

2008

## Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together

Susan Stefan

Center for Public Representation, [sstefan@cpr-ma.org](mailto:sstefan@cpr-ma.org)

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### Recommended Citation

Susan Stefan, *Accommodating Families: Using the Americans with Disabilities Act to Keep Families Together*, 2 St. Louis U. J. Health L. & Pol'y (2008).

Available at: <https://scholarship.law.slu.edu/jhlp/vol2/iss1/8>

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## ACCOMMODATING FAMILIES: USING THE AMERICANS WITH DISABILITIES ACT TO KEEP FAMILIES TOGETHER

SUSAN STEFAN\*

### I. INTRODUCTION

Years ago, when children were born with severe disabilities, especially mental disabilities, they were likely to be institutionalized at birth or shortly thereafter.<sup>1</sup> When women with serious psychiatric disabilities who were clients of the mental health or social service systems became pregnant, their children were often taken away from them at birth and put up for adoption.<sup>2</sup> For years, the social reality was that when one member of the family was born with or developed a serious mental disability, the family did not stay intact.<sup>3</sup>

Beginning in the 1970s, the dominant paradigm in disability policy toward children and adults with mental disabilities began to change.<sup>4</sup> The

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\* Center for Public Representation, Newton, Massachusetts. Much of the social science research in this article was prepared by Sarah Weston, whose assistance and support was invaluable: this article would not have been possible without her. I gratefully acknowledge the groundbreaking work of Joanne Nicholson, Andrea Blanch, and the late Carol Mowbray. This article is dedicated to the memory of my mother, Gabrielle Stefan.

1. See SARAH GEHLERT & TERI ARTHUR BROWNE, *HANDBOOK OF HEALTH SOCIAL WORK* 450 (2006); see generally EDWARD D. BERKOWITZ, *AMERICA'S WELFARE STATE: FROM ROOSEVELT TO REAGAN* (1991); see also U.S. Office of Special Education Programs, *History: Twenty-Five Years of Progress Educating Children with Disabilities Through IDEA*, available at [www.ed.gov/policy/speced/leg/idea/history.pdf](http://www.ed.gov/policy/speced/leg/idea/history.pdf) (last visited Feb. 29, 2009) (discussing hundreds of thousands of children with disabilities living in institutions in the 1960s).

2. Walter E. Barton, *Foreword* to ROBERTA J. APFEL & MARYELLEN H. HANDEL, *MADNESS AND LOSS OF MOTHERHOOD: SEXUALITY, REPRODUCTION, AND LONG-TERM MENTAL ILLNESS*, xv, xv, (1993); Roberta G. Sands, *The Parenting Experience of Low-Income Single Women with Serious Mental Disorders*, 76 *FAMILIES IN SOC'Y: J. CONTEMP. HUMAN SERVICES* 86, 86 (1995).

3. See Barton, *supra* note 2; see also Sands, *supra* note 2.

4. See VALERIE J. BRADLEY & JAMES KNOLL, *SHIFTING PARADIGMS IN SERVICES TO PEOPLE WITH DEVELOPMENTAL DISABILITIES* 3-5 (1990); David Mechanic & David A. Rochefort, *Deinstitutionalization: An Appraisal of Reform*, 16 *ANN. REV. SOC.* 301, 301-04 (1990) (discussing the history of deinstitutionalization and its effects); see generally Gerald N. Grob, *The Forging of Mental Health Policy in America: World War II to New Frontier*, 42 *J. HIST. MED. & ALLIED SCI.* 410 (1987) (discussing the historical shift in the treatment of individuals with disabilities).

new framework went by different names in different fields, but its overarching ideal was community integration and maintaining family integrity. In education, children who had previously been expelled from school for severe behavior problems were given services to keep them in school if possible, a process known as “mainstreaming;”<sup>5</sup> in residential settings the goal was “deinstitutionalization;”<sup>6</sup> in social services, it was called “family preservation” or “family stabilization.”<sup>7</sup> Even when a child was taken out of a family, the goal was generally reunification with the family.<sup>8</sup>

Family integrity and family stabilization efforts focused principally (although not entirely) on situations where the disabled member was the child, not the parent.<sup>9</sup> There has been a consensus for several decades in public policy, the research literature, and advocacy efforts regarding the benefits of keeping families intact when a child has a serious mental disability, and the importance of providing the necessary services and supports to parents, grandparents, and extended family members to ensure that the child can remain with his or her family.<sup>10</sup> More recently, advocacy and public policy initiatives have attempted to ensure that parents will not be required to forfeit custody of their mentally disabled children in order to receive needed mental health services available only to children in state custody.<sup>11</sup> In the last several years, lawsuits have compelled states and cities

5. Conor B. McDonough, *The Mainstreaming Requirement of the Individuals with Disabilities Education Act in the Context of Autistic Spectrum Disorders*, 35 FORDHAM URB. L.J. 1225, 1226 (2008); Leslie Reed, *Is a Free Appropriate Public Education Really Free? How the Denial of Expert Witness Fees Will Adversely Impact Children with Autism*, 45 SAN DIEGO L. REV. 251, 266 (2008).

6. See Mechanic & Rochefort, *supra* note 4, at 303-04 (discussing the reasons for the rise of deinstitutionalization); see also Lisa L. Leitzell & David T. Somppi, *Perspectives on Group Homes*, 4 J. Planning Literature 357, 372 (1989) (discussing the reasoning for deinstitutionalization); THOMAS P. SMITH & MARTIN JAFFE, *SITTING GROUP HOMES FOR DEVELOPMENTALLY DISABLED PERSONS*, ch. 2, available at: [www.mncdd.org/parallels2/pdf/86-SGM-APS.pdf](http://www.mncdd.org/parallels2/pdf/86-SGM-APS.pdf) (last visited Feb. 29, 2009) (discussing literature promoting deinstitutionalization).

7. Julie Odegard, Note, *The Americans with Disabilities Act: Creating “Family Values” for Physically Disabled Parents*, 11 LAW & INEQ. 533, 558 (1993).

8. See generally Lisette Austin, *Giving the Family a Chance: Working Towards Reunification*, THE CONNECTION, Fall 2008, at 10, 10 (promoting family reunification efforts); see also Odegard, *supra* note 7, at 558 (stating that “[b]ecause an essential goal of social services is family preservation, the state has a duty to investigate services such as reunification which will achieve that goal.”).

9. See, e.g., National Family Preservation Network, About NFPN, at [www.nfpn.org/about-nfpn.html](http://www.nfpn.org/about-nfpn.html) (last visited Feb. 29, 2009) (explaining that the purpose of the National Family Preservation Network is to “improve[] the well-being of children”).

10. Austin, *supra* note 8, at 10.

11. Lois A. Weithorn, *Envisioning Second-Order Change in America’s Response to Troubled and Troublesome Youth*, 33 HOFSTRA L. REV. 1305, 1308 (2005); see generally

to provide wraparound services for seriously emotionally disturbed children in their homes under the Early Periodic Screening Diagnosis and Treatment (EPSDT) portion of Medicaid.<sup>12</sup>

Far more modest progress has been made with programs to help parents (usually mothers) with mental disabilities keep their children. One of the first such programs was the Thresholds Program in Chicago,<sup>13</sup> and today a small number of model programs exist across the country.<sup>14</sup> Because of funding and agency structures, however, family unification programs targeted at families where one member has a disability are generally aimed at helping the family in order to benefit a specific individual client, either the child or the parent.<sup>15</sup> It is rare for the entire family to be identified as the client of a program.

During the same period of time in which wraparound and other models of family-based care have developed to keep families intact, advocates have used the Americans with Disabilities Act (ADA)<sup>16</sup> to promote community integration of adults with mental disabilities.<sup>17</sup> In 1999, the Supreme Court's holding in *Olmstead v. L.C.*, that unnecessary institutionalization constituted segregation under the ADA,<sup>18</sup> sparked a national effort to maximize community placement and integration of adults with psychiatric disabilities. Since then, a number of court cases have been brought aimed

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Gwen Goodman, *Accessing Mental Health Care for Children: Relinquishing Custody to Save the Child*, 67 ALBANY L. REV. 301 (2003); Tracy J. Simmons, *Relinquishing Custody in Exchange for Mental Healthcare Services: Undermining the Adoption and Safe Families Act's Promise of Reasonable Efforts Towards Family Preservation and Unification*, 10 J. L. & FAM. STUD. 377 (2008); Judge David L. Bazelon Center for Mental Health Law, *Custody Relinquishment to Obtain Mental Health Services for Children*, at [www.bazelon.org/issues/children/custody/index.htm](http://www.bazelon.org/issues/children/custody/index.htm) (last visited Feb. 29, 2009).

12. See *Rosie D. v. Romney*, 401 F. Supp. 2d 18, 52 (D. Mass. 2006); *Katie A. v. Bontá*, 433 F. Supp. 2d 1065, 1074-75 (C.D. Cal. 2006).

13. Thresholds Psychiatric Rehabilitation Ctrs., *The Thresholds Mothers' Project: Overview*, at [www.thresholds.org/mothers.asp](http://www.thresholds.org/mothers.asp) (last visited Feb. 29, 2009).

14. These programs are described in various places, including APFEL & HANDEL, *supra*, including ROBERTA J. APFEL & MARYELLEN H. HANDEL, *MADNESS AND LOSS OF MOTHERHOOD: SEXUALITY, REPRODUCTION, AND LONG TERM MENTAL ILLNESS* 163 (1993) and "Parental Mental Illness" on the Illinois Department of Children and Family Services website, at <http://dcfsweb.resource.prairienet.org/ras/mental.php> (last visited Feb. 29, 2009). Because of the exigencies of funding, some of these programs may no longer exist. The principles on which they operate, however, remain constant: that both children and parents are better off if the family remains together, with services that maximize their strengths and supports to assist them.

15. See Substance Abuse and Mental Health Servs. Admin., U.S. Dep't of Health & Human Servs., *Critical Issues for Parents with Mental Illness and Their Families*, at [www.mentalhealth.samhsa.gov/publications/allpubs/KEN-01-0109/ch7.asp](http://www.mentalhealth.samhsa.gov/publications/allpubs/KEN-01-0109/ch7.asp) (last visited Feb. 29, 2009).

16. 42 U.S.C. §§ 12101-12213 (2000).

17. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999).

18. *Id.* at 599-601.

at enforcing the finding in *Olmstead* that individuals should not have to give up integrated life in a community setting in order to receive necessary treatment for their disabilities.<sup>19</sup>

Despite obvious parallels between family integration and community integration, efforts to use the ADA to keep families intact in the community when one member of the family has a psychiatric disability have failed almost completely.<sup>20</sup> These cases have generally been brought on behalf of an individual disabled parent in state court, claiming that a state social services agency had an obligation to provide accommodations to the disabled parent prior to terminating parental rights.<sup>21</sup> Despite the fact that a substantial number of families who are subject to termination proceedings have at least one member with a psychiatric disability, both federal and state courts have recoiled from suggestions that the ADA requires state agencies to truly modify their practices, services, or training in recognition of this fact, or to provide more than cursory accommodations (or, in some cases, any accommodations at all) to keep families intact when one member has a psychiatric disability.<sup>22</sup> Some state courts have held that violations of the

19. See *Frederick L. v. Pa. Dep't of Pub. Welfare*, 364 F.3d 487 (3d Cir. 2004), vacated, 422 F.3d 151 (3d Cir. 2005); *Pa. Protection and Advocacy, Inc. v. Pa. Dep't of Public Welfare*, 402 F.3d 374 (3d Cir. 2005); *Arc of Washington v. Braddock*, 427 F.3d 615 (9th Cir. 2005); *Messier v. Southbury Training School*, 562 F. Supp. 2d 294 (D. Conn. 2008); *Martin v. Taft*, 222 F. Supp. 2d 940 (S.D. Ohio 2002).

20. Theresa Glennon, *Walking with Them: Advocating for Parents with Mental Illnesses in the Child Welfare System*, 12 TEMP. POL. & CIV. RTS. L. REV. 273, 275 (2003); Alexis C. Collentine, Note, *Respecting Intellectually Disabled Parents: A Call for Change in State Termination of Parental Rights Statutes*, 34 HOFSTRA L. REV. 535, 562 (2005); Sherry S. Zimmerman, Annotation, *Parents' Mental Illness or Mental Deficiency as Ground for Termination of Parental Rights—Applicability of Americans with Disabilities Act*, 119 A.L.R. 351 (2004); Joanne Nicholson et al., *The Prevalence of Parenthood in Adults with Mental Illness: Implications for State and Federal Policymakers, Programs, and Providers*, in MENTAL HEALTH, UNITED STATES, 2002, at 133 (Ronald W. Manderscheid & Marilyn J. Henderson eds., U.S. Dep't of Health & Human Servs. Pub., 2004) [hereinafter Nicholson et al., *The Prevalence of Parenthood*].

21. See, e.g., *J.H. v. Dep't of Health & Social Servs.*, 30 P.3d 79, 86 (Alaska 2001); *Collins v. Dep't of Human Servs.*, CA02-653, 2003 Ark. App. LEXIS 52, at \*1 (Ark. App. Jan. 22, 2003); *Greenfield v. Dep't of Human Servs.*, CA02-525, 2002 Ark. App. LEXIS 600, at \*1 (Ark. App. Oct. 30, 2002); *Parker v. Dep't of Human Servs.*, CA96-155, 1997 Ark. App. LEXIS 53 at \*1 (Ark. App. Feb. 5, 1997); *In re Anthony P.*, 84 Cal. App. 4th 1112, 1115 (App. Ct. 2000).

22. Some courts have held that no services were required because a parent's mental illness would preclude her from being able to parent, or that the ADA does not apply to termination proceedings, and therefore no accommodations are required. See *In re B.S.*, 693 A.2d 716, 720 (Vt. 1997); *In re Antony B.*, 735 A.2d 893, 899 (Conn. App. 1999). Other courts have held that the ADA does not affect or increase the duty imposed by statute to provide reunification services, so that parents with disabilities are not entitled to any more or

ADA cannot be used as a defense to termination of parental rights and have instructed parents to bring their claims in federal courts.<sup>23</sup> Some federal courts have held that they cannot resolve ADA claims, either because they do not have the jurisdiction under the Rooker-Feldman doctrine to hear appeals of final state decisions regarding parental rights, or because they invoke the Younger abstention doctrine.<sup>24</sup> Other courts have held that parents who asked for accommodations once termination proceedings were underway asked too late;<sup>25</sup> still others have held that parents did receive accommodations and were simply unable to benefit from them.<sup>26</sup>

The central argument of this article is that attempts to apply the ADA to keep families together when one member has a psychiatric disability have used the wrong strategy, at the wrong time, and have employed the wrong argument. Individual claims on behalf of a disabled parent at the time of termination proceedings asking for reasonable accommodations have failed in scores of cases across the country in different jurisdictions and before different judges.

Instead of case-by-case adjudication, disability advocates should bring systemic ADA discrimination cases seeking to expose and confront the exclusion and discrimination inherent in the operation of the interlocking mental health, social service, and legal systems. Those frameworks, presumptions, and structures essentially erase the possibility of keeping the family together, affirmatively undermine family integrity, and create barriers, burdens, and obstacles to people with psychiatric disabilities remaining with their families. Thus, by the time of the individual termination proceedings, the termination outcome is often predetermined.<sup>27</sup>

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different services from parents who are not disabled. *Bartell v. Lohiser*, 215 F.3d 550 (6th Cir. 2000); *In re Torrance P.*, 522 N.W.2d 243, 245-46 (Ct. App. Wis. 1994).

23. *In re Terry*, 610 N.W.2d 563, 570 (Mich. Ct. App. 2000); *In re Anthony P.*, 84 Cal. App. 4th 1112, 1116 (App. Ct. 2000); *Stone v. Daviess County Div. of Child and Fam. Servs.*, 656 N.E.2d 824 (Ind. App. 1995); *In re B.K.F.*, 704 So.2d 314, 317 (La. App. 1994); *In re B.S.* 693 A.2d 716 (Vt. 1997).

24. *Miller v. Nichols*, 2009 U.S. Dist. LEXIS 1533, at \*9-\*12, \*16 (D.Me. Jan. 9, 2009); *Hilger v. Mink*, No. CV 01-1132-AS, 2002 WL 31441221, at \*1 (D. Or. Jan. 28, 2002); see also *Burgess v. Carmichael*, No. 99-17540, 2002 U.S. App. LEXIS 11102, at \*\*3 n.1 (9th Cir. June 7, 2002).

25. *In re C.M.*, 526 N.W. 2d 562, 566 (Iowa App. 1994).

26. *Bartell v. Lohiser*, 12 F. Supp. 2d 640, 648 (E.D. Mich. 1998), *aff'd*, 215 F.3d 550 (6th Cir. 2000); *In re Angel B.*, 659 A.2d 277, 279 (Me. 1995); *In re C.M.*, 526 N.W.2d at 566.

27. It is true that some parents abandon their children or prefer to see them institutionalized. See *Martin v. Voinovich*, 840 F. Supp. 1175, 1184 n.15 (S.D. Ohio 1993) (involving a father who stated that his disabled son should remain in a nursing home the father did not see or correspond with him for over twenty years). Some older children who have lived with their natural families express a desire to be taken from their family and

The attitudes and assumptions of social service agencies and the legal system mirror in many ways the attitudes and assumptions applied to the parenting capacities of people with physical disabilities. Until relatively recently, judges and social service agencies simply did not believe that people who were, for example, blind, deaf, or wheelchair bound could adequately parent a child.<sup>28</sup> These social service agencies and family court judges believed that certain physical disabilities completely precluded successful parenting, and the same is true today for psychiatrically disabled parents. Asking for reasonable accommodations, which requires the agency and court to believe that the barriers to successful parenting can be alleviated by rearranging certain aspects of service delivery, flies in the face of the underlying assumption that the disability itself fundamentally precludes parenting at all.

In addition, it is worthwhile to explore the application of the *Olmstead* integration holding to efforts to keep families together when one member has a disability. This article argues that family integration is not only a natural corollary to community integration, it is a fundamental component of community integration. Community integration (people with disabilities living in the community) is a meaningless concept without family integration (people with disabilities living in intact families). Furthermore, to the extent that family integration and community integration are separate concepts, this article argues that the language and logic of the Supreme Court's decision in *Olmstead* should apply to family integration as much as it applies to community integration, and for many of the same reasons.

Section II of this article will set out research findings reflecting that the psychiatric disability of one member of a family affects all members of the family, that the solution to the problems that families face when one member has a psychiatric disability is to assist the family rather than (literally) dismember it, and that the best way to provide this assistance is to the family as a whole. Section III will review the history of federal anti-discrimination law, including Section 504 of the Rehabilitation Act,<sup>29</sup> and its applications to family integrity. I will focus on several early cases whose significant implications have been lost over the years: the far-sighted district court

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adopted. See *J.T. v. Dep't of Human Servs.*, 947 S.W. 2d 761, 764 (Ark. 1997). This article is not about those families. It is about families with a disabled member who want to stay together when the state seeks termination because of its judgment that the disability of one member means that the family as a unit should be dissolved, as opposed to assisted with its deficits and accommodated with its imperfections.

28. Michael Ashley Stein, *Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities*, 60 BROOK. L. REV. 1069, 1069-70 (1994); Odegard, *supra* note 7, at 534.

29. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (1973).

decisions in *Homeward Bound v. Hissom*<sup>30</sup> and *Joyner v. Dumpson*.<sup>31</sup> Section III will also examine the integration mandate and ignore *Olmstead v. L.C.*, and argue that the language and logic of each of these cases supports the proposition that efforts to keep families with a disabled member together are required by current anti-discrimination law. Section IV of this article will discuss why efforts to use the ADA to maintain family integrity have, for the most part, failed. I contend that lawyers have concentrated too much on individual cases claiming discrimination on the basis of disability, and not enough on the failures of state human service systems to overcome structural prejudices against people with psychiatric disabilities as parents.

Finally, Section V will discuss potential models for ADA cases on behalf of families with a psychiatrically disabled family member. I argue that pursuing community integration without maintaining family integrity is, in some ways, a meaningless concept that perpetuates discriminatory images of people with psychiatric disabilities as disconnected from intimate relationships and incapable of successful parenting, who can never be seen as truly a part of the community.

## II. THE INTERFAMILY AND INTERGENERATIONAL IMPACT OF MENTAL DISABILITY

The majority of people who suffer from mental illness over their lifetimes are parents.<sup>32</sup> Over one million parents of children under eighteen have a serious psychiatric disorder.<sup>33</sup> In fact, people with serious mental illness "may be at least as likely, if not more likely" to have children than people without serious mental illness.<sup>34</sup>

Most parents with mental illness escape the attention of child welfare authorities; however, "those that do are likely to face other serious challenges as well: poverty, single parenthood, few family or other social supports, and domestic violence or childhood sexual abuse."<sup>35</sup> Intervention from state social service agencies and dissolution of the family is often the

30. *Homeward Bound, Inc. v. Hissom Mem'l Ctr.*, No. 85-C-437-E, 1987 WL 27104 (N.D. Okla. July, 24, 1987).

31. *Joyner v. Dumpson*, 533 F. Supp. 233 (S.D.N.Y. 1982), *rev'd*, 712 F.2d 770 (2d Cir. 1983) (citing misapprehension of the scope of Section 504; this misapprehension was corrected by the U.S. Supreme Court less than five years later in *Alexander v. Choate*, 469 U.S. 287 (1985)).

32. Nicholson et al., *The Prevalence of Parenthood*, *supra* note 20, at 120, 128; Kathleen Biebel et al., *The Responsiveness of State Mental Health Authorities to Parents with Mental Illness*, 32 ADMIN. & POL'Y IN MENTAL HEALTH 31, 31-32 (2004).

33. Glennon, *supra* note 20, at 273.

34. Nicholson et al., *The Prevalence of Parenthood*, *supra* note 20, at 123.

35. Glennon, *supra* note 20, at 273.



final blow to parents already struggling under the accumulating impact of stressful and disempowered lives with few choices and fewer opportunities.<sup>36</sup>

There are at least six to nine million children in the United States with serious emotional disturbances.<sup>37</sup> These children are the focus of poorly coordinated interventions by multiple human service systems—social services, mental health services, early intervention educational services, and foster care services—as well as the juvenile correctional system, including juvenile justice and court diversion, among other services.<sup>38</sup>

Both personal memoirs and research literature show that when one member of a family has a serious psychiatric disability—whether the parent or child—it affects the entire family. Disability theorists emphasize that disability is less a trait or characteristic manifested by one person than the product of interaction among individuals, or between an individual and society.<sup>39</sup> The more that individuals interact, the more that the nature and impact of the disability are mediated by that interaction; thus, this dynamic and interactive theory of disability may be most true in the context of a family.<sup>40</sup> Even when only one member of a family has a psychiatric disability, its consequences may have enormous and crucial impact on other members of the family. Other family members themselves may need assistance, both to accommodate the family member with a disability and to help them through the frustration, exhaustion, or confusion that often accompanies having a family member with a mental disability.

36. *In re Juvenile* 2006-833, 937 A.2d 297, 300-02 (N.H. 2007) (holding that a mother's parental rights could be terminated when she failed to take psychotropic medications she could not afford, and that the state's social service agency had no obligation to provide her with the medications or help her pay for them); *In re J.R.*, CP99010717A, 2003 Conn. Super. LEXIS 3665, at \*5-\*6, \*9, \*11, \*47 (Super. Ct. Mar. 31, 2003) (finding that a mother's parental rights could be terminated where she had a psychiatric disability, a co-occurring substance abuse problem, and difficulty finding and maintaining housing).

37. U.S. DEP'T OF HEALTH & HUMAN SERVS., MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL 1999, at 179 (1999), available at <http://download.ncadi.samhsa.gov/ken/pdf/surgeongeneralreport/C3.pdf> (last visited Feb. 16, 2009).

38. Weithorn, *supra* note 11, at 1314-15.

39. MICHAEL OLIVER, UNDERSTANDING DISABILITY: FROM THEORY TO PRACTICE 5, 22 (1996).

40. It is regularly reported that people with disabilities, even seriously impairing disabilities, are successful if they are treated by their parents as "normal" children. See, e.g., ALICE DOMURAT DREGER, ONE OF US: CONJOINED TWINS AND THE FUTURE OF NORMAL (2004); JOSEPH P. SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT (1994). Children adapt to having a disabled parent quite naturally if the disability is presented as an ordinary part of the individual's life. See JOHN HOCKENBERRY, MOVING VIOLATIONS: WAR ZONES, WHEELCHAIRS, AND DECLARATIONS OF INDEPENDENCE (1995). But see, e.g., ALLEN SHAWN, WISH I COULD BE THERE: NOTES FROM A PHOBIC LIFE 93-115 (2007) (attributing life-long and severely impairing phobias to his parents' deeply negative attitudes toward his developmentally disabled sister, who was sent away at an early age).

The discussion above assumes that only one member of the family has a disability, but, like the American household headed by a working father and stay-at-home mother, the family with one seriously emotionally disabled family member may be more of a cultural narrative than a reality.<sup>41</sup> Increasingly, psychiatric disability is recognized as both interfamilial and intergenerational.<sup>42</sup> Statistics reflect that roughly forty percent of children with serious emotional disturbance in the mental health system have had a parent who was psychiatrically hospitalized at least once.<sup>43</sup> Approximately fifty-five percent of children with serious emotional disturbance in the mental health system have a family history of serious psychiatric disability.<sup>44</sup> Between one third and one half of children of mothers with serious mental illness will themselves have a Diagnostic and Statistical Manual of Mental Disorders diagnosable disorder.<sup>45</sup> In one survey of mothers with mental illness, mothers reported that one-third of their adult children had not completed high school, and about one-third experienced psychological problems.<sup>46</sup> "[I]t [also] might be inferred that the adult children in this study had relationship problems, in that, at an average age of 22, only about one in nine were in a committed relationship, although 38 percent were parents."<sup>47</sup> In fact, children whose parents have serious mental health problems are generally accepted by federal and state programs as being "at risk."<sup>48</sup>

41. Both research and case law reflect the prevalence of families where both parents and children have disabilities, or where multiple siblings have disabilities. See *J.B. v. Valdez*, 186 F.3d 1280, 1283-85 (10th Cir. 1999). Although this article concentrates on psychiatric disability, the number of poor families where parents and children have both physical and psychiatric disabilities is strikingly high. See Nat'l Council on Disability, TANF and Disability: Importance of Supports for Families with Disabilities in Welfare Reform 5-6 (2003), available at [www.ncd.gov/newsroom/publications/2003/pdf/familysupports.pdf](http://www.ncd.gov/newsroom/publications/2003/pdf/familysupports.pdf) (last visited Feb. 16, 2009) [hereinafter Nat'l Council in Disability, TANF].

42. Nat'l Council in Disability, TANF, *supra* note 41.

43. CTR. FOR MENTAL HEALTH SERVS., U.S. DEP'T OF HEALTH & HUMAN SERVS., THE COMPREHENSIVE COMMUNITY MENTAL HEALTH SERVICES FOR CHILDREN AND THEIR FAMILIES PROGRAM: EVALUATION FINDINGS, ANNUAL REPORT TO CONGRESS 2002-2003, at 15 fig.4 (2003).

44. *Id.*

45. Carol Mowbray et al., *Parenting of Mothers with a Serious Mental Illness: Differential Effects of Diagnosis, Clinical History, and Other Mental Health Variables*, 26 SOC. WORK RES. 225, 225 (2002) (internal cites omitted); AMERICAN PSYCHIATRIC ASSOCIATION, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (4th ed., 2000).

46. Carol T. Mowbray et al., *Psychosocial Outcomes for Adult Children of Parents with Severe Mental Illnesses: Demographic and Clinical History Predictors*, 21 HEALTH & SOC. WORK 99, 105 (2006) [hereinafter Mowbray et al., *Psychosocial Outcomes*].

47. *Id.*

48. See, e.g., N.Y. COMP. CODES R. & REGS. tit. 10, § 69-4.3(g) (2005) (listing New York's Early Intervention Program risk factors, which include "diagnosed serious and persistent

The fact that mental health problems tend to be intergenerational is well established in the literature.<sup>49</sup> A survey of nearly 6,000 respondents from across the United States that evaluated respondents' mental health in a structured diagnostic interview, then collected information on the mental health status of respondents' natural parents, found significant familial aggregation for all conditions surveyed: major depression, generalized anxiety disorder, antisocial personality disorder, alcohol abuse/dependence, and drug abuse/dependence.<sup>50</sup> This finding is consistent with a broad array of studies that have demonstrated convincingly that parents with depression and anxiety are more likely than the general population to have children with mental health problems.<sup>51</sup> Parental mental health problems have been associated with an increased risk of both internalizing (e.g. depression) and externalizing (e.g. Attention Deficit and Hyperactivity Disorder) emotional difficulties in offspring.<sup>52</sup> Although different study designs and populations produce different probabilities, studies have generally shown that children

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mental illness"); Maternal and Child Health Bureau, U.S. Dep't of Health & Human Servs., Abstracts Details: State Grants for Perinatal Depression—Fiscal Year 2006, The Massachusetts Maternal and Infant Mental Health Project, at <https://perfddata.hrsa.gov/mchb/DGISReports/Abstract/AbstractDetails.aspx?Source=TVIS&GrantNo=P12MC07724&FY=2006> (last visited Feb. 16, 2009). Details about Minnesota's programs to assist at risk children whose mothers have psychiatric difficulties can be found online at Minnesota Dep't of Health, Minnesota Title V MCH Needs Assessment Facy Sheets, Promotion of Maternal & Infant Mental Health Summer 2004, at [www.health.state.mn.us/divs/cfh//na/factsheets/pwmi/maternalmenthlth.html](http://www.health.state.mn.us/divs/cfh//na/factsheets/pwmi/maternalmenthlth.html) (last visited Feb. 16, 2009); see also Mowbray et al., *Psychosocial Outcomes*, *supra* note 46, at 225.

49. Kenneth S. Kendler et al., *The Familial Aggregation of Common Psychiatric and Substance Use Disorders in the National Comorbidity Survey: A Family History Study*, 170 *BRIT. J. PSYCHIATRY* 541 *passim* (1997); Roselind Lieb et al., *Parental Major Depression and the Risk of Depression and Other Mental Disorders in Offspring*, 59 *ARCHIVES GEN. PSYCHIATRY* 365, 365 (2002); William R. Beardslee et al., *Psychiatric Disorder in Adolescent Offspring of Parents with Affective Disorder in a Non-Referred Sample*, 15 *J. AFFECTIVE DISORDERS* 313, 320 (1988) [hereinafter Beardslee et al., *Psychiatric Disorder in Adolescent Offspring*]; Catherine A. Lesesne et al., *Attention-Deficit/Hyperactivity Disorder in School-Aged Children: Association with Maternal Mental Health and Use of Health Care Resources*, 111 *PEDIATRICS* (Supplement) 1232, 1234 (2003); Shelli Avenevoli & Kathleen Ries Merikangas, *Implications of High-Risk Family Studies for Prevention of Depression*, 31 *AM. J. PREVENTIVE MED.* (Supplement 1) S126 *passim* (2006).

50. Kendler et al., *supra* note 49, at 541-43, 545.

51. Lieb et al., *supra* note 49, at 365 (stating that "[s]tudies...have consistently shown that offspring of depressed parents have a substantially increased risk for experiencing not only depressive disorders, but also other psychopathology, such as anxiety or substance-use disorders."); Beardslee et al., *Psychiatric Disorder in Adolescent Offspring*, *supra* note 49, at 320.

52. See, e.g., Lesesne et al., *supra* note 49, at 1233-34 (noting that maternal depression and anxiety and/or emotional problems are associated with a more than four-fold increased incidence of ADHD in their offspring); Lieb et al., *supra* note 49, at 365.

with a parent suffering from major depression has an odds ratio of somewhere between 2.21 to 1 and 3.6 to 1 of suffering from some form of emotional disorder themselves, compared to controls with healthy parents.<sup>53</sup> One study of children enrolled in an HMO found that thirty percent of the children whose parents suffered from major affective disorder suffered from depression themselves, compared to just two percent of the children whose parents did not suffer from major affective disorder.<sup>54</sup> Other studies put this figure even higher.<sup>55</sup> Furthermore, research has revealed that parental depression not only increases the odds that children will have depression, but is also “associated with an earlier onset and a more malignant course (severity, impairment, recurrence) of depressive disorders in offspring.”<sup>56</sup>

In fact, studies have shown that psychiatric disabilities are often a multi-generational phenomenon that extends beyond the individual family. In one three-generational study, researchers found that nearly half of children with both a parent and a grandparent with major depressive disorder suffered from some form of psychopathology, and that those grandchildren with both a parent and grandparent who suffered from major depression were the most impaired.<sup>57</sup> Another study, which followed an original group of participants, their children, and eventually their grandchildren for nearly twenty years, revealed that nearly sixty percent of the grandchildren who had both a parent and a grandparent with major depression suffered from psychopathology, and when it was measured, the mean age of the grandchildren was just twelve years old.<sup>58</sup>

The fact that the impact of psychiatric disability is multi-generational, however, should not lead to a “three generations of melancholics is enough” approach.<sup>59</sup> Not only research, but personal memoirs and accounts, reflect the truth that the best and most enduring accommodation

53. Kendler et al., *supra* note 49, at 545 (collecting studies); Lieb et al., *supra* note 49, at 369 tbl.2.

54. Beardslee et al., *Psychiatric Disorder in Adolescent Offspring*, *supra* note 49, at 320.

55. Avenevoli & Merikangas, *supra* note 49, at S127 (reviewing the literature and citing a study showing that the cumulative risk of major depression in children with depressed parents was nearly 70%).

56. Lieb et al. *supra* note 49, at 365.

57. Virginia Warner et al., *Grandparents, Parents, and Grandchildren at High Risk for Depression: A Three-Generation Study*, 38 J. AM. ACAD. CHILD ADOLESCENT PSYCHIATRY 289, 293 (1999).

58. Myrna M. Weissman et al., *Families at High and Low Risk for Depression: A 3-Generation Study*, 62 ARCHIVES GEN. PSYCHIATRY 29, 29-30, 34 (2005).

59. Justice Oliver Wendell Holmes famously said, in upholding the sterilization of an allegedly mentally retarded woman, that “[t]hree generations of imbeciles are enough.” *Buck v. Bell*, 274 U.S. 200, 207 (1927).

for people with even the most serious disabilities is the love and tenacity of their family, however imperfectly expressed.<sup>60</sup>

When a family member has a psychiatric disability, the family may well need support and services of varying intensity over time. It is not always or even generally the case that dissolving or dismembering the family will improve the situation of all or any of the family members. Often the most powerful incentive a parent, especially a mother, can have to seek treatment or stay in recovery is to keep her child and be a good parent for that child.<sup>61</sup> At the same time, involuntary separation from parents, even imperfect parents, can be one of the most traumatic events of a child's life.<sup>62</sup> Yet the structure and framework of state health, mental health, and protective service agencies which fail to identify and recognize the centrality of family members' attachment to each other, as well as their efforts and accommodations, often do result in family dissolution. Dissolution itself can lead to institutionalization for one or more members of the family in years and sometimes generations to come.

While there is significant evidence demonstrating the intergenerational impact of a psychiatric disability, the mechanism is less clear. One reason may be that "[b]ecause of the stigma attached to mental illness, parents may not ever share the fact that they have a mental illness with their children. This means that even years later, adult children may not have an explanation for parental behavior."<sup>63</sup> One of the most successful and simplest programs for families in which one member has a psychiatric disability is an educational program for the entire family explaining about mental illness and what family members can expect, which is discussed in greater detail *infra*.<sup>64</sup>

Another explanation is that families in which one member has a severe mental illness are also often characterized by stressful environments,

60. See generally ANDREW BRIDGE, *HOPE'S BOY* (2008); KAY REDFIELD JAMISON, *AN UNQUIET MIND* (1995); TRACY THOMPSON, *THE BEAST: A JOURNEY THROUGH DEPRESSION* (1995); JEANNE SAFER, *THE NORMAL ONE: LIFE WITH A DIFFICULT OR DAMAGED SIBLING* (2002); see also *supra* note 40 and accompanying text.

61. See Carol T. Mowbray et al., *Motherhood for Women with Serious Mental Illness: Pregnancy, Childbirth, and the Postpartum Period*, 65 AM. J. ORTHOPSYCHIATRY 21, 21 (1995); APFEL & HANDEL, *supra* note 14, at 4-5, 160-61.

62. See BRIDGE, *supra* note 60.

63. Jared Wadley, *Adult Children of Mothers with Mental Illness Show Problems*, UNIV. OF MICH. NEWS SERVICE, June 1, 2006, at [www.ns.umich.edu/htdocs/releases/story.php?id=276](http://www.ns.umich.edu/htdocs/releases/story.php?id=276) (last visited Feb. 16, 2009) (quoting "Daphna Oyserman, a professor of social work and psychology, and a research professor in the Institute for Social Research . . .").

64. William R. Beardslee et al., *A Family-Based Approach to the Prevention of Depressive Symptoms in Children at Risk: Evidence of Parental and Child Change*, 112 PEDIATRICS e119, e122, e127 (2003), at <http://pediatrics.aappublications.org/cgi/reprint/112/2/e119> (last visited Feb. 16, 2009) [hereinafter Beardslee et al., *A Family Based Approach*].

including uncertain housing, health care, and income for groceries, which also lead to marital discord and depression.<sup>65</sup> Some research indicates that stressful environments increase the likelihood that the children of depressed parents will develop depression.<sup>66</sup> Because of this, programs like Thresholds in Chicago which assist the family to obtain stable housing and employment often show beneficial results in terms of family stability.<sup>67</sup>

Genetics explains only a small piece of the familial aggregation phenomenon.<sup>68</sup> No specific “depression gene” has been identified.<sup>69</sup> Family-environmental factors are thought to be a major driver of family clustering of mental health problems, although findings are not always conclusive.<sup>70</sup> Specifically, studies have focused on the fact that parental mental illness can lead to poor parenting, which in turn is associated with increased mental health problems in children.<sup>71</sup> For example, studies have shown that maternal depression can lead mothers to “exhibit inadequate parenting skills (e.g., less interaction, ineffective control strategies) and model dysregulated affect (e.g., restricted affect, more hostility, irritability, and sadness)”, all of which are associated with the development of mental health and/or behavioral problems in offspring.<sup>72</sup> Similar mental health and/or behavioral problems in offspring emerge in family environments characterized by high levels of “family and marital discord, divorce, inattention, rejection, abuse and stress”.<sup>73</sup>

Given that children with a family history of mental health problems are at a high risk of depression or other psychiatric disorders, and the apparent importance of family-environmental factors, many researchers and clinicians have theorized that interventions targeting the family environment are the

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65. See Nat’l Council on Disability, TANF, *supra* note 41, at 22 (a heartbreaking review by the National Council on Disability of families where both parents and children had disabilities and the parents were forced to work under TANF).

66. See Avenevoli & Merikangas, *supra* note 49, at S128; Mark T. Greenberg et al., *The Prevention of Mental Disorders in School-Aged Children: Current State of the Field*, 4 PREVENTION & TREATMENT, Mar. 30, 2001, at 27-28.

67. Thresholds Psychiatric Rehabilitation Ctrs., The Thresholds Mothers’ Project: Overview, at [www.thresholds.org/mothers.asp](http://www.thresholds.org/mothers.asp) (last visited Feb. 29, 2009).

68. Avenevoli & Merikangas, *supra* note 49, at S127, S128.

69. *Id.* at S128.

70. See *id.* at S128, S132 (explaining that “impaired family environments and social relationships of individuals with depression contribute to the risk for depression among family members”); see Kendler et al., *supra* note 49, at 546 (finding that “only a modest proportion of overall familial aggregation of all disorders, except for [antisocial personality disorder][,]” could be explained by family environmental factors).

71. Avenevoli & Merikangas, *supra* note 49, at S128.

72. *Id.*

73. *Id.*

most useful in mitigating risks to children.<sup>74</sup> Research has shown that family-based interventions can be effective in preventing the onset of psychopathology in children of parents with mental illness.<sup>75</sup>

Beardslee et al. designed and tested a family-based intervention that aimed to increase resilience in adolescents who were at high risk for psychiatric disorders due specifically to having parents with mental illnesses.<sup>76</sup> The intervention was mostly educational, and focused on giving both affected parents and their children more information about their disease.<sup>77</sup> The information included details about the disease itself, how and why it should be discussed with their children, how parental mood disorders affect children and what warning signs to look for, how to help their children develop relationships and behaviors associated with increased resiliency, and how to reduce familial-environmental conditions associated with increased psychopathology in children of parents with mood disorders.<sup>78</sup> The information was delivered in one of two ways. Part of the study group received the information in two separate lectures, with no children present.<sup>79</sup> The other part of the study group participated in six to eleven one-on-one meetings with a care provider, with some of these meetings involving the children and some only involving the child, and with follow-up phone calls and/or meetings at six to nine month intervals.<sup>80</sup> Follow-up interviews with parents and children showed that the children had a better understanding of their parents' disease, and also showed fewer internalizing symptoms, which are considered a precursor to more serious affective disorders.<sup>81</sup> These positive effects were still present when measured four and a half years after the relatively brief intervention.<sup>82</sup>

In a review of interventions designed to prevent childhood mental illness for children at risk for a variety of reasons not limited to family history of psychiatric disorders, Greenberg et al. found thirty-four interventions that had successfully reduced symptoms or direct precursors of childhood mental

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74. *Id.* at S132 (concluding that "findings support family-based programs . . . . Additionally, the large environmental component of depression suggests that alterations in the environments of those at risk for depression (by virtue of a family history) can lower risk for depression.").

75. See William R. Beardslee et al., *Long-Term Effects from a Randomized Trial of Two Public Health Preventive Interventions for Parental Depression*, 21 J. FAM. PSYCHOL. 703, 704, 710 (2007) [hereinafter Beardslee et al., *Long Term Effects*] .

76. Beardslee et al., *A Family Based Approach*, *supra* note 64, at e120.

77. *Id.* at e122.

78. *Id.* at e122.

79. *Id.* at e123.

80. *Id.* at e122.

81. Beardslee et al., *A Family Based Approach*, *supra* note 64, at e127-28.

82. Beardslee et al., *Long Term Effects*, *supra* note 75.

illness, had been rigorously evaluated and published in a peer-reviewed journal, and had targeted children between the ages of five and eighteen.<sup>83</sup> The reviewers concluded that interventions targeting children alone were less effective in reducing psychiatric symptomology than programs that targeted children, parents and schools together.<sup>84</sup> Greenberg et al. also noted that more interventions had been designed that focused on preventing externalizing (i.e. aggression) as opposed to internalizing (i.e. depression) behavior.<sup>85</sup>

Of course, the impact of the disability goes beyond the family. The family is both affected by the person's disability and by the social response to the disability. It can mediate and interpret the social response to the disabled family member by reinforcing it, by discounting it, and by giving the disabled family member acceptance, hope, and support, or by some complex mixture of these elements which may vary over time and individual family members. The family's actions and reactions to disability—support, helplessness, rejection, and abuse, for example—in turn ameliorate or exacerbate the effects of the disability for the individual, and affect how the individual approaches the world—another reason that family supports and services are a key first step to community integration.<sup>86</sup> A family's positive and supportive attitudes and behaviors toward its disabled family member signals to neighbors, school officials, and the community how they should react to the individual with a disability. By the same token, family disparagement, frustration, and negativity may also carry over into the attitudes of providers and community members.

### III. THE ADA AND KEEPING FAMILIES TOGETHER

#### A. *The Integration Mandate*

When Section 504 of the Rehabilitation Act was passed in 1973, it contained a single line prohibiting discrimination on the basis of handicap in programs receiving federal funding.<sup>87</sup> Because programs were federally funded by different agencies across the Executive Branch, from the Department of Transportation to the Department of Housing and Urban Development,<sup>88</sup> each federal agency had to develop its own regulations to

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83. Beardslee et al., *supra* note 66, at 7-8.

84. *Id.* at 33.

85. *Id.* at 34.

86. Susan Stefan, "Discredited" and "Discreditable": The Search for Political Identity by People with Psychiatric Diagnoses, 44 WM. & MARY L. REV. 1341, 1355 (2003).

87. Rehabilitation Act of 1973, Pub. L. No. 93-112, § 504, 87 Stat. 355, 394 (1973).

88. See 28 C.F.R. § 35.190 (1991) for description of agencies charged with enforcing the regulations.



implement Section 504 in the particular programs it funded.<sup>89</sup> Since it was obvious that many definitions and other aspects of the regulations would be identical across the agencies, a “lead agency” was designated to issue so-called “coordination regulations” which applied to all agencies and which had special authority.<sup>90</sup> The then-Department of Health, Education, and Welfare (HEW) was designated the “lead agency.”<sup>91</sup> HEW delayed issuing these coordination regulations, but finally, after significant pressure (including a federal lawsuit,<sup>92</sup> disability activists taking over the San Francisco office of HEW, and picketing the home of Secretary Califano<sup>93</sup>), it reluctantly issued regulations implementing Section 504 of the Rehabilitation Act of 1973.<sup>94</sup>

One of these “coordination” regulations which applied across the board to all recipients of federal funds, regardless of their program, was a provision that was the forerunner of a regulation that came to be known as the “integration mandate.”<sup>95</sup> In the coordination regulations, HHS defined discrimination as a failure to provide equally effective aids, benefits, and services to handicapped individuals as nonhandicapped person.<sup>96</sup> The regulation added that

[f]or purposes of this part, aids, benefits, and services, to be equally effective, are not required to produce the identical result or level of achievement for handicapped and nonhandicapped persons, but must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement, *in the most integrated setting appropriate to the person’s needs.*<sup>97</sup>

Later, the “lead agency” function was shifted to the Department of Justice, which adapted and updated HEW’s regulations.<sup>98</sup> The Department of Justice regulations defined discrimination as failure to provide services in

89. See *id.*

90. See *id.*

91. SHAPIRO, *supra* note 40, at 65-66.

92. *Cherry v. Mathews*, 419 F. Supp. 922, 923 (D.D.C. 1976).

93. RICHARD K. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY 112, 115 (2nd ed. 2001); SHAPIRO, *supra* note 40, at 66. See both SCOTCH and SHAPIRO for accounts of the history behind the battle to obtain regulations for Section 504.

94. These regulations are titled “Nondiscrimination on the Basis of Handicap in Programs or Activities Receiving Federal Financial Assistance” and are found at 45 C.F.R. § 84 (2008).

95. Nat’l Disability Rights Network, Issue Areas-Community Integration: ADA Title II, at [www.napas.org/issues/commint/title2.htm](http://www.napas.org/issues/commint/title2.htm) (last visited Feb. 16, 2009); 28 C.F.R. § 35.130(d) (2008); 28 C.F.R. § 41.51(d) (2008).

96. 28 C.F.R. § 41.51 (2008).

97. 45 C.F.R. § 84.4(b)(2) (2007) (emphasis added).

98. SCOTCH, *supra* note 93, at 129-30.

the most integrated setting appropriate to the individual's needs.<sup>99</sup> The commentary to the Section 504 regulations also added a definition of an integrated setting for the first time. It provided that an integrated setting is "a setting that enables disabled individuals to interact with non-disabled persons to the fullest extent possible".<sup>100</sup>

The first case to recognize that an institutional setting might constitute segregation in violation of antidiscrimination law was decided years before the passage of the ADA, and more than a decade before the Supreme Court's decision in *Olmstead v. L.C.*<sup>101</sup> *Homeward Bound v. Hissom*,<sup>102</sup> more than any case in the intervening twenty-plus years, serves as a model of understanding of the relationship between a person with mental disabilities remaining with his or her family and that person's successful integration in the community. *Homeward Bound* is a tutorial on the necessary connection between family stabilization and community integration. The court in *Homeward Bound* created principles and remedies that remain as alive and true today as they were when it was written over twenty years ago.

B. *Cases Ahead of Their Time: Homeward Bound v. Hissom and Joyner v. Dumpson*

1. *Homeward Bound v. Hissom*

In 1987, three years before the passage of the ADA and twelve years before the U.S. Supreme Court decided *Olmstead v. L.C.*, a Republican-appointed judge in Oklahoma considered a challenge by institutionalized individuals with mental disabilities and their families to the conditions of the institution in which these disabled people were forced to live, and the State's failure to provide services in the community.<sup>103</sup> The judge ruled for the plaintiffs, holding that "Section 504 recognizes the parallels between discrimination suffered by our handicapped citizens and other minority groups. This discrimination is manifested through their segregation from the rest of society. . . . Section 504 prohibits unnecessarily segregated services for retarded persons."<sup>104</sup>

99. 28 C.F.R. § 41.51(d) (2008).

100. 28 C.F.R. § 35.130 App. A (2008).

101. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

102. See *Homeward Bound, Inc. v. Hissom Mem'l Ctr.*, No.85-C-437-E, 1987 WL 27104 (N.D. Okla. July 24, 1987); Timothy M. Cook, *Howard Bound Court Strikes Blow to State-Supported Segregated Services for Disabled Persons*, 11 MENTAL & PHYSICAL DISABILITY L. REP. 358, 358 (1987).

103. *Homeward Bound*, 1987 WL 27104 at \*8-\*14.

104. *Id.* at \*20.

The court held that the plaintiffs were entitled to services that were effective and meaningful and delivered in non-segregated settings. He further held that the institution must be closed, and ordered the State of Oklahoma to develop a new community service system to remedy the effects of its original discriminatory system.<sup>105</sup> In developing its remedy, the court explained the centrality of the family to the goal of community integration, and tailored the remedial plans accordingly.<sup>106</sup> The remedy in *Homeward Bound* focused heavily on family integration and family support.<sup>107</sup>

At the beginning of the Court Plan, Judge Ellison wrote the following words, worth reproducing at length:

As Americans and citizens of Oklahoma, we believe in rugged individualism, the sanctity of the family and in taking care of our own. We grow from the experience of living together in the community. We admire those who work and we work hard so that our children can have the best life and education possible. We have sacrificed to maintain our freedom and a life which is nonrestrictive. These values are our heritage which we preserve so that it can be passed down to our children—all of our children.

The quality of life made available in the United States as a result of this value base is the best in the world for those who are allowed to share in it. The “American Dream” rests at the foundation of the values we defend.

From the evidence presented it is apparent that these values have been denied to that portion of the citizens of Oklahoma who carry the label of “mental retardation”. Therefore, this Order shall include “Guiding Principles” which are intended to direct the remedy developed by the parties as they create community alternatives for persons with mental retardation in Oklahoma. These guiding principles are as follows:

- \* All persons are capable of growth and development.
- \* All persons deserve to be treated with dignity.
- \* All persons have value.
- \* All persons must be involved in and carry the primary responsibility for the decisions which affect their lives.
- \* All persons should live and work in the most natural settings.
- \* All children should live with families.
- \* All children have the right to a free and appropriate education.

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105. *Id.* at \*21, \*30-31.

106. *Id.* at \*23.

107. *Id.* at \*27.

\* All persons should live in and be a part of the community.

\* All citizens have the right to fully exercise their rights as guaranteed by the Constitution of the United States.<sup>108</sup>

The language and the remedy in *Homeward Bound* emphasized that family services, accommodating families, and community integration for individuals with mental disabilities were unitary and inseparable parts of the remedy.<sup>109</sup> The court observed that

[h]istorically the public policy of Oklahoma has been that persons with mental retardation will only receive support in living environments if the individual leaves home and moves to a state operated institution. The State has provided little or no resource to assist a person to stay at home, but has consistently provided immense financial resource to house people away from their own homes. The result has been that families have become frustrated with their inability to respond to the family member's needs. . . . Families have experienced severe pain at having to separate their child from home and family.<sup>110</sup>

The court ordered that "[a] gatekeeping mechanism must be implemented to insure that persons will not be removed from their natural home except in extreme circumstances[,]" and that "[a]ll necessary supports and services must be provided to the home so that it can be the living environment most likely to provide for individual growth and development."<sup>111</sup> The court further ruled that "[i]n home and family support services shall not cost the family any more than would be the cost of raising a child without mental retardation[,]" that "[r]espice, including emergency, occasional and regular respite, as well as in home workers shall be available, as needed, to maintain a balanced, nurturing and supportive home environment . . . ." Further, the court required that "[p]arent/family training will be provided on any issue pertinent to positively maintaining the child at home".<sup>112</sup> But the court also astutely recognized that family support services must be voluntary and tailored to each individual family's needs: "[i]ntrusion into normal home life shall be minimized and no more support or service shall be provided than is required."<sup>113</sup> In addition, the court ordered the provision of transportation to allow involvement in community life and case management to insure access to and coordination of supports and services, including participation in education services.<sup>114</sup> Finally, the

108. *Homeward Bound*, 1987 WL 27104 at \*22-\*23.

109. *Id.* at \*23.

110. *Id.* at \*27.

111. *Id.*

112. *Homeward Bound*, 1987 WL 27104 at \*27.

113. *Id.*

114. *Id.* at \*28.

court directed the State of Oklahoma to ensure that "licensure, policies and procedures of the programs, supports and services which currently exist or those which will be developed" did not have conflicts with or hamper the remedy, and that abundant protective mechanisms be built into the system, including self advocacy training, incident reports and reviews, and independent case management.<sup>115</sup>

The *Homeward Bound* remedy is a detailed blueprint for a community-based system which emphasizes family integrity. Thus, disability advocates' current failure to ensure that *Olmstead* integration claims include family integrity and preservation is hard to understand. If the *Homeward Bound* framework were adopted by social service agencies today as part of the structure of services provided to families of people with mental and psychiatric disabilities, it is likely that those families would be far more likely stay intact and integrated in the community.

## 2. *Joyner v. Dumpson*

Even before *Homeward Bound*, disability advocates challenged New York State's requirement that parents had to give up custody of their children to the Department of Social Services in order for the children to receive residential services for serious emotional needs.<sup>116</sup> The parents challenged this requirement, claiming that it violated the Constitution and Section 504 of the Rehabilitation Act.<sup>117</sup> In language that foreshadowed the decision in *Olmstead v. L.C.* more than fifteen years in the future, plaintiffs argued that this requirement discriminated against them because

among all those eligible to receive any of the various forms of partially federally funded state assistance, only plaintiffs [were] required to submit to state custody as a prerequisite of receipt of needed benefits. Plaintiffs also [asserted] that within the class of handicapped persons, plaintiffs comprise[d] a disadvantaged sub-class that alone [was] subject to the custody transfer requirement prior to the receipt of special services. Plaintiffs argue[d] that the pre-condition imposed only on them as a result of their need for treatment in residential facilities [limited] their access to needed benefits and [discouraged] their use of needed benefits in direct violation of § 504 and 45 C.F.R. § 84.52(a) (1980).<sup>118</sup>

The District Court, noting that defendant could not proffer any reasonable explanation for why parents would have to give up custody of their children to receive services, and underscoring that this rule applied only to children with mental disabilities, granted summary judgment both on

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115. *Id.*

116. *Joyner v. Dumpson*, 533 F. Supp. 233, 234-35 (S.D.N.Y. 1982).

117. *Id.*

118. *Id.* at 238.

the Section 504 claims and on the accompanying constitutional claims.<sup>119</sup> The Second Circuit reversed on the grounds that Section 504 did not apply to disparate impact claims,<sup>120</sup> a premise with which the Supreme Court disagreed only a few years later in *Alexander v. Choate*.<sup>121</sup> The Second Circuit did find, however, that plaintiffs had stated a viable constitutional claim and remanded the case to the District Court.<sup>122</sup>

Years after *Joyner*, parents still have to surrender custody of their children across the country to obtain the mental health services that their children need. This is clearly discriminatory under *Olmstead*, and very likely a constitutional violation as well, and will be discussed more fully in Section V.

### C. *The Americans with Disabilities Act*

Section 504 of the Rehabilitation Act proved disappointing to advocates and people with disabilities, both in its scope and the interpretations of the courts.<sup>123</sup> Prior to passing the ADA, Congress gathered an unprecedented amount of testimony regarding discrimination against people with disabilities, including at least some testimony by people with physical disabilities who were not permitted to adopt children.<sup>124</sup>

As a result of this testimony Congress had a much broader view of the nature and impact of disability discrimination in America, and by the time the ADA was passed, the language of integration was clearly at the heart of the ADA's mandate.<sup>125</sup> In reports pertaining to the ADA, both houses of Congress concluded that

there is a compelling need to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities and *for the integration of persons with disabilities into the economic and social mainstream* of American life. Further, there is a need

119. *Id.* at 239, 242.

120. *Joyner v. Dumpson*, 712 F.2d 770, 772 (2d Cir. 1983).

121. *Alexander v. Choate*, 469 U.S. 287 (1985).

122. *Joyner*, 712 F.2d at 772.

123. See *Helen L. v. DiDario*, 46 F.3d 325, 331 (3d Cir. 1995) (discussing the shortcomings of Section 504).

124. See S. REP. NO. 101-116, at 5-20 (1989) (testimony regarding the need for legislation prohibiting disability discrimination); see H.R. REP. NO. 101-485, pt. 2, at 43-47 (1990) (testimony regarding the effects of disability discrimination on society). This discrimination has by no means ended. See generally *Doe v. Nebraska*, 345 F.3d 593 (8th Cir. 2003) (child removed from prospective adoptive parents' home when it was discovered that mother was HIV-positive); *Doe v. Division of Youth and Family Servs.*, 148 F. Supp. 2d 462 (D.N.J. 2001) (infant removed from mother at the hospital when hospital reported to Division of Youth and Family Services that mother had HIV and was refusing to take AZT).

125. See S. REP. NO. 101-116, at 20 (1989); see H.R. REP. NO. 101-485, pt. 2, at 50 (1990).

to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.<sup>126</sup>

In furtherance of the objective of eliminating discrimination against the disabled, Congress stated that “the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, *full participation, independent living*, and economic self-sufficiency for such individuals[.]”<sup>127</sup>

Title II of the ADA applies to state and local governments, mental health agencies, social service agencies, and the state courts and incorporates the anti-discrimination principles of Section 504.<sup>128</sup> The anti-discrimination prohibitions of Title II, like those of Section 504, were written in several lines.<sup>129</sup> In the ADA, Congress directed the Attorney General to promulgate regulations necessary to implement Title II,<sup>130</sup> and mandated that those regulations “be consistent with this chapter and with the coordination regulations under part 41 of title 28, Code of Federal Regulations” under Section 504 of the Rehabilitation Act of 1973.<sup>131</sup> Accordingly, the regulations that the Department of Justice promulgated under Title II are patterned after the Section 504 coordination regulations, including the integration mandate.<sup>132</sup>

The position of the Department of Justice is that “integration is fundamental to the purposes of the Americans with Disabilities Act.”<sup>133</sup> The Department has adopted regulations, some similar or identical to the coordination regulations of Section 504.<sup>134</sup> One such regulation, the integration mandate, is almost identical to the Section 504 integration regulation that has been in effect since 1981, which provides that “[a] public entity shall administer services, programs, and activities in the most

126. S. REP. NO. 101-116, at 20 (1989); H.R. REP. NO. 101-485, pt. 2, at 50 (1990) (emphasis added).

127. *Helen L.*, 46 F.3d at 332 (quoting 42 U.S.C. § 12101(a)(8) (2000) (emphasis added)).

128. 42 U.S.C. §§ 12131-12134 (2000).

129. 42 U.S.C. § 12132 (2000).

130. 42 U.S.C. § 12134(a) (2000).

131. 42 U.S.C. § 12134(b) (2000).

132. See 28 C.F.R. § 35.130 (2007) (prohibiting disability discrimination by public entities and mandating that public entities administer services, programs, and activities in the most integrated setting appropriate); 29 U.S.C. § 794(a) (2000).

133. *Helen L.*, 46 F.3d at 332-33 (quoting 28 C.F.R. § 35.130, App. A (2007)).

134. 28 C.F.R. § 35.130(a) (2007) (“No qualified individual with a disability shall, on the basis of disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any public entity.”).

integrated setting appropriate to the needs of qualified individuals with disabilities."<sup>135</sup>

In the seven years between the time that the ADA's integration mandate took effect and the Supreme Court's 1999 decision in *Olmstead v. L.C.*, a number of cases were brought seeking to enforce integration mandate provisions and to ensure that services were provided to disabled individuals in the community.<sup>136</sup> In many of these cases, the facts of the case reveal that the plaintiffs were members of families.<sup>137</sup> In some cases the court explicitly noted the desires of the plaintiffs and family members to be together;<sup>138</sup> in others, the fact is provided as an aside, leaving the reader to imagine the sadness of the back story.<sup>139</sup> In *Helen L. v. Didario*, for example, we learn that the sole remaining plaintiff, Idell S., had been

135. 28 C.F.R. § 35.130(d) (2007); 28 C.F.R. § 41.51(d) (1981); 28 C.F.R. § 35.130(d) (2007); 28 C.F.R. § 41.5(a) (2007); 29 U.S.C. § 794 (2000).

136. See *Helen L.*, 46 F.3d at 331 (suit alleging that the Department of Public Welfare violated the ADA by mandating that she receive required care services in the segregated setting of a nursing home rather than through an attendant care program in her own home); see also *Cercpac v. Health and Hospitals Corp.*, 147 F.3d 165, 166, 168 (2d Cir. 1998) (suit alleging that a municipal agency failed to deliver medical care in the most integrated setting available); *Onishea v. Hopper*, 126 F.3d 1323, 1326 (11th Cir. 1997) (suit brought by HIV-positive Alabama inmates alleging that state prisons violated § 504 of the Rehabilitation Act of 1973 by excluding HIV positive prisoners from programs offered); *Heather S. v. Wisconsin*, 125 F.3d 1045, 1047, 1051 (7th Cir. 1997) (suit brought by parents alleging that the state discriminated on the basis of their child's disability by failing to adequately provide educational opportunities to her); *Kathleen S. v. Dep't of Pub. Welfare*, 10 F. Supp. 2d 476, 478 (E.D.Pa. 1998) (suit alleged discrimination for "Commonwealth's failure to adequately plan and develop community placements" for those whom treatment was deemed appropriate); *Wyatt ex rel. Rawlins v. Rogers*, 985 F. Supp. 1356, 1360, 1432 (M.D.Ala. 1997) (suit alleging that the conditions in the Alabama Mental Health and Mental Retardation System facilities violated the residents' rights); *Shultz ex rel. Shultz v. Hemet Youth Pony League, Inc.* 943 F. Supp. 1222, 1226 (C.D.Cal. 1996) (finding that defendants' failure to make necessary and reasonable attempts to ascertain what modifications, if any, were plausible in order to accommodate plaintiff's disability was "discriminatory inaction against [p]laintiff on the basis of [p]laintiff's disability").

137. See *Heather S.*, 125 F.3d at 1047 (parent brought action on behalf of child); *Wyatt ex rel. Rawlins*, 985 F. Supp. at 1365 (stating that "[e]arlier in the year, the committee had reported to plaintiffs' counsel and the court its concern that the majority of the children at the center were not in need of the type of restrictive and isolated environment the facility provides, and that these children could be more appropriately served in a less restrictive program closer to their homes and families."); *Cercpac*, 147 F.3d at 166 (stating that the case was brought by "Lincoln CERCPAC, an association of individuals and families concerned with health care services for children with developmental disabilities, and four parents or guardians of minor children . . ."); *Shultz*, 943 F. Supp. at 1222 (father brought claim on behalf of son to mandate integration).

138. See, e.g., *Martin v. Voinovich*, 840 F. Supp. 1175, 1181 (S.D.Ohio 1993).

139. See, e.g., *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1995).



physically disabled since 1973 from meningitis.<sup>140</sup> She had a child around the time that she became disabled, and later had another child.<sup>141</sup> When her two children were eight and sixteen, she was forced to enter a nursing home because of basic needs that could easily have been accommodated with attendant care services.<sup>142</sup> She was placed on a waiting list to receive these services because Pennsylvania insufficiently funded home-based services.<sup>143</sup> Idell S. lost six crucial years with her children while she was unnecessarily confined in a nursing home.<sup>144</sup> The damage and injury done by Pennsylvania's policies favoring nursing home placement over community services was not solely to Idell S., but to her children, who lost their mother for important years of their childhood and adolescence.

D. *Olmstead v. L.C.*

In *Olmstead v. L.C.*, the Supreme Court heard the case of two women with mental retardation and psychiatric disabilities who were ready for discharge from an institution but continued to be confined because there were no appropriate community placements available for them.<sup>145</sup> In *Olmstead*, the Supreme Court applied the ADA's integration mandate and held that unjustified isolation was segregation that violated the ADA, regardless of whether a comparison class existed.<sup>146</sup> In explaining why segregation of disabled people constituted discrimination, Justice Ginsberg noted that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations,"<sup>147</sup> and reinforced stigmatizing ideas that people with disabilities were incapable or unworthy of participating in community life.<sup>148</sup> In a later case, the Supreme Court emphasized that barriers to marriage and having a family on the basis of disability were examples of the kind of discrimination that Title II was designed to address.<sup>149</sup>

The Court in *Olmstead* held that the ADA did not require plaintiffs to show that a comparison class existed in order to prevail on claims under the integration mandate, but also noted that a comparison class did exist: non-mentally disabled people who were not required to forego their liberty to

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140. *Id.* at 328.

141. *Id.*

142. *Id.* at 328-29.

143. *Id.* at 329.

144. *Helen L v. DiDario*, 46 F.3d at 329.

145. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 593-94 (1999).

146. *Id.* at 596-97.

147. *Id.* at 601.

148. *Id.* at 600.

149. *Tennessee v. Lane*, 541 U.S. 509, 524 & n.8 (2004).

receive needed health services.<sup>150</sup> In his concurring opinion, Justice Kennedy argued that liberty is not the only due process right that mentally disabled people forego to receive needed health services, and recognized that non-disabled people need not forego association with their families to receive needed health services.<sup>151</sup> Family association, no less than the liberty to live in the community, is destroyed by unnecessary institutionalization, isolation, and segregation. In many ways, it is an equally important right because it helps give meaning and substance to life in the community. In a moving account, Atlanta Legal Services reported on the success of the two plaintiffs in *Olmstead v. L.C.*, Elaine Wilson and Lois Curtis, once they were able to live in the community.<sup>152</sup> Strikingly, both their accounts of the joys of life in the community included interaction with family that had previously been denied to them: Lois Curtis “has (after many years) reconnected with her mom and sister,” and Elaine Wilson “made regular weekend trips home to be with her extended family.”<sup>153</sup>

Two years prior to its decision in *Olmstead*, the Supreme Court held in *M.L.B. v. S.L.J.* that

[c]hoices about marriage, family life, and the upbringing of children are among [the] associational rights this Court has ranked as of ‘basic importance in our society,’ rights sheltered by the Fourteenth Amendment against the State’s unwarranted usurpation, disregard, or disrespect. [A case] involving the State’s authority to sever permanently sever a parent-child bond[] demands the close consideration the Court has long required when a family association so undeniably important is at stake.<sup>154</sup>

Although a family does not have the right to state funds or new programs to keep it together,<sup>155</sup> it does have the right, pursuant to the ADA and *Olmstead*, to require that services *already* offered by the State are not contingent on having to choose between family and association in the community and receipt of services in an isolated institutional setting. While the Seventh Circuit held in *Bruggeman v. Blagojevich* that Medicaid does not create the right to services nearer to the recipient’s family, the court remanded the plaintiffs’ ADA and Section 504 claims.<sup>156</sup>

150. *Olmstead*, 527 U.S. at 596, 611-12.

151. *Id.* at 611-12.

152. See Atlanta Legal Aid Society, Impact Cases, *Olmstead v. LC and EW*, at [www.atlanta.legalaid.org/impact.htm](http://www.atlanta.legalaid.org/impact.htm) (last visited Feb. 16, 2009).

153. See *id.*

154. *M.L.B. v. S.L.J.*, 519 U.S. 102, 116-17 (1996).

155. *Bowen v. Gilliard*, 483 U.S. 587, 607-08 (1987).

156. *Bruggeman v. Blagojevich*, 324 F.3d 906, 911-12, 913 (7th Cir. 2003).

### E. Cases about Family Integrity in the Wake of *Olmstead* v. L.C.

Very few cases have attempted to apply the integration mandate in the context of family integrity. Recently, a federal district court in Connecticut granted summary judgment to state agency defendants with respect to a parent's *Olmstead* claim; the case challenged the disparity between Connecticut's cap on both home-based services and family preservation services for seriously emotionally disturbed children and its unlimited provision of hospitalization for the same child.<sup>157</sup> In addition, the plaintiff challenged the provision of inadequate services, and reduction of even those services, as making institutionalization inevitable and thus violating the integration mandate.<sup>158</sup>

As to the second claim, the court held that the integration mandate did not support a claim for inadequate services, or create a right to stay out of institutions.<sup>159</sup> It rejected the mother's *Olmstead* claim regarding the disparity between the cap on funding for community-based family preservation services as opposed to hospitalization by noting that the child's hospitalizations came at the request of the mother and/or the orders of a Probate Court.<sup>160</sup> This analysis completely misses the point of the claim: it is as though the court in *Homeward Bound*, *Helen L.*, or *Olmstead* had rejected the plaintiffs' claims on the grounds that they had voluntarily placed their children at the state institution, or stayed in institutional settings, when the state's failure to fund community services gave them no choice.

Several systemic challenges to the services received by children with emotional disabilities touch on family integration, but those claims have not been adjudicated on the merits. In *J.B. v. Valdez*, plaintiffs challenged the defendant's practice of failing to maintain family integrity by splitting siblings in foster care, but lost their motion for class certification.<sup>161</sup> In *Katie A. v. Bontá*, the plaintiffs challenged the failure of Los Angeles County and the State of California to provide home-based and community-based mental health services to seriously emotionally disturbed children in the child welfare system.<sup>162</sup> The plaintiffs sought the provision of wraparound home-based services and therapeutic foster care services, which they argued would permit at least half of the children currently institutionalized in residential facilities to return home, or at least to therapeutic foster care homes in the community.<sup>163</sup> Although the case included an *Olmstead*

157. *M.K. ex rel. Mrs. K. v. Sergi*, 554 F. Supp. 2d 175, 197, 201 (D.Conn. 2008).

158. *Id.* at 195-96.

159. *Id.* at 198.

160. *Id.* at 199.

161. *J.B. v. Valdez*, 186 F.3d 1280, 1284, 1290 (10th Cir. 1999).

162. *Katie A. v. Bontá*, 443 F. Supp. 2d 1065, 1067 (C.D.Cal. 2006).

163. *Id.*

claim, Los Angeles County settled with the plaintiffs, and the District Court granted a preliminary injunction against California on the Medicaid claims without reaching the ADA claims.<sup>164</sup> The Ninth Circuit reversed on narrow grounds, accepting many of the district court's findings of fact and conclusions of law.<sup>165</sup> The plaintiffs have renewed their request for a preliminary injunction, which is pending with the District Court.<sup>166</sup>

The plaintiffs' success in cases such as *Katie A. and Rosie D. v. Romney*<sup>167</sup> in obtaining wraparound and home-based services have been based on the provisions of the EPSDT portion of the Medicaid statute, which applies only to children.<sup>168</sup> Although the right is the child's, one of the remedies—wraparound services—provides services for the family, enabling it to better accommodate the child. Ironically, despite the Constitution's embrace of family association and the ADA integration mandate, Medicaid EPSDT claims are presently the most successful vehicles to provide services to keep families together when one member has a disability.

#### IV. ADA LITIGATION IN TERMINATION PROCEEDINGS: A BLUEPRINT FOR FAILURE

The principal ADA-based argument used to date to try to keep families together is that disabled parents must be accommodated in reunification services provided by social service agencies.<sup>169</sup> Advocates have argued that in order for parents with disabilities to have effective access to these services, the ADA requires social service agencies and other public entities to modify the assistance and reunification services they provide to accommodate a parent's disability.<sup>170</sup> These cases have generally been

164. *Id.* at 1078.

165. *Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150 (9th Cir. 2007).

166. See Plaintiff's Memorandum of Points and Authorities in Support of Motion for Preliminary Injunction, available at [www.bazelon.org/issues/children/incourt/KatieA/PlaintiffsBrief1-11-08.pdf](http://www.bazelon.org/issues/children/incourt/KatieA/PlaintiffsBrief1-11-08.pdf) (last visited Feb. 16, 2009).

167. *Rosie D. ex rel. John D. v. Romney*, 474 F. Supp. 2d 238 (D.Mass. 2007).

168. *Katie A.*, 433 F. Supp. 2d 1065; *Rosie D. ex rel. John D.*, 474 F. Supp. 2d 238.

169. This argument only works, however, if the state requires the agency to provide reunification services, which several states do not. See Chris Watkins, *Beyond Status: The Americans with Disabilities Act and the Parental Rights of People Labeled Developmentally Disabled or Mentally Retarded*, 83 CAL. L. REV. 1415, 1444 (1995); ALA. CODE § 26-18-7(a) (2007), at [www.legislature.state.al.us/CodeofAlabama/1975/coatoc.htm](http://www.legislature.state.al.us/CodeofAlabama/1975/coatoc.htm) (last visited Feb. 16, 2009); DEL. CODE. ANN. tit. 13, § 1103(d) (2006) at <http://delcode.delaware.gov/title13/c011/index.shtml#TopOfPage> (last visited Feb. 19, 2009); GA. CODE. ANN. § 15-11-58 (2008), at [www.lexis-nexis.com/hottopics/gacode/default.asp](http://www.lexis-nexis.com/hottopics/gacode/default.asp) (last visited Feb. 16, 2009); HAW. REV. STAT. § 587-26 (2006), at [www.capitol.hawaii.gov/hrscurrent/Vol12\\_Ch0501-0588/HRS0587/HRS\\_0587-0026.htm](http://www.capitol.hawaii.gov/hrscurrent/Vol12_Ch0501-0588/HRS0587/HRS_0587-0026.htm) (last visited Feb. 16, 2009); MO. REV. STAT. § 211.183 (2008), at [www.moga.mo.gov/statutes/C200-299/2110000183.HTM](http://www.moga.mo.gov/statutes/C200-299/2110000183.HTM) (last visited Feb. 16, 2009).

170. Watkins, *supra* note 169, at 1473.

brought individually, as opposed to a class action suit, and they have generally been unsuccessful.<sup>171</sup>

Although the social service agencies are undeniably covered by Title II of the ADA and Section 504 of the Rehabilitation Act, the resistance of state and federal courts to accommodation-based arguments in termination of parental rights proceedings is legendary.<sup>172</sup> Courts have reasoned, for example, that termination proceedings are not “services, programs or activities” covered by the ADA,<sup>173</sup> that the ADA cannot be used as a defense to the termination of parental rights of a disabled parent,<sup>174</sup> that the ADA does not apply to an individual termination proceeding because of the *Younger* abstention doctrine, and that even if the family services agency violates the parent’s ADA rights, it shouldn’t change the ultimate decision about terminating parental rights.<sup>175</sup> Ultimately, the perspective in most of these cases distills down to the view that the federal ADA rights of the parents must be subordinated to the rights of the child, a view which explicitly frames the parent and child as adversaries.<sup>176</sup>

This resistance seems explicitly rooted in courts’ hostility toward the psychiatrically disabled parent, which often appears to be a reflection of the social service agencies’ hostility to the disabled parent. Several courts have faulted disabled mothers for exhibiting a “know-it-all” attitude and for being uncooperative or hostile with social workers who wanted to take their children away.<sup>177</sup>

This hostility may be inevitable when parental termination proceedings inherently and structurally set up a framework that predisposes a court to regard the parental interests in keeping the child as fundamentally in conflict with the best interests of the child, who has usually already been removed from the home pursuant to a finding of abuse or neglect. By bringing parental termination proceedings, a family services agency has made the

171. See *M.K. ex rel. Mrs. K. v. Sergi*, 554 F. Supp. 2d 233, 236 (D.Conn. 2008); *J.T. v. Dep’t of Human Servs.*, 947 S.W.2d 761, 762 (Ark. 1997); *In re P.B.*, No. 7-528 / 07-1042, 2007 Iowa App. LEXIS 1009, at \*1 (Iowa Ct. App. 2007); *In re Torrance P.*, 522 N.W.2d 243, 244 (Wis. Ct. App. 1994); *In re C.M.*, 526 N.W.2d 562, 564 (Iowa Ct. App. 1994).

172. See Glennon, *supra* note 20, at 289.

173. *In re C.M.S.*, 646 S.E.2d 592, 595 (N.C. App. 2007).

174. *In re Torrance P.*, 522 N.W.2d at 246.

175. *J.T. v. Dep’t of Human Servs.*, 947 S.W.2d at 768.

176. *Stone v. Daviess County Div. of Children & Family Servs.*, 656 N.E.2d 824, 831 (Ind. App. 1995) (quoted in *J.T.*, 947 S.W.2d at 768).

177. *In re P.B.*, No. 7-528 / 07-1042, 2007 Iowa App. LEXIS 1009, at \*5 (2007); *In re M.B. and C.B. v. Del. County Dept. of Pub. Welfare*, 570 N.E.2d 78, 80-81 (Ind. Ct. App. 1991).

determination that the parent is irredeemably abusive or neglectful,<sup>178</sup> and although the State technically has the burden of proof, a court may well be predisposed to credit an agency's determination, especially in the case of a disabled parent.<sup>179</sup> A disabled parent asking for accommodations is placed in the anomalous and paradoxical role of asserting that he or she can parent adequately, and simultaneously requesting what may well be perceived as "special" and "additional" services. Reasonable accommodations have a troubled and inaccurate history of being equated in the minds of judges with affirmative action in race cases, and this may strike courts as a particularly inapposite right to assert when the welfare of a child is at stake. Implicitly or explicitly, the accommodations to the parent are somehow seen as coming at the expense of the child.<sup>180</sup>

In addition, litigating accommodation cases one at a time inevitably involves a focus on the parent's difficulties and flaws as a parent. Whatever aspect of the disability needs to be accommodated will inevitably be presented this way, rather than looking at the failure of the agency in planning to serve disabled parents and children when it has every reason to know that this group will constitute a large proportion, perhaps even a majority, of the people to whom it is mandated to provide services. The specific problems of the parent before the judge is compared with the problems of an abstract alternative called "the foster care system." Very few courts, and almost all of them appellate or state supreme courts, are willing to relegate the child to an imperfect family rather than a foster care system whose flaws are usually not before the court. In addition, few family service workers or judges are aware of the voluminous research literature reflecting the harm suffered by many children placed in foster care.<sup>181</sup>

In any event, "accommodations" are the wrong way to characterize what is needed. Accommodations presume a neutral service system that needs adjustment to be accessible to a person with a disability, rather than a systemic framework which is, in virtually every way, from state termination

178. See, e.g., Esme Noelle DeVault, Note, *Reasonable Efforts Not So Reasonable: The Termination of the Parental Rights of a Developmentally Disabled Mother*, 10 ROGER WILLIAMS U. L. REV. 763, 767 (2005).

179. See Watkins, *supra* note 169, at 1436-38.

180. *In re Anthony P.*, 84 Cal.App.4th 1112, 1116 (2000) (quoting *M.C. v. Dep't of Children and Families*, 750 So.2d 705, 706 (Fla. Ct. App. 2000) ("dependency proceedings are held for the benefit of the child, not the parent. Therefore, the ADA is inapplicable when used as a defense by the parent(s) in [those] proceedings.")).

181. See Michael S. Wald, *State Intervention on Behalf of "Neglected" Children: Standards for Removal of Children from Their Homes, Monitoring the Status of Children in Foster Care, and Termination of Parental Rights*, 28 STAN. L. REV. 623, 640-41 (1976); Arlene E. Fried, Note, *The Foster Child's Avenues of Redress: Questions Left Unanswered*, 26 COLUM. J.L. & SOC. PROBS. 465-66 (1993).

statutes to the judicial proceedings themselves, built on a framework of discriminatory assumptions about the abilities of psychiatrically disabled women to parent, especially to parent children with special needs. As I will argue in Section V, this framework has also been applied to parents with physical disabilities. In that context, “accommodations” were not a viable solution because it was societal attitudes and perceptions of physical disability that needed to be changed.

Ultimately, what is missing from these individual termination cases is a perception of the parent and child as part of one family, and an understanding that preserving this family is a good and valuable goal that is worth attempting to achieve for the benefit of all members of the family and for the community as a whole. I have tried to show that this is because each individual case focuses necessarily on the parent rather than on the structure of the interlocking systems that predetermine adverse outcomes. In the next section, I suggest that the ADA be used to confront those systems head-on. Instead of requesting accommodations, which assumes that the systemic framework and services are neutral and disabled people only need an adjustment or two for the system to work for them, advocates should expose systems as deeply and structurally discriminatory in ways that harm and undermine families with a disabled member, especially a disabled parent.

Of course, not all parents with psychiatric disabilities can successfully parent, with or without accommodations, any more than all non-disabled individuals can successfully parent. But individual exceptions have never justified a system that is structured in a discriminatory way, and the argument of this article is that if human services—mental health systems, child protective services systems, social services, and housing systems—began with a goal and assumption of family preservation when any member of the family had a psychiatric disability, the system would look very different, and outcomes would be very different. Psychiatric disability no more carries with it an automatic inability to parent than it does an automatic inability to live in the community. Over the course of an individual’s life, these prophecies of incapacity can become self-fulfilling, but they are not and never have been innate.

## V. THE ADA'S ANTIDISCRIMINATION PROVISIONS, THE INTEGRATION MANDATE, AND FAMILY INTEGRITY

### A. *The Integration Mandate and Family Preservation*

The court in *Homeward Bound*, a class action lawsuit, recognized the fundamental importance of keeping families together.<sup>182</sup> In that case, parents wanted to keep their disabled children in a family environment, but, as the court recognized, they needed services and assistance to succeed.<sup>183</sup> Yet this framework has largely been lost in the twenty years following *Homeward Bound*, and neither the anti-discrimination provisions of the ADA nor the integration mandate has been used as a tool to obtain services that families need to help them stay together.

Being able to be part of a family is a distinct and crucial component of community integration.<sup>184</sup> As the Supreme Court noted in *Roberts v. United States Jaycees*,

[f]amily relationships, by their nature, involve deep attachments and commitments to the necessarily few other individuals with whom one shares not only a special community of thoughts, experiences and beliefs but also distinctively personal aspects of one's life. Among other things, therefore, they are distinguished by such attributes as relative smallness, a high degree of selectivity in decisions to begin and maintain the affiliation, and seclusion from others in critical aspects of the relationship.<sup>185</sup>

Families of origin are not the same as foster families,<sup>186</sup> nor are they similar to group homes.<sup>187</sup>

The Supreme Court held in *Olmstead* that a citizen should not have to trade his or her liberty to receive needed health services.<sup>188</sup> It is equally

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182. *Homeward Bound, Inc. v. Hissom Mem'l Ctr.*, No. 85-C-437-E, 1987 WL 27104, at \*17-\*18 (N.D. Okla. July 24, 1987).

183. *Id.* at \*18.

184. See generally Bonnie R. Kraemer et al., *Adolescents with Severe Disabilities: Family, School, and Community Integration*, 22 J. ASS'N. FOR PERSONS WITH SEVERE HANDICAPS 224 (1997).

185. *Roberts v. United States Jaycees*, 468 U.S. 609, 619-20 (1984).

186. See *Smith v. Org. of Foster Families for Equal. & Reform*, 431 U.S. 816, 845-46 (1977) (discussing "a foster family which has its source in state law and contractual arrangements.").

187. *Wimber v. Dep't of Soc. & Rehab. Servs.*, No. 94-4042-SAC, 1994 WL 192039, at \*11 n.8 (D. Kan. Apr. 13, 1994) (stating that "[t]he plaintiffs have not attempted to show that their decision to live in a group home is in the same nature as the deep, personal decisions and commitments associated with marriage, procreation, and raising children.").

188. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 601 (1999) (noting that "[i]n order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable



repugnant for parents and children to have to give up their rights to family association in order to receive needed mental health services, yet in the years since *Joyner v. Dumpson* thousands of parents had to give up custody of their children in order for those children to receive the mental health services that they need.<sup>189</sup> As subsequent courts have held, the integration mandate protects people at risk of institutionalization, and the goal of the integration mandate is to help prevent unnecessary institutionalization and isolation as well as end it where it exists.<sup>190</sup>

This article argues that keeping families together is, necessarily, a key component of the integration mandate. Research shows that if families receive the services that they need, the chances that those children will be institutionalized or placed out of the home in segregated residential placements is greatly reduced.<sup>191</sup> Although there is less research on the benefits of home-based services to the family when the disabled family member is the parent, both research and program results also tend to indicate that families are more likely to stay together when family support is provided in the community.<sup>192</sup> Mothers with mental illness have identified being able to parent their children as a primary motivating factor for treatment,<sup>193</sup> while also expressing hesitation to access available treatment because of fears that their children will be removed.<sup>194</sup>

Psychiatrically disabled mothers describe termination proceedings, the risk of removal, court proceedings, and removal of their children as inordinately stressful, an indication of fundamental personal failure, and crisis of enormous proportions which often precipitates deterioration and

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accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.”).

189. Weithorn, *supra* note 11, at 1375; see also Goodman, *supra* note 11; Simmons, *supra* note 11.

190. See *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 607-08 (7th Cir. 2004); *Helen L. v. DiDario*, 46 F.3d 325, 332-33 (3d Cir. 1995).

191. Editorial, *Unkept Promises to the State's Disabled*, STAR-LEDGER (Newark, N.J.), Nov. 10, 2002, at 2; Goodman, *supra* note 11, at 324-25.

192. See generally Joanne Nicholson et al., *A Qualitative Study of Programs for Parents with Serious Mental Illness and Their Children: Building Practice-Based Evidence*, 34 J. BEHAV. HEALTH SERVS. & RES. 395 (2007) [hereinafter Nicholson et al., *A Qualitative Study*].

193. Carol T. Mowbray et al., *Motherhood for Women with Serious Mental Illness: Pregnancy, Childbirth, and the Postpartum Period*, 65 AM. J. ORTHOPSYCHIATRY 21, 21 (1995) [hereinafter Mowbray et al., *Motherhood for Women with Serious Disabilities*]; APFEL & HANDEL, *supra* note 14, at 4-5, 160-61.

194. Mowbray et al., *Motherhood for Women with Serious Mental Illness*, *supra* note 193, at 33; Dale Russakoff, *A Failed Mother Returns to Her Children*, WASH. POST, Jan. 20 1998, at A1.

hospitalization.<sup>195</sup> In one parental termination case, the caseworker noted that

'[f]irst, it appears that much of the mother's inappropriate and angry outbursts have been due to her being separated from the minor . . . [s]he has never been abusive to the minor . . . the mother copes very poorly under stress, and both the [c]ourt process as well as being separated from her child have put her under tremendous pressure and stress, and appear to have escalated her mental health problems.'<sup>196</sup>

The caseworker, who had previously recommended reunification, recommended that the child not be returned home until "these issues subside."<sup>197</sup>

As the cases described above illustrate, the story of institutionalized people is so often the story of people separated from their families: grieving angry women who have lost their children, and insecure adolescents who bounced from one foster home to the other before winding up in residential care.

In order to fully integrate individuals with psychiatric disabilities into every day community life, they must be seen, as is already the case with most physically disabled people, as capable of playing all potential roles in a family: not only children, but husbands and wives, mothers and fathers, grandparents, aunts and uncles—the essential components of the family unit, which is in turn, one of the essential building blocks of community. Until this is the case, people with psychiatric disabilities will be "isolated" even if they are deinstitutionalized; in the community but not part of it, hangers-on who peer into the warm windows of family life at the heart of community, but do not have a place at the table inside.

*B. The Fundamental Discriminatory Framework of the Human Services and Legal Systems With Regard to Parents with Psychiatric Disabilities*

The understanding of people with psychiatric disabilities as "almost genderless,"<sup>198</sup> unsuitable to marry, unable to parent, and not even much use as siblings, is a legacy of the days of institutionalization and is a discriminatory stereotype which is embedded in state statutes, the practices of mental health agencies, the attitudes of social service professionals, the services provided by social services agencies, and in the court system.

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195. See Mowbray et al., *Motherhood for Women with Serious Mental Illness*, *supra* note 193, at 33-34.

196. *In re Kristin H. v. Kimberly I.*, 46 Cal.App.4th 1635, 1645-46 (1996).

197. *Id.* at 1646.

198. Mary Ann Test & Sharon B. Berlin, *Issues of Special Concern to Chronically Mentally Ill Women*, 12 PROFESSIONAL PSYCHOL. 136, 136 (1981).

The first step is transforming this situation for advocates is to step back and conduct a multi-system analysis of the structural impediments and barriers to keeping families together when one member has a psychiatric disability in their own state's human service systems.

### 1. State Statutes

Far from requiring reasonable accommodations for psychiatric disabilities, a number of state parental termination statutes refer explicitly to diagnoses of mental illness or mental health conditions to expedite termination proceedings or limit the participation of parents with psychiatric disabilities.<sup>199</sup> For example, in many states, the statutory requirement that reunification services be provided does not apply if the reason for termination is the parent's mental illness.<sup>200</sup> In some states the services need not be provided if the court finds by clear and convincing evidence that the parent is suffering from a mental disability as defined by statute "that renders him or her incapable of utilizing those services",<sup>201</sup> a requirement that does not include the reasonable accommodation provisions of federal antidiscrimination law.

As discussed previously, some states still have statutes requiring some form of parental relinquishment of rights in order for children to obtain needed mental health treatment. While New York, where *Joyner v. Dumpson* was brought, has made substantial steps to provide family-based services, many other states lag far behind, and even states with statutes banning permanent relinquishment of custody in exchange for mental health services still permit a requirement of temporary relinquishment of custody to receive services.<sup>202</sup>

### 2. Mental Health Agency Policies and Practices

Mental health agencies erase the reality that many of their clients are parents, or even that they could have satisfying sexual, romantic, and parental relationships. In fact, the vast majority of mental health agencies

199. ELIZABETH LIGHTFOOT ET AL., UNIV. OF MINN., GUIDE FOR CREATING LEGISLATIVE CHANGE: DISABILITY IN THE TERMINATION OF PARENTAL RIGHTS AND OTHER CHILD CUSTODY STATUTES 2, available at <http://cehd.umn.edu/SSW/cascw/attributes/PDF/LegislativeChange.pdf> (last visited Feb. 16, 2009) (finding that thirty six states list mental illness as a ground for termination of parental rights); see also ARIZ. REV. STAT. § 8-533(B)(3) (West 2008); 750 ILL. COMP. STAT. ANN. 50/1(D)(p) (West 2007); KY. REV. STAT. ANN. § 625.090(3)(a) (West 2008).

200. *In re Custody and Guardianship of La'Asia S.*, 739 N.Y.S.2d 898, 908 (Fam. Ct. N.Y. County 2002).

201. *In re A.O. v. Diane O.*, No. E039235, 2006 WL 872767, at \*7 (Ct. App. Cal. Apr. 5, 2006) (citing CAL. WELF. & INST. CODE § 361.5(b)(2) (2006)).

202. Goodman, *supra* note 11, at 328.

have no idea which of their clients are parents, and eighty percent of them have no policies on pregnant clients or clients who are parents.<sup>203</sup> Most state psychiatric facilities do not permit children to visit their parents.<sup>204</sup> A recent survey revealed that not one mental health agency had a visitation policy for hospitalized mothers and their children.<sup>205</sup> Most group homes and community residential settings do not permit residents to marry or cohabit, and certainly not to live with children.<sup>206</sup> Mental health agencies rarely include pregnancy and postpartum assistance as part of the services that they provide, let alone parenting assistance<sup>207</sup> or help in planning for temporary placement of their children if the mother should have to be hospitalized.<sup>208</sup> Mental health agencies often take the position that parenting assistance is a function of social service agencies,<sup>209</sup> but social service agencies are generally only involved after a complaint has been made that parenting is inadequate.<sup>210</sup> State mental health agencies vary widely in terms of the family-oriented services that they provide to clients with psychiatric disabilities.<sup>211</sup>

### 3. Mental Health and Social Service Professionals' Attitudes

Mental health professionals are also notoriously judgmental about the abilities of people with psychiatric disabilities to parent: study after study, from Deborah Le Belle's classic *Lives in Stress*, to more recent work, reflects that mothers with psychiatric disabilities are hesitant to seek mental health services because of their fear that their children will be removed.<sup>212</sup>

203. Biebel et al., *supra* note 32, at 31-32.

204. See Diana M. C. Cassell, *Mother and Baby Admissions: Survey of Resources*, 14 PSYCHIATRIC BULL., 654, 654 (1990) (stating that thirty years ago, some hospitals had programs where mothers could be hospitalized with their children); Andrea K. Blanch et al., *Parents with Severe Mental Illness and Their Children: The Need for Human Services Integration*, in WOMEN'S MENTAL HEALTH SERVICES: A PUBLIC HEALTH PERSPECTIVE 201, 201 (Bruce Lubotsky Levin et al. eds., 1998).

205. Biebel et al., *supra* note 32, at 32.

206. APFEL & HANDEL, *supra* note 14, at 161.

207. Mowbray et al., *Motherhood for Women with Serious Mental Illness*, *supra* note 193, at 21; Daphna Oyserman et al., *Resources and Supports for Mothers with Severe Mental Illness*, 19 HEALTH & SOC. WORK 132, 134 (1994).

208. See, e.g., Nicholson et al., *A Qualitative Study*, *supra* note 192, at 202; Joanne Nicholson & Andrea Blanch, *Rehabilitation for Parenting Roles for People with Serious Mental Illness*, 18 PSYCHOSOCIAL REHAB. JOURNAL 109 (1994); J. Nicholson et al., "Sylvia Frumkin" Has a Baby: A Case Study for Policy Makers, 47 PSYCHIATRIC SERVS. 497 (1996).

209. Blanch et al., *supra* note 204, at 202; Nicholson et al., *The Prevalence of Parenthood*, *supra* note 20, at 130-31.

210. Blanch et al., *supra* note 204, at 202.

211. *Id.* at 202-03.

212. *Id.* at 206; see also Deborah Belle et al., *Mental Health Problems and Their Treatment*, in LIVES IN STRESS: WOMEN AND DEPRESSION 197, 201 (Deborah Belle ed., 1982).

Hundreds of individual termination cases confirm that the person calling child protective services is often the parent's mental health case worker or other mental health professional.<sup>213</sup> Even when mental health workers do not act to remove the child from the parent's custody, they often discourage parenting rather than take steps to assist the parent:

One mother, Lindy Fox, who later became a researcher into the needs of parents with mental illnesses, describes how her early treatment providers viewed her children as major stressors. Rather than offering her parenting education and family-centered treatment, her counselors encouraged her to believe that she could not cope with parenting. Likewise, her husband was given no education about her disease, and her marriage fell apart. Fox reports:

I feel that I was pressured by my treatment providers to give up the care of my children . . . . Early on, there should have been education about mental illness for me and my family. Keeping the family unit intact should have been a primary goal . . . . Instead of being convinced I couldn't cope, I needed support and encouragement to care for them. I needed someone to believe I could do it. Regular day care for the children and someone coming into my home to help when the girls were small were possibilities that were not even considered . . . . Ongoing family treatment should be part of every treatment plan for mothers with a mental illness, with an emphasis on developing parenting skills, communication skills, problem-solving skills, and ability to manage stress.<sup>214</sup>

The degree to which many professionals believe that individuals with psychiatric disabilities are committed to retaining their children is illustrated by the perspective one professional took in explaining one mother's complete compliance with court orders and her determination to retain her parental rights:

During the termination proceeding, Dr. Wunderman [a clinical psychologist] opined that the mother was 'addicted' to the termination proceeding, and that she had completed the required parenting course, visited her children at the scheduled times, and appeared in court '[a]s a means of escaping a feeling of tremendous emptiness, tremendous loneliness, tremendous nothingness that the borderline personality disorder does feel.'<sup>215</sup>

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213. Blanch et al., *supra* note 204, at 207.

214. Glennon, *supra* note 20, at 293-94.

215. Simms v. Dep't of Health & Rehab. Servs., 641 So.2d 957, 962 n.2 (Fla.App.3d 1994).

The mother in this case lost her parental rights despite completely complying with the agency's plans and scheduled court appearances because her very compliance was framed as a symptom of her mental illness.<sup>216</sup>

For twenty to thirty years, child protection workers and agencies had similar views of people with physical disabilities: fathers in wheelchairs couldn't be fathers because they couldn't play baseball with their children or provide for their needs.<sup>217</sup> These perspectives were shared by the judges who heard the termination cases and adoption cases. As Laura Rothstein pointed out, each disability came with its own presumptions,<sup>218</sup> presumptions so strong that even when a deaf mute couple had successfully parented their own children, a judge ordered that the application "of these poor unfortunate people" to adopt a child be refused because the child deserved a "normal" home.<sup>219</sup> In a later case, parents who were HIV-positive had to fight to keep their children.<sup>220</sup> In 2009, most of these scenarios strike us as wrong-headed and almost absurd. The agencies in those cases did not think in terms of what accommodations might be needed to assist physically disabled individuals to parent, because they didn't think that physically disabled people should be parenting in the first place. People with psychiatric disabilities continue to face a presumption of incapacity to parent in 2009, and requesting reasonable accommodations from agencies and judges who don't think they should be parenting in the first place runs up against the same obstacles.

#### 4. Social Service and Family Service Agency Framework and Service Structure

Family service and child protection agencies rarely have services tailored to the needs of people with psychiatric disabilities, even though such

216. *Id.* at 962.

217. *In re Marriage of Carney*, 598 P.2d 36, 37, 40 (Cal. 1979) (reversing lower court decision removing custody of children from father in a wheelchair because he couldn't play baseball with them or take them fishing).

218. LAURA F. ROTHSTEIN, *RIGHTS OF PHYSICALLY HANDICAPPED PERSONS* 185-87 (1984).

219. See Stein, *supra* note 28, at 1083-84; see also Robert L. Hayman, Jr., *Presumptions of Justice: Law, Politics, and the Mentally Retarded Parent*, 103 HARV. L. REV. 1201, 1240 (1990).

220. See, e.g., Carol Levine, *AIDS and Changing Concepts of Family*, 68 MILBANK Q. (Supplement 1) 33, 50-51 (1990) (discussing a father's custody battle in which his HIV-positive status was at issue); *Stewart v. Stewart*, 521 N.E.2d 956, 959, 965 (Ind. Ct. App. 1988); see *Meriweather v. Dep't of Health & Human Servs.*, 255 S.W.3d 505, 506-08 (Ark. App. 2007) (finding that woman with mental retardation who "completed the lion's share of the case plan" and who cared for her diabetic mother was not a fit parent; noting also that her arthritis made it difficult for her to hold the child).

individuals form a substantial proportion of the parents they see.<sup>221</sup> Nor do these agencies have employees with expertise in psychiatric or developmental disability conditions, and usually a social worker does not have a clear understanding of basic mental health issues such as how psychiatric medications may affect an individual.<sup>222</sup> This lack of education and understanding may also translate into stereotypical assumptions that an individual with a psychiatric disability cannot parent, although it is not clear that mental health professionals do not also share some of these stereotypes.

Family service workers and judges are also largely unaware of social science research on the harm caused by taking children out of their families and placing them in foster care. It is a harm so great that a matched study of "crack babies," which compared newborns placed in foster care with newborns allowed to stay with their mothers, 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."<sup>223</sup>

##### 5. State Court Prejudice and Stereotypes

Education of state court judges should be one of the top priorities of advocates trying to keep families together when one member has a disability. It is worth listing 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;<sup>224</sup>

\* Requiring assistance to parent means unfitness to parent;

221. See Duncan McLean et al., *Are Services for Families with a Mentally Ill Parent Adequate?*, in PARENTAL PSYCHIATRIC DISORDER: DISTRESSED PARENTS AND THEIR FAMILIES 333, 338-39 (Michael Göpfert et al. eds., 2d. ed. 2004) (discussing that eighty-eight percent of agency service providers report that services for parents with psychiatric disorders and their children are inadequate).

222. *Id.* at 339 ("Lack of knowledge and expertise was perceived as a significant barrier by slightly less than half (46%) of service providers.").

223. Kathleen Wobie et al., *To Have and To Hold: A Descriptive Study of Custody Status Following Prenatal Exposure to Cocaine*, (paper presented at joint annual meeting of the American Pediatric Society and the Society for Pediatric Research, May 3, 1998).

224. See *In re C.W.*, 211 S.W.3d 93, 102 (Mo. 2007) (reversing the decision of the lower court which had terminated parental rights based, inter alia, on the assumption that the mother's bipolar disorder was permanent); see also *Benedict v. Dep't of Human Servs.*, 242 S.W.3d 305, 317 (Ark. Ct. App. 2006), *aff'd*, No. CA 08-268, 2008 WL 2515678, at \*1 (Ark. App. Ct. June 25, 2008) (discussing a woman diagnosed with post partum psychosis who won appellate argument to regain custody of her children only to lose her children permanently after suffering one further episode of psychosis).

\* Being disrespectful to the social worker means unfitness to parent; and

\* Attempting suicide means unfitness to parent.

## 6. Outline of Remedies

Although the problems discussed above are pervasive and fundamental, they have also been recognized for many years. Thoughtful people have put together detailed solutions, which, not coincidentally, mirror the requirements of the ADA.<sup>225</sup> In New York State over a decade ago, the Department of Social Services (DSS) and the Office of Mental Health (OMH) created a joint task force on parents with mental illness.<sup>226</sup> The Task Force included professionals from both systems, consumers, researchers, advocates, providers, and members of local government.<sup>227</sup> After compiling data and taking testimony at public hearings, the Task Force recommended, among other approaches, to: “[d]evelop ‘family services’ that do not divide adults from children”, “[i]ncrease capacity for in-home services”, “increase capacity for off-hour services (not just crisis)”, “[p]rovide flexible respite services”, “[e]ducate parents and children regarding mental illness”, “[t]arget public day care slots for children of mentally ill parents”, and “[i]ncrease staff competencies for both DSS and OMH staff”.<sup>228</sup>

The Task Force recommended that the OMH include parenting programs and day care as part of its outpatient programs, that mental health outpatient providers “develop linkages with family support services”, that parental status and needs be added to mental health data forms and treatment plans, that visitation be established for hospitalized parents, and that its supported housing and residential programs include as a matter of course housing for parents with children.<sup>229</sup> The Task Force also recommended that DSS revise its intake and eligibility policies “to ensure sensitivity to the needs and capacities of parents” with psychiatric disabilities.<sup>230</sup> As the Task Force recognized, however, interagency coordination remained a serious and ongoing problem.<sup>231</sup>

One interesting aspect of the recommendations made by the New York Task Force is how similar many of them are to the programs instituted by the

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225. 42 U.S.C. §§ 12101-12213 (2000).

226. Blanch et al., *supra* note 204, at 203.

227. *Id.*

228. *Id.* at 209 tbl.1.

229. *Id.* at 211.

230. *Id.*

231. Blanch et al., *supra* note 204, at 213.



court in *Homeward Bound v. Hissom* described previously in this article.<sup>232</sup> It is not the case that we do not know, and have not known for over twenty years, what services are necessary to keep families together when one member has a disability. Instead, we are unwilling to adjust our belief that these families *shouldn't* be together, that splitting these families is ultimately a favor to the child who can be raised "normally" and the parent who is being asked to do more than his or her disability will permit. To transform these multiple systems may seem daunting. Yet no one disagrees that coordinating systems of care provides better and more efficient services, and services delivered to families are less expensive and have better outcomes than removing disabled family members from the home and paying for expensive and unnecessary residential care.

Advocates can pursue one of several kinds of systemic cases. First, a challenge to state policies requiring parents to relinquish custody of their mentally disabled children in order to receive necessary services for them, framed in terms of Section 504 and *Olmstead*, that only parents of children with psychiatric disabilities are required to surrender parental and associational rights in order for their children to receive services that the state already provides.<sup>233</sup> Second, a systemic challenge in a state with a statute precluding parents with psychiatric disabilities from receiving reunification services provided to other parents, framed on behalf of families in which one or more members of the family is a client of a state mental health agency, where the family is at risk of dissolution and one or more family members is at risk of institutionalization because of the absence of family-based services that the mental health agency has reason to know that the family needs. A case brought against multiple systems by a class of families is complex, to be sure, but it has at least a chance of creating change, unlike the individual appeals to the ADA in single parental termination proceedings. As discussed previously, in a significant number of cases both parents and children will suffer from psychiatric or emotional disabilities, and in the absence of services received as a family, either or both parents and children are greatly at risk of institutionalization, segregation, and losing family ties that both children and parents cherish and need.

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232. See *Homeward Bound, Inc. v. Hissom* Mem'l Ctr., No. 85-C-437-E, 1987 WL 27104, at \*33, \*35, \*36 (N.D. Okla. July 24, 1987); *supra* notes 103-115 and accompanying text.

233. *Helen L. v. DiDario*, 46 F.3d 325, 338 (3d Cir. 1995) (quoting H.R. REP. 485, 101st Cong., as reprinted in 1990 U.S.C.C.A.N. at 473, (emphasis added)).

## VI. CONCLUSION

The psychiatric disability of one family member profoundly affects all family members, and the best services and supports are those that are provided to the family as a whole. Hence the title of my article: a family with one or more mentally disabled members is, by definition, an accommodating family, one that has made accommodations, however imperfect, to ensure the inclusion and participation of the parent, child, or sibling with a disability in the family. A significant and surprising body of research shows that when families struggle to stay together, even when the mother has serious emotional or substance abuse problems, the children often fare significantly better than children who are removed from their homes.<sup>234</sup> As the writings of families where one member has a disability reflect, families—parents and children alike—are often more successful at accommodating disabilities than might be imagined. But it would help these families if society accommodated them, too. As advocates, service providers, and policymakers, we need to start thinking more about accommodating families, about family integration as the first building block of community integration. As the Supreme Court recognized in *Olmstead*, the fundamental damage of segregation is exclusion from the normal activities of community life.<sup>235</sup> Families are at the very core of community life, and until the ADA is used successfully to protect families, its promise will be incomplete.

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234. See Danson Jones et al., *When Parents with Severe Mental Illness Lose Contact with Their Children: Are Psychiatric Symptoms or Substance Use to Blame?*, 13 J. LOSS & TRAUMA 261, 262 (2008) (discussing that children who are separated or removed from their parents often suffer from psychiatric illness such as depression, feelings of rejection, and anxiety).

235. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 583 (1999).

