the Disability Coordinator and the relevant Regional Disability Liaison, as well as other relevant DCF staff, will evaluate the complaint and determine whether it falls within the definition of Disability-Related Complaint in this Agreement.
 - b. Where DCF determines that a complaint falls outside the definition of Disability-Related Complaint herein, DCF will provide written notice to the parent(s) of the decision and underlying reasoning within one (1) week of the decision.
 - c. Where DCF determines a complaint falls within the definition of Disability-Related Complaint herein, the complaint will be referred to an ADA Meeting to be held within three (3) weeks of DCF’s initial review of the complaint.
 - d. Within one (1) week of the ADA Meeting being held, DCF will provide written notice to regional staff and the parent(s) of what was agreed upon, including when and how remedial measures will be implemented.
 - e. If a complaint is not fully resolved at the ADA Meeting, the Disability Coordinator and relevant Regional Disability Liaison will review any outstanding issues and reach a final determination regarding resolution of the complaint within two (2) weeks of the ADA Meeting being held. Within one (1) week thereafter, DCF will notify the parents in writing of DCF’s final decision. Where remedial measures are required, DCF will also notify regional staff and provide instructions for when and how such measures will be implemented. Where DCF determines that no remedial measures are warranted, DCF’s notice to the parents will explain the reasons for the determination and how the parent can appeal the decision.
 - f. In all instances where a complaint originated from DOJ or HHS, notices required by this Part will also be provided to the Departments.
51. Any Disability-Related Complaint within the scope of this Agreement that is pending with or received by the Departments during the term of this Agreement will either be submitted to DCF for processing and resolution through the above processes, or be closed by the Departments at their discretion. If, at any time, the Departments are unsatisfied with how a Disability-Related Complaint has been handled or resolved by

DCF, the Departments will utilize the dispute resolution processes described in paragraph 58 *infra*.

VII. DCF REPORTING

52. Every six (6) months, DCF will provide the Departments with the contents of the database(s) or log(s) maintained by the Disability Coordinator (in a readily searchable format), which shall include, consistent with Parts III and IV and Appendix A, the following:
- a. all requests for reasonable accommodations and auxiliary aids and services for DCF-involved parents with disabilities and the status of those requests;
 - b. all Disability-Related Complaints by or on behalf of a DCF-involved parent with a disability, including complaints of disability discrimination;
 - c. the status and progress of all such requests and complaints;
 - d. the resolution of all such requests and complaints, including DCF decisions by the Area, Regional, and Central Offices;
 - e. the reasons for full and partial denials of requests for reasonable accommodations and auxiliary aids and services; and
 - f. the Area and/or Regional Office(s) handling the DCF-involved parent's case.

In sharing this information with the Departments, DCF will take all steps required by law to protect the confidentiality and privacy of all individuals involved.

53. Following each production under the preceding paragraph, at least one representative for each of the Parties will make themselves available to meet in person or by phone if needed to discuss DCF's performance under the Agreement.
54. DCF will provide additional information pertaining to its performance under this Agreement upon the Departments' reasonable request as allowed by law.
55. If either DOJ or HHS requests information or makes an inquiry related to DCF's compliance with this Agreement, DCF will respond and will provide the information reasonably requested by the relevant agency in a timely manner and otherwise cooperate in good faith with the request or inquiry. DCF will make a good faith effort to comply with the timeframes requested by the Departments, will communicate in good faith with the Departments, and will not obstruct an inquiry by either DOJ or HHS into DCF's compliance with this Agreement.
56. All materials to be submitted to the Departments will be sent by email to Megan.Schuller@usdoj.gov and Susan.Rhodes@hhs.gov. For hard copy documents, all materials will be sent by courier service (such as UPS or FedEx) to Megan E.

Schuller, Disability Rights Section, Civil Rights Division, U.S. Department of Justice, 4 Constitution Square, 150 M Street NE, 9th Floor, Washington, DC 20002, with a reference to DJ # 204-36-216.

VIII. ENFORCEMENT AND OTHER PROVISIONS

57. In consideration for this Agreement, except as provided in the subsequent paragraph, the Departments will not institute any civil action alleging discrimination under the ADA or Section 504 or recommend any other enforcement action authorized by law based on the Departments' findings in their joint Letter of Findings dated January 29, 2015, or based on Disability-Related Complaints received by the Departments up to and including the Effective Date of this Agreement, except as set forth in Part VI of this Agreement and the subsequent paragraph. In consideration for this Agreement, the Departments will also close their respective investigations of DJ # 204-36-216 and HHS # 14-182176, as well as any Disability-Related Complaints that have been satisfactorily resolved through the processes established in Part VI and/or through the dispute resolution process in the subsequent paragraph. Nothing in this Agreement limits or modifies the investigative or enforcement authority of DOJ or HHS with respect to any other complaints of discrimination under the ADA, Section 504, or any other law.
58. The Departments may review DCF's compliance with this Agreement, Title II of the ADA, Section 504, or their implementing regulations at any time. If any Party believes that this Agreement or any portion of it has been violated, that Party will give notice (including reasonable particulars) of the alleged violation(s) to all other Parties. The noticed Party must respond to the notice as soon as practicable but no later than twenty-one (21) calendar days thereafter. The Parties will negotiate in good faith in an attempt to resolve any dispute. If DOJ or HHS believes after thirty (30) calendar days of negotiations that resolution cannot be achieved, it shall promptly notify the other Parties in writing and shall specify its final position with regard to the dispute. Thereafter, DOJ may institute a civil action against DCF in the appropriate United States District Court to enforce this Agreement, Title II of the ADA, Section 504, and their implementing regulations. HHS also may take any other enforcement action authorized by law, which may include initiation of administrative proceedings to suspend, terminate, or refuse to grant or continue HHS financial assistance.
59. The Effective Date of this Agreement is the date of the last signature below.
60. This Agreement shall terminate in three (3) years from the Effective Date.
61. Notwithstanding paragraph 60, this Agreement will terminate earlier than three (3) years from the Effective Date if the Departments determine that DCF has demonstrated compliance with Title II of the ADA, Section 504, and their implementing regulations with respect to parents with disabilities and their participation in and benefit from DCF's services, programs, and activities and maintained that compliance for one year.

62. Notwithstanding paragraph 61, if the Departments determine that DCF has demonstrated compliance with a Part of the Agreement, maintained that compliance for one year, and that Part is sufficiently severable from the other requirements of the Agreement, the Parties agree to terminate that Part of the Agreement. In determining whether DCF has demonstrated compliance with a Part of the Agreement, the Departments may assess collectively all the requirements of the Agreement to determine whether the intended outcome of the Part has been achieved.
63. This Agreement is without prejudice to any private right of action provided by law. This Agreement is also without prejudice to any person's rights under any other settlement agreements, consent decrees, court orders, or laws, and is not intended to supersede any other agreements, decrees, orders, or laws.
64. This Agreement and its appendices contain the entire agreement of the Departments and DCF concerning the subject matter described herein, and no other prior or contemporaneous statement, promise, or agreement, either written or oral, made by any Party or agents of any Party, that is not contained in this Agreement, including its appendices, will be enforceable. Any modification to this Agreement or its appendices requires the written consent of all Parties.
65. This Agreement is binding on the Parties.
66. Any time limits for performance imposed by this Agreement may be extended by the mutual written consent of the Parties. With regard to any of the deadlines specified in this Agreement, DCF shall notify the Departments as soon as practicable, and if possible at least ten (10) business days, before the deadline of an anticipated inability to meet the deadline and the reason(s) why, and shall request an extension of time to a specific date. The Departments shall not unreasonably withhold consent to a request for an extension of time made in good faith.
67. Failure by the Departments to enforce this Agreement, or any part of it, pursuant to its terms with respect to any instance or provision will not be construed as a waiver to enforce the Agreement with regard to any instance or provision.
68. Should any provision of this Agreement be declared or determined by any court to be illegal, invalid, or unenforceable, the remaining parts, terms, or provisions will not be affected. The Parties will not, individually or in combination with one another, seek to have any court declare or determine that any portion of this Agreement is invalid, illegal, or unenforceable.
69. This Agreement does not supersede the rights, obligations, and responsibilities of the Parties under any laws, court orders, or other settlements involving compliance with civil rights statutes.
70. DCF will provide a copy of this Agreement to any person upon request.

71. The signatories represent that they have the authority to bind the respective Parties identified below to the terms of this Agreement.
72. This Agreement may be executed in counterparts.

AGREED AND CONSENTED TO:

FOR THE UNITED STATES DEPARTMENT OF JUSTICE:

ANDREW E. LELLING
United States Attorney
District of Massachusetts

JENNIFER A. SERAFYN
Chief
Civil Rights Unit

ERIC S. DREIBAND
Assistant Attorney General
Civil Rights Division

CYNTHIA McKNIGHT
Deputy Assistant Attorney General
Civil Rights Division

REBECCA B. BOND
Chief

ANNE S. RAISH
Principal Deputy Chief
KATHLEEN P. WOLFE
Special Litigation Counsel
AMANDA MAISELS
Deputy Chief
Disability Rights Section
Civil Rights Division



MICHELLE LEUNG
Assistant United States Attorney
U.S. Attorney's Office
John Joseph Moakley
Federal Courthouse
1 Courthouse Way, Suite 9200
Boston, Massachusetts 02210
(617) 748-3626
michelle.leung@usdoj.gov



MEGAN E. SCHULLER
ADAM F. LEWIS
CHERYL ROST
Trial Attorneys
Disability Rights Section
U.S. Department of Justice
950 Pennsylvania Ave., N.W. – 4CON
Washington, D.C. 20530
(202) 305-0170
Megan.Schuller@usdoj.gov

Dated: November 17, 2020

Dated: November 19, 2020

FOR THE UNITED STATES DEPARTMENT OF HEALTH & HUMAN SERVICES:



Roger Severino
Director
Office for Civil Rights
U.S. Department of Health and Human
Services

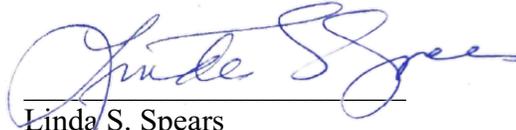
Dated: 11/17/2020 _____



Susan Pezzullo Rhodes
Regional Manager
Office for Civil Rights, New England Region
U.S. Department of Health and Human
Services

Dated: 11/17/2020 _____

FOR THE MASSACHUSETTS DEPARTMENT OF CHILDREN & FAMILIES:



Linda S. Spears
Commissioner
Massachusetts Department of Children & Families
600 Washington Street
Boston, MA 02111

Dated: 11/18/2020 _____

APPENDIX A

Parents with Disabilities Policy

The Parents with Disabilities Policy shall include, at minimum:

- **General Requirements:**
 - The obligations listed in Part II of the Parties' Agreement, and how those requirements apply in the child welfare context, including examples:
 - regarding reasonable accommodations for DCF-involved parents with disabilities, and
 - regarding how DCF's decisions about child safety and whether a DCF-involved parent with a disability represents a direct threat to the safety of the child must be based on an individualized assessment and objective facts and may not be based on stereotypes or generalizations about persons with disabilities; and how such decisions will also take into account whether reasonable accommodations or the provision of auxiliary aids and services will mitigate the risk;
 - The role and responsibilities of investigators, social workers, and family resource workers in implementing the Parents with Disabilities Policy, as well as the role and responsibilities of their direct supervisors; and
 - The contact information, role, and responsibilities of the Disability Coordinator and Regional Disability Liaisons.
- **Process to Request Reasonable Accommodations & Auxiliary Aids & Services:¹**
 - A process for individuals with disabilities and their representatives to request reasonable accommodations and auxiliary aids and services within DCF, including from a social worker or the applicable Regional Disability Liaison. The policy must make clear that an individual does not need to reference the ADA,

¹ Any requests for reasonable accommodations and auxiliary aids and services that are resolved through this process do not need to be submitted to the Disability-Related Complaints Process. Whether or not an accommodation is reasonable is a fact- and case-specific inquiry. Examples of reasonable accommodations in the child welfare context may include, where reasonable: changes in frequency, duration, or location of parent-child visitation; hands-on training during a child's medical and early intervention services appointments; plain language training materials at appropriate literacy levels; adaptations in the manner in which specific training is conducted; more frequent support from a social worker; modified action planning; assessment by an expert on working with parents with disabilities; and other modified family preservation and reunification services.

Section 504, their implementing regulations, or any provisions therein, or use any terms of art, such as “reasonable accommodation,” to make such a request;

- A process for DCF to address such requests for reasonable accommodations and auxiliary aids and services for DCF-involved parents with disabilities in a timely manner, and pursuant to the specified timeframes below. The policy also must make clear that requests subject to this policy must be resolved at the earliest point of contact possible;
- A process for DCF to take all necessary and appropriate steps to ensure appropriate auxiliary aids and services are provided where necessary to ensure effective communication with DCF-involved parents with disabilities, including, if necessary, a process for DCF to work with the Massachusetts Commission for the Deaf and Hard of Hearing to timely provide interpreters and other auxiliary aids and services for DCF-involved parents who are deaf or hard of hearing. The policy also must make clear how DCF will determine what types of auxiliary aids and services are necessary to ensure effective communication, which shall be consistent with all the requirements of the Title II regulation at 28 C.F.R. § 35.160 and the Section 504 regulation at 45 C.F.R. § 84.52;
- A process for informing service providers for a DCF-involved parent with a disability, including contractors, vendors, and other state agencies, when a reasonable modification or auxiliary aid or service may be necessary for a DCF-involved parent with a disability in such a way as to protect the privacy of the DCF-involved parent with a disability;
- A process for reviewing what reasonable accommodations and auxiliary aids and services have been requested and/or provided to date, and whether they are still adequate and appropriate, at action planning meetings with the family. The policy will make clear that action planning should be a collaborative, interactive process with the family, and may state that DCF’s decisions throughout the process will be made in the best interests of the child;
- A process for referring requests for reasonable accommodations and auxiliary aids and services that have not been resolved by DCF in thirty (30) calendar days to the Disability Coordinator and/or Regional Disability Liaisons for consideration and resolution in a reasonable amount of time in light of the facts and circumstances, and generally within fifteen (15) calendar days barring extenuating circumstances, for a total of forty-five (45) calendar days from DCF’s receipt of the request; and
- A process for notifying the requester of the outcome of his or her request in writing. The notice must include, at minimum, any actions taken by DCF in response to the request, the decision made by DCF, and an explanation of next steps (including timing of the same). DCF will take appropriate steps to ensure

that the notice is provided in understandable and appropriate alternate formats to ensure effective communication with individuals with disabilities.

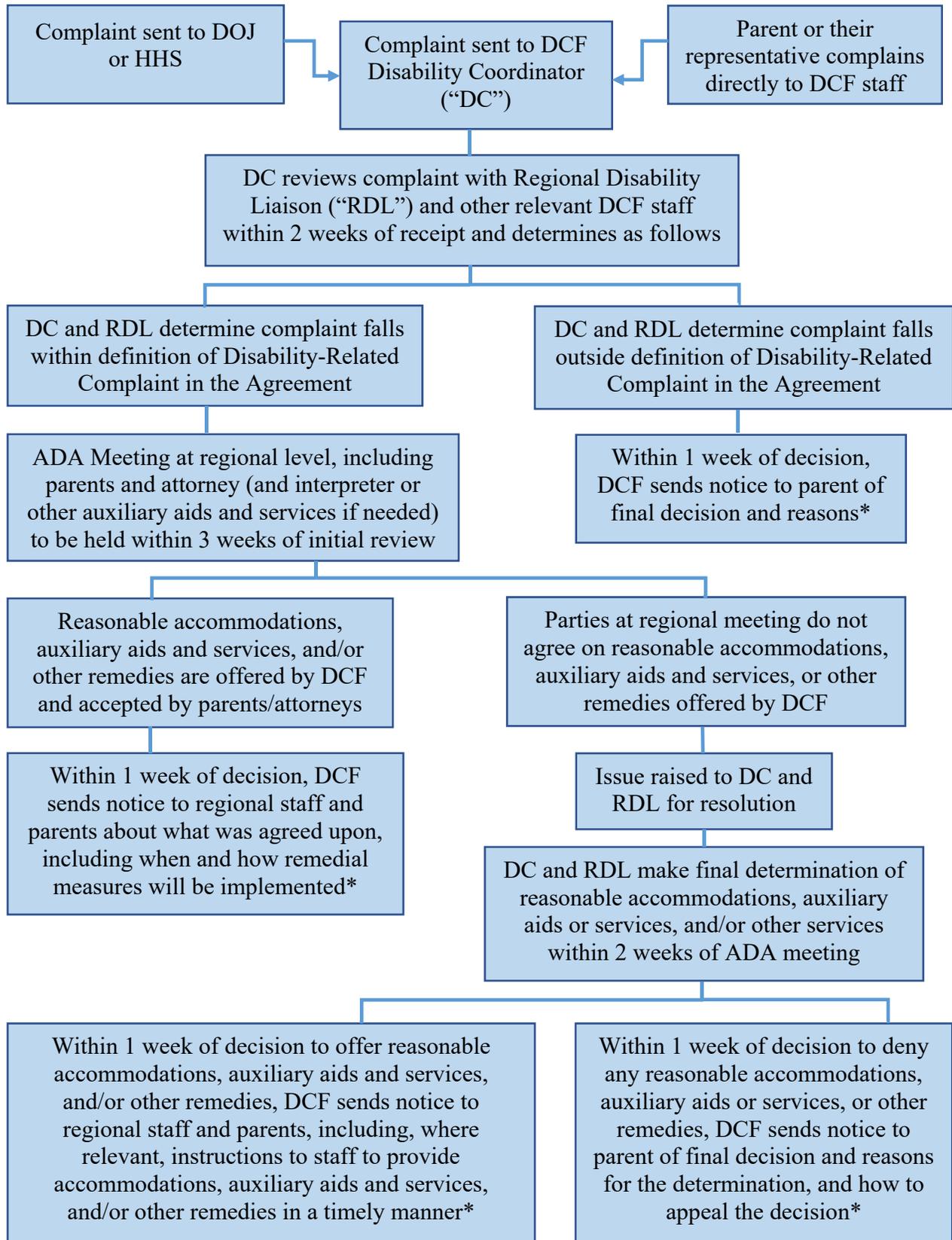
- The Parents with Disabilities Policy shall also make clear that clinical case records for DCF-involved parents with disabilities must identify the reasonable accommodations and auxiliary aids and services DCF will provide, is providing, or will work to arrange for.
- Disability-Related Complaints Process:
 - A process for DCF-involved parents and their representatives to make a Disability-Related Complaint (including a complaint of disability discrimination) to DCF, including to the Regional Disability Liaisons, Disability Coordinator, and General Counsel's Office. This process must make clear that Disability-Related Complaints should be resolved at the earliest point of contact, if possible;
 - A process for DCF to review, investigate, and respond to Disability-Related Complaints in a timely manner and pursuant to the timeframes in Appendix B. The review and investigation must include review of the complaint, relevant documents and testimony if needed, and any evidence submitted by the DCF-involved parent and his or her representatives;
 - A process for DCF to take all necessary and appropriate steps to arrange for appropriate auxiliary aids and services where necessary to afford individuals with disabilities an equal opportunity to participate in DCF's Disability-Related Complaint Process; and
 - A process for notifying the DCF-involved parent or representative of the outcome of the complaint in writing. The notice must include, at minimum, an explanation of the outcome, any actions taken by DCF in response to the complaint, the decision made by DCF, and an explanation of next steps (including timing of the same). DCF will take appropriate steps to ensure that the notice is provided in appropriate alternate formats to ensure effective communication with individuals with disabilities.
- Reporting & Confidentiality:
 - Subject to appropriation and systems capacity, a process for ensuring that all relevant case record documents and systems (such as iFamilyNet) reflect: (i) all requests for reasonable accommodations and auxiliary aids and services for a DCF-involved parent with a disability that are denied in full or in part; (ii) all reasonable accommodations and auxiliary aids and services that DCF is providing on a repeated or on-going basis for a DCF-involved parent with a disability; (iii) all Disability-Related Complaints filed with DCF by or on behalf of a DCF-involved parent with a disability (including disability discrimination complaints); (iv) the status and progress of all such requests and complaints; (v) the resolution

of all such requests and complaints, including DCF decisions by the Area, Regional, and Central Offices; and (vi) the reasons for full and partial denials of requests for reasonable accommodations and auxiliary aids and services; and

- A process for safeguarding the confidentiality of any medical records provided in support of a complaint or request for reasonable accommodations or auxiliary aids or services pursuant to this policy, except that the Departments and DCF employees and contractors may be informed regarding necessary accommodations and auxiliary aids and services to the extent permitted by law.

APPENDIX B

Complaint Process



*In all instances where a complaint originated from DOJ or HHS, notice will also be provided to the Departments. Notice to the parent will be provided in writing and in an accessible format in all cases.