

Report on Parents With Disabilities Highlights Pervasive Prejudices

In the United States, 6.2% of parents with children age 18 or younger—4.1 million mothers and fathers—have disabilities, including intellectual and developmental, psychiatric, sensory, and physical disabilities. As social integration and new technologies present more lifestyle options to people with disabilities, the number who become parents will increase. However, unless laws and policies are changed, many will face “persistent, systemic, and pervasive discrimination,” warns a new report from the National Council on Disability (NCD). “Even today, 22 years after the passage of the Americans With Disabilities Act (ADA), parents with disabilities are the only distinct community of Americans who must struggle to retain custody of their children,” the report notes.

The aim of the groundbreaking 445-page report, *Rocking the Cradle: Ensuring the Rights of Parents With Disabilities and Their Children*, is to provide a comprehensive overview of the current state of knowledge, attitudes, and practices toward parents with disabilities and their children. The report shows how application of U.S. disability law and policy in the child welfare and family law systems results in disparate treatment of parents with disabilities and their children, and it recommends immediate actions to ensure that their rights are protected. The methodology for the report included an extensive literature review and a legal analysis of federal disability laws and cases and their implications for parents and prospective parents with disabilities. Federal and state legislation concerning child welfare, family law, and adoption was also reviewed to determine the extent to which people with disabilities are included and to identify problems and gaps as they relate to parents and prospective parents with disabilities. Federal agencies and other entities with missions related to this group and programs that currently provide treatment to this group were also

reviewed. Subject matter experts and parents and prospective parents with disabilities were interviewed.

Ongoing discrimination against parents with disabilities has roots in the eugenics movement of the first half of the 20th century, as the report notes. During that era, more than 30 states passed legislation permitting involuntary sterilization, a movement endorsed by the Supreme Court. By 1970 more than 65,000 Americans had been involuntarily sterilized, and several states continue to have some form of involuntary sterilization law on their books, according to research cited in the report. In today’s child welfare and family law systems, parents with disabilities lose custody of their children at disproportionately high rates. In two-thirds of states, child welfare laws allow courts to determine that a parent is unfit solely on the basis of a disability. Although provisions in most laws require that a link be shown between the parent’s disability and lasting harm to the child (“a detriment that cannot be alleviated”), such provisions are often ignored, according to cases cited in the report. Removal rates as high as 80% have been noted for parents with a psychiatric disability or an intellectual disability. In addition, prospective parents with disabilities have more difficulty accessing assisted reproductive technologies, and they face significant barriers to adopting children.

The report presents 20 key findings and related recommendations. A primary finding is “a paucity of data and research on the prevalence of parents with disabilities, their needs, and their experiences.” As a remedy the NCD calls on the Administration to create an Interagency Committee on Parents With Disabilities, with members from more than a dozen federal departments and agencies. The NCD also strongly recommends that states eliminate disability from their statutes as grounds for termination of parental rights and that all states enact legislation to ensure the rights of parents with disabilities. NCD also calls on Congress to address the disparate treatment of this group by adding specific protections to existing legislation and by shifting funding priorities so that states have a greater incentive to provide services to families while the children are living at home. In addition, the U.S. Department of Justice, in collaboration with the Department of Health and Human Services, should issue guidance to states (child welfare agencies and dependency courts) reinforcing their legal obligations under the ADA and reiterating that presumptions of parental incompetence based on disability violate the ADA. Such guidance should also address the duty of child welfare agencies and dependency courts to provide reasonable accommodations to parents with disabilities.

The full report is available on the NCD Web site at www.ncd.gov/publications/2012/Sep272012/

IOM Report Highlights Health System Inefficiencies

America’s health care system has become too complex and costly to continue business as usual, according to a new report from the Institute of Medicine (IOM) that calls for a systemwide transformation. IOM analyses indicate that about 30% of health spending in 2009—more than \$750 billion—was wasted on unnecessary services, inefficient delivery of care,

excess administrative costs, inflated prices, prevention failures, and fraud. Inefficiencies have other costs: as many as 75,000 deaths might have been averted in 2005, according to research cited in the report, if every state had delivered care at the quality level of the best-performing state.

The changes called for in the 360-page report, *Best Care at Lower*