Advancing The Self-Determination Of Clients With Disabilities

Phoebe Ball, J.D., Legislative Affairs Specialist
Robyn Powell, J.D., Attorney Advisor

Agenda

- The National Council on Disability
- Representing People with Disabilities
- Example: Representing Parents with Disabilities
  - Parenting with a Disability: Past & Present
  - The Child Welfare System & Parents with Disabilities
    - Disability Law
    - DOJ/HHS Letter of Findings
    - Parenting Assessments
  - Strategies and Solutions
- Questions & Answers

National Council on Disability

NCD is a small, independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities. NCD is comprised of a team of 15 Presidential appointees,* an Executive Director, and 12, full-time professional staff.

* As of July 22, 2014, the passage of the Workforce Innovation and Opportunities Act (WIOA), the Council will transition to nine Members including four appointments which will be made by Congress.

Client Under a Disability

(a) Maintenance of Normal Relationship. When a client's ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability, or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client. *Florida Bar Rule 4-1.14*

A Few Words About Disability

- Age
- Physical Disability
- Mental Health
- Cognitive Impairments
- Intellectual Disabilities
- Experience
- Situational
- Temporary

Competing Responsibilities

- Responsibility to Client
  - Representative/Agent
  - Advisor
  - Advocate
  - Objectives and scope
- Responsibility to Society
  - Officer of the Court
  - Personal Values Regarding Outcome
  - Competing Social Values

Responsibility to Client

- Representative/Agent
  - You may step into the person's shoes, your actions may depend on their capacity
- Advisor
  - independent professional judgment
  - candid advice
  - may refer to moral, economic, social, and political factors that may be relevant to the client's situation.

Responsibility to Client

- Advocate
  - Duty to use legal procedure for the fullest benefit of the client's cause
  - Good faith arguments in support of the client’s positions
- Objectives and scope of representation
  - Leave the client better off
  - Consult with client and abide by their decisions

Decision-Making Alternatives

- Self-Determination
- Substituted Judgement
- Best Interest

Self-Determination

- Right to determine for oneself how to live and what to live for
- Liberal ideal that has not been assumed for people with disabilities
- Key principle of disability rights movement, particularly complex in light of perceived or actual need for supports

Self-Determination

- Freedom
- Authority
- Support
- Responsibility
- Confirmation

Operationalizing Self-Determination

- Need for support ≠ lack of autonomy
- From “program-centered” to “person-centered”
- Dignity of risk
- Supported decision-making
  - MAP, PATH, ELP

Least Restrictive Option

- Olmstead v. L.C. 527 U.S. 581 (1999)
- This concept not only applies to living environment
  - Extension to employment
  - Decision-making options

Informed Consent

- Disclosure to the person of relevant information
- Freedom of choice in a non-coercive environment
- Ability to make and communicate a decision

Substituted Judgment

- Determining what the individual would choose if they had capacity
  - Based on known values and preferences
    - May be as presently expressed or prior to lost capacity
    - Statements and actions
    - Person's lifestyle and enduring characteristics
    - Conversations with family and friends

Best Interest Standard

- Acting in the interests of the person's health, welfare and wellbeing
- May be overarching goal of justice system in a particular context
- What's best as determined by "reasonable person"
  - Many lawyers seem to default to this problematic standard, don't!

Practical Considerations

- Formal and Informal Supports
  - Decision-making
  - Public Benefits
- Recognizing when things go wrong
  - Abuse/Neglect
  - Exploitation

Formal and Informal Supports

- Decision-making options
  - What tools and supports does the person need?
  - May be circles of support, banking options, POA, trust, representative payee, guardian advocacy or guardianship
- Public Benefits
  - What services and supports does the person need?
  - Medicaid (waivers), Medicare, HUD, food stamps etc.

Transition

- IDEA requirements
- Vocational Rehabilitation
- Transition/ discharge planning
- Ongoing and dynamic

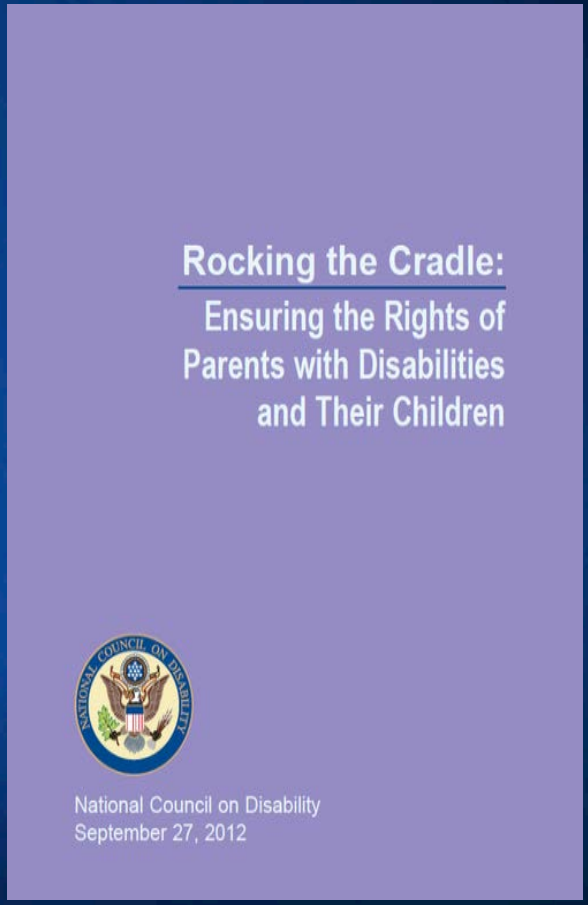
Example

Representing Parents with Disabilities

(Image: Property of National Council on Disability)

Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children

- Groundbreaking compendium
- National and international attention
- 445 pages
- Over 1,000 citations
- Dozens of interviews with experts and parents with disabilities
- A useful tool in advocating for your clients!



Available at www.ncd.gov

Parenting with a Disability: Past & Present

(Image: Property of National Council on Disability)

Buck v. Bell, 274 U.S. 200 (1927)

- "*It is better for the world*, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind… *Three generations of imbeciles are enough*."

Parenting with a Disability Today: The Eugenic Movement's Backdoor?

- Nearly 25 years after the passage of the ADA…
- *Buck v. Bell* has never been overturned
- Several states still have some form of involuntary sterilization laws on their books
  - A few even retain the original statutory language, which labels the targets of these procedures as possessing hereditary forms of "idiocy" and "imbecility," and state that the best interests of society would be served by preventing them from procreating
- Today, women with disabilities contend with coercive tactics designed to encourage sterilization or abortions because they are deemed not fit for motherhood
- Pervasive myth that people with disabilities are either sexually unwilling or unable

Parenting with a Disability Today, Continued…

- Removal rates of parents with psychiatric disabilities are as high as 70-80%
- Removal rates of parents with intellectual disabilities are as high as 80%
- Extremely high removal rates and loss of parental rights for parents with sensory or physical disabilities
- More than two-thirds of dependency statutes include disability as grounds for termination of parental rights (TPR)
- In every state, disability may be considered when determining the best interest of a child for purposes of a custody determination in family or dependency court

Parenting with a Disability Today, Continued…

- Parents with disabilities are more likely to lose custody of their children after divorce
  - Parents with disabilities will often stay in bad – sometimes abusive – marriages out of fear of losing their children
- Prospective adoptive parents with disabilities regularly encounter barriers erected by discrimination and bias
- People with disabilities face significant barriers to receiving assisted reproductive technologies

(Image: Property of National Council on Disability)

Who are parents with disabilities and their children?

- At least 4.1 million parents with reported disabilities in the United States have children under age 18; meaning that at least 6.2 percent of American parents who have children under age 18 have at least one reported disability.
- Estimates indicate 6.1 million children in the U.S. have parents with disabilities – Nearly 1 in 10, almost 10% of the population.

Source: Kaye, H. Steven. (2012). Current Demographics of Parents with Disabilities in the U.S. Berkeley, CA: Through the Looking Glass.

(Image: Property of National Council on Disability)

The Child Welfare System & Parents with Disabilities

(Image: Property of National Council on Disability)

The Child Welfare System & Parents with Disabilities

- Parents with disabilities and their children are overly, and often inappropriately, referred to child welfare services and, once involved, are permanently separated at disproportionately high rates. Recurring barriers include:
  - State statutes that include disability as grounds for TPR
  - Disparate impact of certain provisions of the ASFA
  - Perceived limits on the application of the ADA, especially at the termination phase
  - Bias and speculation
  - A lack of training regarding parents with disabilities

(Image: Property of National Council on Disability)

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.

The ADA and the Child Welfare System

- Title II applies to public entities, which include state and local governments, and their departments and agencies, such as DCF. 42 U.S.C. § 12131(1)
- Accordingly, the child welfare 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." 42 U.S.C. § 12131 *et seq*.

The ADA and the Child Welfare System, Continued...

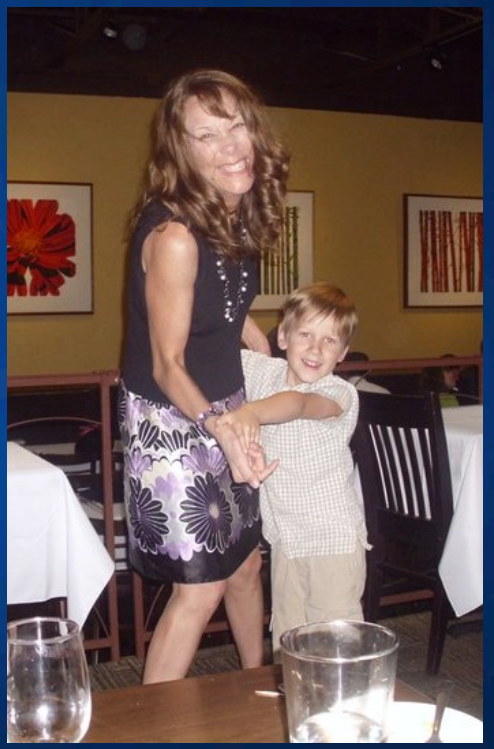
- Pursuant to Title II, child welfare agencies must do the following:
  - Provide parents with disabilities an equal opportunity to participate in programs, services, and activities. To implement this mandate, the agencies must make reasonable modifications in policies, practices, or procedures, unless such modifications would fundamentally alter the nature of the service, program, or activity. 28 C.F.R. § 35.130(b)
  - Administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified people with disabilities. 28 C.F.R § 35.130(d).
  - 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. 28 C.F.R. § 35.130(b)(8).

The ADA and the Child Welfare System, Continued…

- Pursuant to Title II, child welfare agencies must do the following:
  - Furnish auxiliary aids and services when necessary to ensure effective communication, unless an undue burden or fundamental alteration would result. 28 C.F.R. § 35.160(a)(1),(b)(1), 28 C.F.R. § 35.164.
  - Provide, as needed, benefits, services, or advantages beyond those required by the regulation to people with disabilities. 28 C.F.R. § 35.130(c).
  - 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. 28 C.F.R. § 35.130(f).
  - Not deny the benefits of programs, activities, and services to people with disabilities because entities' facilities are inaccessible. 28 C.F.R. § 35.149.
  - Provide services, programs, and activities that, when viewed in their entirety, are readily accessible to and usable by people with disabilities. 28 C.F.R. § 35.150.
  - A public entity may impose legitimate safety requirements necessary for the safe operation of its services, programs, or activities only if those safety requirements are based on actual risks, not on mere speculation, stereotypes, or generalizations about individuals with disabilities. 28 C.F.R. § 35.130(h).

The ADA and the Child Welfare System, Continued…

- 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. *See* ADA Technical Assistance Manual, II-3.9000, http://www.ada.gov/taman2.html.
- Thus, the ADA protects the children of parents with disabilities involved in TPR proceedings.



(Image: Property of National Council on Disability)

The ADA: Limits and Lessons

- Discrimination against parents with disabilities was an issue documented during congressional hearings on the ADA at passage.
- Almost every case has found that the ADA is not a defense to termination of parental rights.
- There seems to be a misconception that Title II does not therefore apply to child welfare practice.
- Reasonableness: "Agencies must make reasonable modifications in policies, practices, or procedures, unless such modifications would fundamentally alter the nature of the service, program or activity." 28 CFR § 35.130(b)(7). Onus on the state to show why not reasonable.
- Equal Access: Also must provide people with disabilities an equal opportunity to participate in programs, services and activities." 28 CFR § 35.130(b).
- Broadness: "The ADA's broad language makes no exception for activities that implicate strong state interests." *Pennsylvania Dept. of Corrections v. Yeskey*, 524 U.S. 2006 (1998).

DOJ & HHS OCR Joint Letter

- January 29, 2015 Letter of Findings to DCF
- Mother with I/DD, lost custody of newborn
- State violated ADA and Section 504
- State must provide mother appropriate supports and opportunity to demonstrate fitness
- Available at http://www.ada.gov/ma_docf_lof.pdf
- Family was reunited after 2 years, 3 months, and 12 days!

DOJ & HHS OCR Joint Letter, Continued…

- Withdraw the petition to terminate Ms. Gordon's parental rights.
- Immediately take all necessary actions to address the violations identified in this letter, including:
  - Implement appropriate services and supports to provide \a full and equal opportunity to seek reunification consistent;
  - Once implemented for an appropriate amount of time, evaluate the then-current functioning of the family based on the opinions of the experts, community-based service providers, and DCF's Foster Care Review;
  - Pay compensatory damages ;
  - Develop and implement procedures addressing how ADA and Section 504 requirements apply to DCF programs, services, and activities, including assessments, service planning and implementation, visitation, and safety requirements; and
  - Implement a training program for all investigators, social workers, family resource workers, supervisors, and Area Program Managers on compliance with Title II and Section 504

Filing Complaints with DOJ & HHS

DOJ

- Investigates and enforces the ADA if a state or local government (including a state child welfare agency) or place of public accommodation has discriminated against a person with a disability
- Attorneys can assist their clients with filing a complaint with DOJ
- Complaints can be filed electronically or by mail http:// www.ada.gov/ filing_complaint.htm
- Complaints should include:
  - Parent's contact in-formation
  - Brief description of the acts of discrimination, including the dates they occurred and the names of individuals involved
  - Any supporting documentation
- Due to the large volume of complaints DOJ receives, it may take up to three months for the agency to review

HHS OCR

- Investigates disability-based discrimination com-plaints based on ADA and Section 504 violations against health and human services programs, including state child welfare agencies
- Typically, complaints must be filed within 180 days from the date of the alleged discriminatory act unless good cause for the delay can be demonstrated
- Attorneys can assist their clients in filing complaints with OCR electronically or by mail http://www.hhs.gov/ocr/civilrights/ complaints/index.html
- Complaints should include:
  - Parent's contact information
  - Brief description of the alleged discrimination
  - Names and contact information of the agency that discriminated against the parent
  - Any supporting evidence

Parenting Assessments

- Often crucial in child welfare proceedings
- Evaluators may harbor their own biases regarding parents with disabilities
- Evaluators often have no training or experience assessing parents with disabilities and are unaware of supports and the use of adaptive equipment
- Parenting assessments are often inaccessible
  - 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
- ADA and Rehabilitation Act require evaluations to be accessible, including modifications
- Inappropriate reliance on IQ testing
  - Researchers have consistently found that there is no clear relationship between parental fitness and intelligence (Booth & Booth, 1993; Dowdney & Skuse, 1993; Tymchuk & Feldman, 1991)

American Psychological Association Guidance

- Guidelines for Psychological Evaluations in Child Protection Matters (http://www.apa.org/practice/guidelines/child-protection.aspx)
- Guidelines for Assessment of and Intervention with Persons with Disabilities (http://www.apa.org/pi/disability/resources/assessment-disabilities.aspx)

Strategies and Solutions

(Image: Property of National Council on Disability)

Tips for Representing Parents with Disabilities

- Connect the parent with appropriate disability services (e.g., local Center for Independent Living) that can provide assistance with housing, employment, transportation, personal assistance services, and financial or health benefits.
- Make sure the parent receives an adapted parenting assessment by someone with experience evaluating parents with disabilities.
- Help the parent make a claim under the ADA as soon as possible. A parent may make an ADA claim by demonstrating that he or she is a qualified person with a disability who requires a reasonable accommodation of that disability by a public entity.

Tips for Representing Parents with Disabilities, Continued...

- Consider appealing and/or filing an ADA complaint in the federal court if:
  - the removal was based solely on the parent's disability;
  - the court will not order accommodations of hearings, meetings, or services; or
  - a decision of the court to continue jurisdiction over the child is not reasonable based on witness and expert testimony and other evidence.
- Also, if the parent is denied a reasonable accommodation, be prepared to appeal (where such process exists) or to file a complaint with the departmental, state, or federal agency empowered to investigate discrimination by the court or child welfare agency.
  - At the federal level, a complaint can be filed with the U.S. Department of Justice (DOJ) as well as the U.S. Department of Health and Human Services (HHS) Office for Civil Rights.

Tips for Representing Parents with Disabilities, Continued…

- Know your client's disability
- Communicate with providers and support systems; obtain referrals – skill-building services, groups, classes, education, etc.
- Know your client's strengths/abilities – when advocating for accommodations in services, and the kind of services
- Encourage providers/peers to be advocates for a parent!
- Evidentiary and legal standards around mental health records, privilege, evaluations/assessments, competence and capacity
- Be creative and practical to reach solutions
- BE A ZEALOUS ADVOCATE!

Examples of Reasonable Modifications

- Increase frequency/extend length of service provision
- Provide in-home parent modeling
- Links of parent with a co-parent or mentor
- Tailor parenting education to the needs of the parent
- Provide services at an individual's home or alternative accessible site
- Give frequent reminders for appointments/services
- Provide accessible transportation
- Provide all information in large print, audio tape, Braille, or digital format
- Offer note-taking or transcriptions of meetings and court activities
- Assist in reading materials
- Provide interpreters

See University of Minnesota, Center for Advanced Studies in Child Welfare, *Guide for Creating Legislative Change: Disability in the Termination of Parental Rights and Other Child Custody Statutes* (2007).

Examples of Reasonable Accommodations

- Day care services
- Respite care
- Family or informal support networks (church, neighbors)
- Parent helper/child care assistant
- Aide or personal assistant
- Supported housing
- Pictorial representation or reminders of tasks (step by step)
- Housekeeping services
- Adaptive equipment (e.g. adaptive cribs and child care equipment, communication devices, specialized computer software, cooking/feeding equipment)
- Adaptation to physical environment (e.g. ramps, lower counters, level handled door knobs)

See University of Minnesota, Center for Advanced Studies in Child Welfare, *Guide for Creating Legislative Change: Disability in the Termination of Parental Rights and Other Child Custody Statutes* (2007).

Resources

- National Council on Disability (www.ncd.gov)
- Through the Looking Glass (www.lookingglass.org)
- Center for Rights of Parents with Disabilities (www.disabledparentrights.org)
- Bazelon Center for Mental Health Law (www.bazelon.org)
- The Association for Successful Parenting (www.achancetoparent.net)

Questions

Contact Information

Phoebe Ball
Legislative Affairs Specialist
National Council on Disability
1331 F Street NW,
Suite 850
Washington, DC 20004
pball@ncd.gov
202-272-2004

Robyn M. Powell
Attorney Advisor
National Council on Disability
1331 F Street NW,
Suite 850
Washington, DC 20004
rpowell@ncd.gov
202-236-9651