

## NOTES

### CARING FOR NEW JERSEY'S CHILDREN WITH AUTISM: A MULTIFACETED STRUGGLE FOR PARITY

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*This Note will examine both health insurance coverage for children with autism in New Jersey under the federal and state Mental Health Parity statutes, Medicaid, and the State Children's Health Insurance Program (SCHIP), and special education coverage for children with autism in New Jersey under the Individuals with Disabilities Education Act (IDEA). This Note ultimately proposes that despite overlapping coverage in the various acts providing mental health insurance and special education benefits for children with autism, the New Jersey Legislature should pass Assembly Bill 2238 in order to ensure the provision of urgently-needed therapies for children with autism.*

#### INTRODUCTION

Living on the edge of fear.  
Voices echo like thunder in my ear.  
See me hiding every day.  
I'm just waiting for the fear to lift away.  
I want so much to be a part of your world.  
I want so much to break through.  
And all I need is to have a bridge,  
a bridge built from me to you.<sup>1</sup>

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1. THOMAS A. MCKEAN, SOON WILL COME THE LIGHT: A VIEW FROM INSIDE THE AUTISM PUZZLE 37 (2d ed. 1994) (quoting from "Build Me a Bridge," a song about autism written by Thomas McKean, an individual with autism).

One in 150 children in the United States has autism, and New Jersey leads the nation with one in ninety-four children affected.<sup>2</sup> When viewed in light of the debilitating effects of the disorder,<sup>3</sup> the rapidly-increasing incidence of autism nationwide,<sup>4</sup> and the demonstrated success of early intervention therapies,<sup>5</sup> this fact calls for a mechanism to ensure access to appropriate treatment for children with autism.<sup>6</sup> In a 2007 report, the Centers for Disease Control and Prevention stated: "It is important that we treat [autism spectrum disorders] as conditions of urgent public health concern, do all we can to identify children's learning needs, and begin intervention as early as possible to enable all children to reach their full potential."<sup>7</sup> Even in New Jersey, arguably the state with greatest

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2. See MELODY STEVENS ET AL., PREVALENCE OF THE AUTISM SPECTRUM DISORDERS (ASDs) IN MULTIPLE AREAS OF THE UNITED STATES, 2000 AND 2002, at 12 (2007), [http://www.cdc.gov/ncbddd/autism/documents/](http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf)

[AutismCommunityReport.pdf](http://www.cdc.gov/ncbddd/autism/documents/AutismCommunityReport.pdf) [hereinafter AUTISM PREVALENCE REPORT]. The Autism Prevalence Report is based on data from the Centers for Disease Control and Prevention's (CDC) "only collaborative network" in the nation. *Id.* at 7. The report summarizes two prior CDC reports that studied the prevalence of autism in six states (2000), and 15 states (2002), respectively. *Id.* at ii. The medical records of 407,578 eight-year-olds were reviewed, revealing that 2,685 children had autism spectrum disorder (ASD). Ctrs. for Disease Control & Prevention, *Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002*, 56 MORBIDITY & MORTALITY WKLY. REP. SURVEILLANCE SUMMARIES 12, 12 (2007), <http://www.cdc.gov/mmwr/PDF/ss/ss5601.pdf> [hereinafter CDC MMWR Report]. Thus in 2002, the nationwide prevalence of ASD was one in 150 children, ranging from one in 303 in Alabama to one in ninety-four in New Jersey. AUTISM PREVALENCE REPORT, *supra* note 2, at 12; see Terry Jean Seligmann, *Rowley Comes Home to Roost: Judicial Review of Autism Special Education Disputes*, 9 U.C. DAVIS J. JUV. L. & POL'Y 217, 249 n.145 (2005) ("Another study by the CDC of children 3 to 10 years of age in Brick Township, New Jersey found a prevalence rate of 6.7 cases per 1000 children for all autism spectrum disorders, and of 4.0 cases per 1000 for cases meeting the full diagnostic criteria for autistic disorder.") (citing Jacquelyn Bertrand et al., *Prevalence of Autism in a United States Population: The Brick Township, New Jersey Investigation*, 108 PEDIATRICS 1155 (2001)). Note that quality of information may have influenced the state-by-state relative prevalence rates of children with autism.

New Jersey had more evaluations per child and a qualitative review of information indicated more detailed behavioral descriptions. However, if higher prevalence in New Jersey was caused by better symptom documentation in evaluation records, that would suggest that prevalence in other sites might have been underestimated, which would indicate that ASDs could be more common than [sic] previously thought.

CDC MMWR Report, *supra*, at 26.

3. See discussion *infra* Part I.A.

4. See AUTISM PREVALENCE REPORT, *supra* note 2, at 36.

5. See discussion *infra* Part I.C.

6. See AUTISM PREVALENCE REPORT, *supra* note 2, at 36.

7. *Id.*

need in this area, coverage for such interventions is unfortunately far from comprehensive.

The federal Mental Health Parity Act of 1996<sup>8</sup> and New Jersey Mental Health Parity Statutes<sup>9</sup> seek to ensure that all classes of dependents with medical needs will be covered equally, regardless of the nature of their illness. The stated purpose of the Individuals with Disabilities Education Act<sup>10</sup> (IDEA) is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education.”<sup>11</sup> Importantly, the IDEA also provides to these children “related services designed to meet their unique needs and prepare them for [further education,] employment, and independent living.”<sup>12</sup>

The task of ensuring that children receive equal coverage for their mental illnesses poses additional difficulties, but at the same time, more opportunities for coverage beyond those of adults with mental illnesses. Because children with autism also have a pressing need for early intervention to prevent developmental delays, this Note will focus on children with the disorder. A child with autism is classified as both a “child with a disability” under the IDEA,<sup>13</sup> and a child with a “biologically-based mental illness” under the New Jersey Mental Health Parity statutes.<sup>14</sup>

Both IDEA and health insurance coverage of autism therapies need to be significantly enhanced. IDEA is severely underfunded, receiving only about 17-18% rather than the 40% of federal funding it is authorized to receive.<sup>15</sup> This dearth of funding has remained

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8. Mental Health Parity Act of 1996, Pub. L. No. 104-204, 110 Stat. 2944 (2006) (codified in scattered sections of 29 U.S.C. & 42 U.S.C.).

9. Act of May 13, 1999, ch. 1-8, 1999 N.J. Laws 106 (codified as amended at N.J. STAT. ANN. § 17:48-6v (West 2007); *id.* § 17:48A-7u; *id.* § 17:48E-35.20; *id.* § 17B:26-2.1s; *id.* § 17B:27-46.1v; *id.* § 17B:27A-7.5; *id.* § 17B:27A-19.7).

10. 20 U.S.C. §§1400-1482 (2006).

11. *Id.* §1400(d)(1)(A).

12. *Id.*

13. *Id.* §1401(3)(A).

14. N.J. STAT. ANN. § 52:14-17.29d (West 2007).

15. IDEA FUNDING COALITION, IDEA FUNDING: TIME FOR CONGRESS TO LIVE UP TO THE COMMITMENT 3 (2006), <http://www.nea.org/lac/idea/images/mandatory2006.pdf> (“In 2006, the national average per pupil expenditure is expected to be \$8,668. With 6,878,000 students served under IDEA, schools are qualified to receive \$23.8 billion in federal funds. Unfortunately, school districts are only receiving \$10.6 billion. In other words, states and school districts are currently receiving roughly 17.73% rather than the federal commitment of 40% of APPE” (footnotes omitted)); ConnSENSE Bulletin, *CEC Briefs Compare the 2004 IDEA Regulations to the 1997 IDEA Regulations and Include CEC Comments and Analysis*, <http://www.connsensebulletin.com/cecoc13mk.html> (last visited Aug. 22, 2008).

relatively constant since 1987,<sup>16</sup> and has compromised the special education and treatment of children with autism.<sup>17</sup> Health insurers have a mandate to provide adequate health coverage to all of their constituents, and in New Jersey, this mandate includes coverage for those with mental health illnesses. However, health carriers often refuse coverage for certain autism treatments by asserting that the sought-after treatments are experimental, or arguing that the treatments fall under special education costs rather than medical costs.<sup>18</sup> In doing so, health carriers effectively discriminate against their insured children with autism. As soon as a child is diagnosed with autism, that child requires immediate therapy to facilitate his or her social and verbal development at critical stages in infancy and childhood.<sup>19</sup> New Jersey Assembly Bill 2238<sup>20</sup> (Assembly Bill 2238), currently before the 213th Legislature, would be a direct remedy for this problem because it provides for specific mandatory coverage of behavioral therapy and other treatments for children with autism.<sup>21</sup>

This Note will examine the impact of Mental Health Parity legislation, administrative regulations, and case law on the coverage of children with autism in New Jersey. This Note will also examine the overlaps and gaps between health insurance coverage and special education coverage for children with autism under the federal and New Jersey Mental Health Parity Acts, Medicaid, SCHIP, and IDEA. Part I of this Note describes autism and its prevalence, impact, treatment modalities, and current insurance coverage. Part II provides an overview of the statutory coverage available to children with autism. Part III describes the current loophole in coverage for children with autism despite overlapping statutory provisions. Part

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16. See Thomas B. Parrish & Jean Wolman, *Trends and New Developments in Special Education Funding: What the States Report*, in FUNDING SPECIAL EDUCATION 203, 215 (Thomas B. Parrish et al. eds., 1999) (surveying expenditures in 24 states and finding federal funding for IDEA to range from 4% to 17%); Seligmann, *supra* note 2, at 286 & n.274 (citing Thomas B. Parrish & Jay G. Chambers, *Financing Special Education*, 6 SPECIAL EDUCATION FOR STUDENTS WITH DISABILITIES 121, 122 (Richard E. Behrman ed., 1996) (reporting that in 1987-88, federal aid ranged from 65% of total special education expenditures in Kentucky to 3% in Minnesota and New York)).

17. See discussion *infra* Part II.A.

18. See discussion *infra* Part I.D.

19. See AUTISM PREVALENCE REPORT, *supra* note 2, at 35; NAT'L INST. OF MENTAL HEALTH, DEP'T OF HEALTH & HUMAN SERVS., AUTISM SPECTRUM DISORDERS: PERVERSIVE DEVELOPMENTAL DISORDERS WITH ADDENDUM JANUARY 2007 at 4, 11-12 (2007), <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf> [hereinafter NIMH REPORT].

20. Gen. Assem. 2238, 213th Leg., 1st Sess. (N.J. 2008), [http://www.njleg.state.nj.us/2008/Bills/A2500/2238\\_11.PDF](http://www.njleg.state.nj.us/2008/Bills/A2500/2238_11.PDF) ("An Act concerning health benefits coverage for certain therapies for the treatment of certain autism disorders . . .").

21. *Id.*

IV includes examples of legislation that suggest that there is a nationwide trend toward increasing coverage of children with autism. Finally, Part IV also argues that Assembly Bill 2238 would significantly benefit children with autism in New Jersey by providing them with access to urgently-needed behavioral therapy.

## I. WHAT IS AUTISM?

A 2½-year-old boy is brought to a pediatrician by his parents[, who] recently placed their son in day care for 2 half-days a week. However, he has not adjusted well . . . . The teacher cannot seem to make him follow directions and notes that he does not look at her when she is near him and attempting to interact with him. [He] has only a limited vocabulary of perhaps 10 words . . . . His favorite toys are often used inappropriately—he performs single, repetitive movements with them for what seems like hours on end.<sup>22</sup>

Speech is hard for me. I can make people think I am “normal,” but it takes much effort and energy. . . . There are, on occasion, still times when I want to talk, but I can’t. I can try and try and try, but I can’t talk. . . .

. . . .

I have been trying, as I have been writing this, to come up with a way to describe that curious, withdrawn, “other world.” I have been unable to do so. Again, I suspect it is because I have nothing to compare it to.<sup>23</sup>

Autism is a complex neurological disorder that typically appears by age three and impairs development in the areas of social interaction and communication skills.<sup>24</sup> “Parents are usually the first to notice unusual behaviors [and autistic traits] in their child.”<sup>25</sup>

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22. EUGENE C. TOY & DEBRA KLAMEN, *CASE FILES: PSYCHIATRY* 335 (2d. ed. 2007). “Most likely diagnosis: Autistic Disorder. Prognosis: The child will likely experience a number of developmental delays, but with intensive treatment at home and at school, he could achieve near-normal or normal development. Language development is the most important indicator of future developmental potential in [children with autism].” *Id.* at 336.

23. Thomas, the 28-year-old narrator diagnosed with autism late in his teens, in MCKEAN, *supra* note 1, at 39, 50.

24. Autism Society of America, About Autism, [http://www.autism-society.org/site/PageServer?pagename=about\\_home](http://www.autism-society.org/site/PageServer?pagename=about_home) (last visited Aug. 22, 2008) [hereinafter Autism Society of America]; AUTISM PREVALENCE REPORT, *supra* note 2, at 14 (“Between 51% and 91% of children with an ASD had documented developmental concerns before the age of 3 years.”); NIMH REPORT, *supra* note 19, at 2.

25. NIMH REPORT, *supra* note 19, at 2 (“In some cases, the baby seemed ‘different’ from birth, unresponsive to people or focusing intently on one item for long periods of time. The first signs of an ASD can also appear in children who seem to have been developing normally. When an engaging, babbling toddler suddenly becomes silent,

Though autism first appears in children, and several therapies have proven very effective in treating it, it is ultimately a lifelong disorder that currently has no cure.<sup>26</sup> However, many ongoing research endeavors are investigating better treatments and possible cures for autism.<sup>27</sup>

Autism is described clinically as "autism spectrum disorder"<sup>28</sup> (ASD), with features ranging from severe developmental impairments to slight developmental delays that allow more mildly impaired individuals to function relatively normally in society.<sup>29</sup> Autism was first described in 1943 by Dr. Leo Kanner, who described its classic symptoms as "isolated play, unusual language traits, insistence on ritual behavior, and resistance to change."<sup>30</sup> Dr. Hans

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withdrawn, self-abusive, or indifferent to social overtures, something is wrong. Research has shown that parents are usually correct about noticing developmental problems, although they may not realize the specific nature or degree of the problem."); cf. AUTISM PREVALENCE REPORT, *supra* note 2, at 3 ("There is no medical test for ASDs. Typically, a diagnosis is made after a thorough evaluation. Such an evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and possibly the use of one or more autism diagnostic tests."); DOUGLAS J. GELB, INTRODUCTION TO CLINICAL NEUROLOGY 379 (3d. ed. 2005) ("The differential diagnosis for developmental delay depends on the pattern of impairment. . . . When abnormal social development and restricted activities and interests accompany language delay, [autism] is a prime consideration.").

26. Autism Society of America, *supra* note 24; AUTISM PREVALENCE REPORT, *supra* note 2, at 3; NIMH REPORT, *supra* note 19, at 25-26.

27. See, e.g., NIMH REPORT, *supra* note 19, at 28-31; Ian Dempsey & Phil Foreman, *A Review of Educational Approaches for Individuals with Autism*, 48 INT'L. J. DISABILITY, DEV. & EDUC. 103 (2001); L. Juane Heflin & Richard L. Simpson, *Interventions for Children and Youth with Autism: Prudent Choices in a World of Exaggerated Claims and Empty Promises*, 13 FOCUS ON AUTISM & OTHER DEV. DISABILITIES 194 (1998); Rose Iovannone et al., *Effective Educational Practices for Students with Autism Spectrum Disorders*, 18 FOCUS ON AUTISM & OTHER DEV. DISABILITIES 150 (2003); Seligmann, *supra* note 2, at 238 n.84 (citing Susan E. Bryson et al., *Autism Spectrum Disorders: Early Detection, Intervention, Education, and Psychopharmacological Management*, 48 CAN. J. PSYCHIATRY 506 (2003); Juliann J. Woods & Amy W. Wetherby, *Early Identification of and Intervention for Infants and Toddlers Who Are at Risk for Autism Spectrum Disorder*, 34 LANGUAGE, SPEECH & HEARING SERVS. SCHS. 180 (2003)).

28. NIMH REPORT, *supra* note 19, at 2.

29. *Id.*

30. Rachel Ratcliff Womack, Comment, *Autism And The Individuals With Disabilities Education Act: Are Autistic Children Receiving Appropriate Treatment In Our Schools?*, 34 TEX. TECH L. REV. 189, 190 n.3 (2002) (citing J. Gregory Olley, *Autism: Historical Overview, Definition, and Characteristics*, in AUTISM IDENTIFICATION, EDUCATION, AND TREATMENT 3, 3-4 (Dianne E. Berkell ed., 1992)); see N.J. MANDATED HEALTH BENEFITS ADVISORY COMM'N, N.J. DEPT OF BANKING AND INS., A STUDY OF ASSEMBLY BILL A-999, at 3 (2007), [http://www.state.nj.us/dobi/mhbac/070314\\_A999rpt\\_MHBAC.pdf](http://www.state.nj.us/dobi/mhbac/070314_A999rpt_MHBAC.pdf) [hereinafter A-999 STUDY]; NIMH REPORT, *supra* note 19, at 1; Seligmann, *supra* note 2, at 240-41.

Asperger, a German scientist, simultaneously “described a milder form of the disorder . . . known as Asperger syndrome.”<sup>31</sup> The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV),<sup>32</sup> the standard diagnostic manual developed by the American Psychiatric Association, classifies autism as one of five “Pervasive Developmental Disorders.”<sup>33</sup>

#### A. *Prevalence of Autism*

In recent years, the rate at which children are being diagnosed with autism has exploded. “Surveys to find the prevalence of autism started in the mid-1960s in England. . . . For decades, the best estimate for the prevalence of autism was 4 to 5 per 10,000 children.”<sup>34</sup> Recent reports by the Centers for Disease Control and Prevention (CDC) have consistently found a tenfold increase in the prevalence of ASDs.<sup>35</sup> California is an alarming example of such a trend, having reported a 634% increase in the population of individuals with autism from 1987 to 2002, including an increase of 97% between the years of 1998 and 2002 alone.<sup>36</sup> Autism is three to four times more prevalent in boys than in girls.<sup>37</sup> Differences in autism prevalence by race have not been consistently demonstrated across many states.<sup>38</sup>

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31. NIMH REPORT, *supra* note 19, at 1.

32. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS, DSM-IV-TR (4th ed., Text Revision, 2000).

33. *Id.* at 69-84 (Pervasive Developmental Disorders (PDD) are subclassified in the DSM-IV as Autistic Disorder, Asperger Disorder, Childhood Disintegrative Disorder (CDD), Rett's Disorder, and PDD Not Otherwise Specified (PDD NOS)). Autistic Disorder must have onset prior to age 3 and is diagnosed when a child meets diagnostic criteria of qualitative impairment in both social interaction and communication, and the child displays “restricted repetitive and stereotyped patterns of behavior, interests, and activities.” *Id.* at 70-75.

34. AUTISM PREVALENCE REPORT, *supra* note 2, at 5-6.

35. *Id.* at 6; Seligmann, *supra* note 2, at 249 (citing, *inter alia*, Marshelyn Yeargin-Allsopp, *Prevalence of Autism in a US Metropolitan Area*, 289 J. AM. MED. ASS'N 49, 53 (2003)).

36. Seligmann, *supra* note 2, at 249-50 (citing CAL. DEPT OF DEV. SERVS., CAL. HEALTH AND HUMAN SERVS. AGENCY, AUTISM SPECTRUM DISORDERS: CHANGES IN THE CALIFORNIA CASELOAD; AN UPDATE: 1999 THROUGH 2002, at i (2003), <http://www.mindfully.org/Health/2003/Autism-1999-2002-CA-Apr03.htm> [hereinafter CALIFORNIA REPORT]).

37. AUTISM PREVALENCE REPORT, *supra* note 2, at 12 (indicating prevalence rates: “Boys: 5.0 to 16.8 per 1,000 8-year-old children. Girls: 1.4 to 3.1 per 1,000 8-year-old children.”); CDC MMWR Report, *supra* note 2, at 18-19.

38. CDC MMWR Report, *supra* note 2, at 18-19, 18 tbl.2. Though “prevalence was higher among non-Hispanic white children than among non-Hispanic black children [and] prevalence was lower for Hispanic than for non-Hispanic white children,” this difference was statistically significant only for a few sites. *Id.* at 18-19, 23.

Due to several confounding factors, the reasons for this increase in the rate of diagnosis are a matter of continuing debate.<sup>39</sup> One reason is that the diagnostic criteria have been modified since they were first introduced in 1980.<sup>40</sup> Other reasons that have been proposed include increased recognition and awareness of autism by medical professionals,<sup>41</sup> better public health surveillance,<sup>42</sup> earlier detection of autism, and the incentive created by the addition of autism as a disability for IDEA purposes.<sup>43</sup> An absolute increase in the numbers of children with autism may also be found because the risk factors and causes of autism are being continuously researched.<sup>44</sup>

Regardless of the reasons, there has been a real increase in the number of children diagnosed with autism.<sup>45</sup> It is clear that "ASDs are the second most common serious developmental disability after mental retardation/intellectual impairment,"<sup>46</sup> surpassing the

39. See AUTISM PREVALENCE REPORT, *supra* note 2, at 36 ("While it is clear that more children than ever before are being classified as having an Autism Spectrum Disorder, it is unclear how much of this increase is due to changes in how we identify and classify ASDs in people, or whether this is due to a true increase in prevalence.").

40. AUTISM PREVALENCE REPORT, *supra* note 2, at 5. Compare M.I.N.D. INST., UNIV. OF CAL., THE EPIDEMIOLOGY OF AUTISM IN CALIFORNIA 42 (2002), [http://www.ucdmc.ucdavis.edu/mindinstitute/newsroom/study\\_final.pdf](http://www.ucdmc.ucdavis.edu/mindinstitute/newsroom/study_final.pdf) ("The [study] did not find evidence that the rise in autism cases can be attributed to . . . loosening of the diagnostic criteria for autism . . ."), with Paul T. Shattuck, *The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education*, 117 PEDIATRICS 1028, 1035 (2006), <http://pediatrics.aappublications.org/cgi/reprint/117/4/1028> ("[B]roadening clinical diagnostic criteria have been used to understand changes in population-based estimates of prevalence.").

41. See AUTISM PREVALENCE REPORT, *supra* note 2, at 5 (noting "the fact that autism and related disorders are diagnosed by behavioral observation of development makes describing the population of people with ASDs challenging").

42. See *id.* ("Another challenge is that the United States has not had a population-based system to track the full range of ASDs over time.").

43. *Id.* at 32; Seligmann, *supra* note 2, at 251 (citations omitted).

44. Seligmann, *supra* note 2, at 251 (citing, *inter alia*, M.I.N.D. INST., *supra* note 40, at 4); see M.I.N.D. INST., *supra* note 40, at 42 ("Without evidence for an artificial increase in autism cases, we conclude that some, if not all, of the observed increase represents a true increase in cases of autism . . ."). There has been public concern in the past few years about a link between autism and thimerosal, a preservative used in vaccines until recently. NIMH REPORT, *supra* note 19, at 28. Since then, several large studies have failed to show a link between the two. *Id.* The 2004 final report from the Institute of Medicine found no link after conducting a review of the studies. See INST. OF MEDICINE, IMMUNIZATION SAFETY REVIEW: VACCINES AND AUTISM (2004), [http://www.nap.edu/catalog.php?record\\_id=10997](http://www.nap.edu/catalog.php?record_id=10997).

45. Seligmann, *supra* note 2, at 251.

46. AUTISM PREVALENCE REPORT, *supra* note 2, at 36.



prevalence of many childhood illnesses, including juvenile diabetes, Down Syndrome, and childhood cancer.<sup>47</sup>

### B. *Social and Economic Impact of Autism*

Economic analyses of the exact annual costs of autism vary. In a report released earlier this year, the CDC estimated that autism costs the United States approximately \$35 billion per year in special education costs and medical treatments.<sup>48</sup> In 2001, researchers at the Institute of Psychiatry in London estimated that “the average lifetime cost for someone with autism is £2.4 million.”<sup>49</sup> Basing their estimate on the UK study, the Autism Society of America estimated the annual U.S. societal cost of autism to be \$90 billion per year, with 90% of the costs being for adult services.<sup>50</sup> Lifespire Inc.<sup>51</sup> estimated the total costs for an autistic disabled adult to be \$225,000 per year.<sup>52</sup> Notably, the cost of lifelong care can be reduced by two-thirds with early diagnosis and intervention.<sup>53</sup>

Applied Behavioral Analysis (ABA), a key treatment modality for autism, is an expensive therapy that can impose varying costs depending upon the number of hours of treatment and the expertise of the provider. In 2004, one court estimated that ABA therapy costs

47. *Id.* at 31-32 (footnotes omitted); Seligmann, *supra* note 2, at 249-50 (citing CALIFORNIA REPORT, *supra* note 36, at i).

48. AUTISM PREVALENCE REPORT, *supra* note 2, at 6 (citing M.L. Ganz, *The Costs of Autism*, in UNDERSTANDING AUTISM: FROM BASIC NEUROSCIENCE TO TREATMENT 475, 475-502 (Steven O. Moldin & John L.R. Rubenstein eds., 2006)).

49. Krister Järbrink & Martin Knapp, *The Economic Impact of Autism in Britain*, 5 AUTISM 7, 17 (2001). Because societal care of individuals with autism is based on economic factors and availability of medical therapies, estimates of annual cost vary by country. “The Canadian Broadcasting System (CBC) . . . estimated the lifetime cost of supporting an untreated autistic child is at least \$1.7 million, not including opportunity cost or even lost tax revenues. Life long [sic] opportunity cost has been estimated at an additional \$1,276,000. Based on these estimates, using an average lifespan of 75 years, the annual cost per untreated person with autism is \$39,503.” A-999 STUDY, *supra* note 30, app. at 3.

50. Autism Society of America, *Facts and Statistics*, [http://www.autism-society.org/site/PageServer?pagename=about\\_what\\_is\\_factsstats](http://www.autism-society.org/site/PageServer?pagename=about_what_is_factsstats) (last visited Aug. 22, 2008) [hereinafter *Autism Facts*].

51. Formerly the Association for Children with Retarded Medical Development – NY, NJ. See Lifespire History, [http://www.lifespire.org/lifespire\\_history.htm](http://www.lifespire.org/lifespire_history.htm) (last visited Aug. 22, 2008).

52. A-999 STUDY, *supra* note 30, app. at 3. (“The lifespan costs based on a 45 year adult life span (to age 66 – conservative estimate of lifespan based on actuarial tables) [is estimated at] \$10,125,000. These estimates do not include any costs for the period up to and including age 21!”).

53. *Autism Facts*, *supra* note 50. In 2003, the Autism Society of America estimated that in 10 years the annual cost of autism in America could increase to \$200-400 billion. *Id.*

between \$50,000 and \$63,800 per year per student.<sup>54</sup> A 2007 New Jersey report assessed the annual cost for thirty hours per week of ABA therapy as \$50,787 per student.<sup>55</sup>

Another reason that estimates of the economic impact of autism vary is that many secondary costs of autism are excluded in different studies.<sup>56</sup> Furthermore, the social costs of autism are severe, including parental stress from raising children with autism,<sup>57</sup> increased demand for family support and reduction in total family earning capacity, and compromised longevity.<sup>58</sup>

When parents are financially unable to secure mental health services, they are sometimes forced to relinquish custody of their child. Parents may have to allow the state to provide services if “community services are not available, the school system has not classified the child as requiring services, private insurance refuses to pay or Medicaid is inaccessible.”<sup>59</sup> State custody further fractures the home as the child is removed and placed into either foster care or a residential facility.

### C. Treatment Modalities for Autism

Currently, physical, occupational, speech, and behavioral therapies are all being used to treat autism based on the individual needs of each patient.<sup>60</sup> There is no single approach that is ideal for all individuals with autism.<sup>61</sup> Several educational approaches to autism involve extensive use of behavioral therapies, including ABA and its counterpart, Discrete Trail Therapy (DTT).<sup>62</sup> There are also

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54. Seligmann, *supra* note 2, at 285 (citing L.B. *ex rel.* K.B. v. Nebo Sch. Dist., 379 F.3d 966, 973 (10th Cir. 2004), and noting “the [school] district’s entire preschool budget was . . . \$360,000 to \$400,000 per year”).

55. A-999 STUDY, *supra* note 30, app. at 8.

56. *Id.* at 8-9 (noting that studies are based on “distribution of hours by provider type and estimated charges per hour” and do not factor in other costs).

57. See *Autism: The Hidden Epidemic* (NBC television broadcast Feb. 25, 2005) (discussing studies that suggest that the divorce rate for parents caring for children with autism is between 75% and 85%).

58. See A-999 STUDY, *supra* note 30, app. at 3.

59. Gwen Goodman, Comment, *Accessing Mental Health Care for Children: Relinquishing Custody to Save the Child*, 67 ALB. L. REV. 301, 302-03 (2003) (citations omitted).

60. A-999 STUDY, *supra* note 30, app. at 4; see also AETNA, CLINICAL POLICY BULLETIN: PERVASIVE DEVELOPMENTAL DISORDERS, at pt. I.P., [www.aetna.com/cpb/medical/data/600\\_699/0648.html](http://www.aetna.com/cpb/medical/data/600_699/0648.html) (last visited Aug. 22, 2008) [hereinafter AETNA POLICY] (stating that “physical and occupational therapy for co-morbid physical impairments” may be covered). But see discussion *infra* Part II.E.

61. A-999 STUDY, *supra* note 30, app. at 4; Seligmann, *supra* note 2, at 245 (citing, *inter alia*, Heflin & Simpson, *supra* note 27, at 194; Iovannone et al., *supra* note 27, at 153).

62. Seligmann, *supra* note 2, at 245-247; Womack, *supra* note 30, at 224-25.

classroom-based educational therapies, notably the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) method, developed in the early 1970s at the University of North Carolina at Chapel Hill.<sup>63</sup> This approach, emphasizing clear structuring of the students' physical environment and daily schedules in addition to communication and coping skills, was "the first legislatively mandated statewide program of treatment and services for children with autism."<sup>64</sup> TEACCH has been widely adopted in the United States and other countries.<sup>65</sup>

One autism treatment that has received increasingly popular support by both doctors and patient advocacy groups is the ABA method, which involves extensive one-on-one behavioral modification therapy.<sup>66</sup> This therapy was pioneered by Dr. Ivar Lovaas at the University of California, Los Angeles, in the 1960s.<sup>67</sup>

Applied Behavior Analysis (ABA) teaches complex tasks by breaking them down into bite-size pieces that can be learned more easily, with each piece building upon the previous one. Rewards, called "reinforcers" are given for correct responses or behaviors while inappropriate responses are corrected, ignored, or redirected. Precise data on each learning trial is recorded, and adjustments in the educational program are made accordingly.

ABA targets development in many areas of skill, including, but not limited to, attending, imitation, language, social, play, self-help, and academics.<sup>68</sup>

Studies indicate that ABA is an effective therapy for autism.<sup>69</sup> According to a 1999 report by the U.S. Surgeon General, "[t]hirty

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63. Division TEACCH, <http://www.teacch.com> (last visited Aug. 22, 2008).

64. Seligmann, *supra* note 2, at 247 (citing, *inter alia*, Dempsey & Foreman, *supra* note 27, at 111; Heflin & Simpson, *supra* note 27, at 207).

65. *Id.* at 247-48 (citations omitted); see TEACCH – International Priorities, <http://www.teacch.com/internationalpriorities.html> (last visited Aug. 22, 2008).

66. See generally Womack, *supra* note 30, at 224-25 (citing MITCHELL L. YELL, THE LAW AND SPECIAL EDUCATION 157 (1998); Autism Speaks, *Treatments for Autism*, [http://www.autismspeaks.org/whattodo/what\\_is\\_aba.php](http://www.autismspeaks.org/whattodo/what_is_aba.php) (last visited Aug. 22, 2007); Gina Green, *Applied Behavior Analysis for Autism*, CAMBRIDGE CTR. FOR BEHAVIORAL STUDIES, <http://www.behavior.org/autism> (follow table of contents hyperlink, "Applied Behavior Analysis for Autism") (last visited Aug. 22, 2008)).

67. Womack, *supra* note 30, at 225; A-999 STUDY, *supra* note 30, at 5-6; cf. O. Ivar Lovaas, *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*, 55 J. CONSULTING & CLINICAL PSYCHOL. 3 (1987).

68. A-999 STUDY, *supra* note 30, at 5 (citation omitted).

years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”<sup>70</sup> A number of other government and scientific organizations have also endorsed ABA and other therapies.<sup>71</sup> Courts, noting the widespread support for ABA’s success, have issued decisions in favor of implementing ABA therapy.<sup>72</sup> Studies are, however, less unanimous in their findings on whether ABA therapy should be the exclusive

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69. *Id.* at 6-7 (acknowledging, however, that other techniques are as effective); NIMH REPORT, *supra* note 19, at 18 (“Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment.”); Seligmann, *supra* note 2, at 246 (citing Dempsey & Foreman, *supra* note 27, at 109); Womack, *supra* note 30, at 225-26 (citing Olley, *supra* note 30, at 14).

70. NIMH REPORT, *supra* note 19, at 18 (quoting U.S. DEP’T OF HEALTH AND HUMAN SERVS., MENTAL HEALTH: A REPORT OF THE SURGEON GENERAL 164 (1999), <http://www.surgeongeneral.gov/library/mentalhealth/home.html> [hereinafter SURGEON GENERAL’S REPORT]).

71. The following are examples of such groups:

1) National Institute of Mental Health. See NIMH REPORT, *supra* note 19, at 18-19; Autism Speaks, *Arguments in Support of Private Insurance Coverage of Autism-Related Services* 11 (2007), [http://www.autismspeaks.org/docs/family\\_services\\_docs/arguments\\_for\\_private\\_insurance\\_coverage.pdf](http://www.autismspeaks.org/docs/family_services_docs/arguments_for_private_insurance_coverage.pdf) [hereinafter *Arguments for Private Insurance Coverage*].

2) National Institute of Child Health and Human Development. See *Arguments for Private Insurance Coverage*, *supra*, at 11 (citing National Institute of Child Health and Human Development website: Questions and Answers (2006), <http://www.nichd.nih.gov/publications/pubs/autism/QA/sub18.cfm>).

3) National Research Council. See *id.* (citing NATIONAL RESEARCH COUNCIL, EDUCATING CHILDREN WITH AUTISM (Catherine Lord & James P. McGee eds. 2001)).

4) Association for Science in Autism Treatment. See *id.* (citing Association for Science in Autism Treatment, <http://www.asatonline.org/resources/resources.htm> (last visited Aug. 22, 2008)).

5) New York State Department of Health. See *id.* (citing NEW YORK DEPARTMENT OF HEALTH, CLINICAL PRACTICE GUIDELINE: REPORT OF THE RECOMMENDATIONS, AUTISM/PERVASIVE DEVELOPMENTAL DISORDERS, ASSESSMENT AND INTERVENTION FOR YOUNG CHILDREN (AGE 0-3 YEARS) (1999), [http://www.health.state.ny.us/community/infants\\_children/early\\_intervention/autism/index.htm](http://www.health.state.ny.us/community/infants_children/early_intervention/autism/index.htm)).

6) Maine Administrators of Services for Children with Disabilities. See *id.* (citing MAINE ADMINISTRATORS OF SERVICES FOR CHILDREN WITH DISABILITIES, REPORT OF THE MADSEC AUTISM TASK FORCE (2000), <http://www.madsec.org/docs/ATFReport.pdf>).

72. See, e.g., *Malkentzos v. DeBuono*, 923 F. Supp. 505, 509 (S.D.N.Y. 1996), *vacated on other grounds*, 102 F.3d 50 (2d Cir. 1996) (“There are several educational modalities for autistic children, but ABA therapy is the only one that enjoys any quantifiable success.”); Womack, *supra* note 30, at 191 (citing *T.H. v. Bd. of Educ.*, 55 F. Supp. 2d 830, 836 (N.D. Ill. 1999)).

therapy for autism, and whether it should be used at intensive levels of twenty to forty hours per week.<sup>73</sup>

#### *D. Insurance Coverage for Autism Treatment*

Unfortunately, many individuals with autism have difficulty obtaining adequate health insurance coverage for ABA and other therapies and must pay out-of-pocket when therapies are not offered in schools. Furthermore, health insurance carriers often classify certain therapies, and perhaps most notoriously ABA therapy, as “experimental and investigational,” thereby excluding them from coverage.<sup>74</sup> Health carriers assert that the evidence for ABA therapy has not consistently shown that ABA is superior to other autism therapies.<sup>75</sup> However, even health carriers admit that ABA therapy is indicated when “delivered in the *education and other settings*.”<sup>76</sup>

The uncertainty between what constitutes special educational therapy and what constitutes medical therapy for individuals with autism further confounds the issue of autism therapy coverage.<sup>77</sup> For example, Aetna’s policy covers “[i]ntensive educational interventions in which the child is engaged in systematically planned and developmentally appropriate educational activity . . . including services rendered by a speech-language pathologist to improve communication skills.”<sup>78</sup> Yet the first footnote to that section states that “[m]any Aetna plans exclude coverage of educational services. Speech therapy for [Pervasive Developmental Disorders, including Autism Disorder,] is primarily educational in nature and would be excluded under these plans.”<sup>79</sup>

## II. DISCUSSION OF SELECTED STATUTES AND CASE LAW THAT PROVIDE COVERAGE FOR CHILDREN WITH AUTISM

### *A. The Individuals with Disabilities Education Act*

The Individuals with Disabilities Education Act (IDEA) provides compliant states with funding for special education programs for

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73. A-999 STUDY, *supra* note 30, at 6-7; Seligmann, *supra* note 2, at 246 (citing Heflin & Simpson, *supra* note 27, at 213).

74. A-999 STUDY, *supra* note 30, at 6.

75. *Id.* at 7; see AETNA POLICY, *supra* note 60, at pt. I.N. n.3 (“There is insufficient evidence for the superiority of any particular intensive educational intervention strategy (such as applied behavioral analysis, structured teaching, or developmental models) over other intensive educational intervention strategies.”).

76. A-999 STUDY, *supra* note 30, at 7 (emphasis added).

77. See discussion *infra* Part III.

78. AETNA POLICY, *supra* note 60, at pt. I.N.

79. *Id.* at pt. I.N. n.1.

children with disabilities.<sup>80</sup> The IDEA provides a federal right to a “free appropriate public education” (FAPE)<sup>81</sup> to every qualified disabled student. This goes beyond the educational rights provided by the various state constitutions, including New Jersey’s Constitution,<sup>82</sup> because it also grants the right to preschoolers ages three through five<sup>83</sup> and provides early intervention services for infants and toddlers before age three.<sup>84</sup> The IDEA also requires that this FAPE be given in the “least restrictive environment” (LRE),<sup>85</sup> preferring integration in regular classrooms to segregation.<sup>86</sup> These services are comprehensively set forth in the Individualized Education Program (IEP),<sup>87</sup> a specialized document developed through collaboration between designated personnel from the school district and the child’s parents.<sup>88</sup> The costs of providing necessary services for the child are free to the parents, and expense to the school district cannot be a bar to a student’s FAPE.<sup>89</sup>

Part of a child’s protections under the IDEA include extensive procedural due process safeguards and rights regarding a child’s evaluation for an IEP, creation of an IEP, and resolution of disputes regarding his or her IEP.<sup>90</sup> These provisions make the child’s parents

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80. 20 U.S.C. §§1400-1487 (2006).

81. *Id.* §1412(a)(1)(A).

82. N.J. CONST. art. VIII, § 4, ¶ 1 (“The Legislature shall provide for the maintenance and support of a thorough and efficient system of free public schools for the instruction of all the children in the State between the ages of five and eighteen years.”); *see also* *Abbott ex rel. Abbott v. Burke*, 710 A.2d 450, 462 (N.J. 1998) (recognizing the necessity of providing “early childhood education for three- and four-year olds in the poorest school districts” according to title 18A, subtitle 4A, chapter 7F, section 16 of the New Jersey Code). Note that the provision cited in *Abbott* has been recently repealed. Act of Jan. 13, 2008, ch. 84, 2007 N.J. Laws 260.

83. 20 U.S.C. §§ 1411-1419 (2006); *see also* Alefia E. Mithaiwala, Note and Comment, *Universal Preschool: A Solution to a Special Education Law Dilemma*, 2004 BYU EDUC. & L.J. 373, 373 (2004).

84. §§ 1431-1444 (2006).

85. *Id.* § 1412(a)(5).

86. Individuals with Disabilities Education Act Regulations, 34 C.F.R. §§ 300.114-117 (2007) (formerly at 34 C.F.R. §§ 300.130, 300.550-.553) (“To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled . . .”).

87. 20 U.S.C. § 1414(d)(1)(A) (West Supp. 2008) (defining an IEP and its elements).

88. *See id.*

89. Seligmann, *supra* note 2, at 223-24 (citing *Cedar Rapids Cmty. Sch. Dist. v. Garret F. ex rel. Charlene F.*, 526 U.S. 66, 79 (1999) (rejecting cost-based objections to providing health aide services, including suctioning of breathing tube). *But cf.* Ashley Oliver, *Should Special Education Have a Price Tag? A New Reasonableness Standard for Cost*, 83 DENV. U. L. REV. 763, 787-90 (2006) (arguing in favor of a reasonableness standard for cost).

90. *See* 20 U.S.C. §§ 1414-1415; *see also* 34 C.F.R. §§ 300.500-.520 (2007).

participants in the IEP team process, and require the school district to notify the child's parents of the parents' rights and the district's actions towards the child.<sup>91</sup> In the event of a dispute, the provisions require that the two parties have a "resolution session" prior to referral before a state administrative hearing officer.<sup>92</sup> If the parties are not satisfied with the hearing outcome, they may then file a civil action in federal district court.<sup>93</sup>

The United States Supreme Court created a two-prong test for an "appropriate" FAPE in *Board of Education v. Rowley*.<sup>94</sup> The first prong examines whether procedural fairness has been satisfied.<sup>95</sup> The second prong determines whether the IEP is "reasonably calculated to enable the child to receive educational benefits."<sup>96</sup> The *Rowley* Court stated that IDEA requires "access to specialized instruction and related services which are individually designed to provide educational benefit to the handicapped child."<sup>97</sup> However, the Court held that IDEA's relative absence of substantive requirements, in addition to the requirement that education plans be submitted to the Secretary of Education for approval, demonstrates Congress's intent to limit judicial review of the substance of the IEP.<sup>98</sup> Thus, the FAPE requirements of individual design and educational benefit are deferential to the school district's expertise, especially regarding matters of educational methodology.<sup>99</sup> This deference has generated several colorful metaphors, one of which deems the child "entitled to a 'serviceable Chevrolet' as opposed to a Cadillac."<sup>100</sup>

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91. Seligmann, *supra* note 2, at 230-31 & nn.54-56 (citing various provisions of 20 U.S.C. §§ 1414-15 (2000)).

92. See 20 U.S.C. § 1415(f)(1)(B) (2000).

93. *Id.* § 1415(i)(2); see also Seligmann, *supra* note 2, at 231 & nn.58-62 (detailing the federal court's permissions regarding review of evidence, methods of relief, and award of attorney's fees).

94. 458 U.S. 176, 206-07 (1982), *superseded in part by statute*, Individuals with Disabilities Education Act Amendments of 1997, Pub. L. No. 105-17, 111 Stat. 37. "While commentators have argued that other statutory provisions or policies, IDEA amendments after *Rowley*, and related legal developments justify a more rigorous standard for assessing an appropriate education, the courts have continued to apply the *Rowley* educational benefit standard." Seligmann, *supra* note 2, at 230 (citations omitted).

95. *Rowley*, 458 U.S. at 206.

96. *Id.* at 207.

97. *Id.* at 201.

98. See *id.* at 205-06.

99. See D. Patrick Lacy, Jr. & Kathleen S. Mehfoed, *Education Law*, 39 U. RICH. L. REV. 183, 196 (2004); Seligmann, *supra* note 2, at 232-33. *But cf.* Seligmann, *supra* note 2, at 287-88 (arguing that too much deference to the school district is counterproductive).

100. Seligmann, *supra* note 2, at 228 (citing *Doe v. Bd. of Educ.*, 9 F.3d 455, 459-60 (6th Cir. 1993)); see also *id.* at 228 n.47 ("But the Chevy has to run. See *Nein v.*

The concepts of FAPE and LRE are in inherent tension, for while the former requires an "appropriate education," the latter mandates that the education be provided in the "least restrictive" alternative.<sup>101</sup> The United States Supreme Court has never applied or interpreted the definition of the LRE, instead leaving federal appellate courts to develop three different tests:<sup>102</sup> the Sixth, Fourth, and Eighth Circuits have adopted the *Roncker* test;<sup>103</sup> the Fifth, Third, and Eleventh Circuits, plus one district in the Second Circuit, have used the *Daniel R.R.* test;<sup>104</sup> and courts in the Ninth and Seventh Circuits have applied the *Rachel H.* test.<sup>105</sup>

The *Roncker* test determines the nature of the special education services that will be provided, and then examines "whether it is feasible to deliver" those services in a regular classroom.<sup>106</sup> Because this test "suggests that courts should make decisions regarding which educational methods are feasible in the regular classroom,"<sup>107</sup> the *Daniel R.R.* test replaced the "feasibility" test with an analysis of whether education "can be satisfactorily achieved" in the regular

Greater Clark County Sch. Corp., 95 F. Supp. 2d 961, 977 (S.D. Ind. 2000) (finding district's plan was a 'Chevrolet without a transmission—even if the engine might run, no power ever reached the wheels.');

see also *Metro. Nashville County Sch. Sys. v. Guest*, 900 F. Supp. 905, 909 (M.D. Tenn. 1995) (referring to parents' argument that the service provider in the student's IEP was 'a Yugo').

101. Allan Kickert, *Holistic Learning: Amending the Rowley Test to Clarify the Inclusion Debate*, 29 W. NEW ENG. L. REV. 733, 745 & n.85 (2007) (citing *Oberti v. Bd. of Educ.*, 995 F.2d 1204, 1214 n.18 (3d Cir. 1993)).

102. See *id.* at 745-46.

103. See *Roncker ex rel. Roncker v. Walter*, 700 F.2d 1058, 1063 (6th Cir. 1983). The Eighth Circuit adopted the *Roncker* test in *A.W. v. Northwest*, 813 F.2d 158 (8th Cir. 1987), and the Fourth Circuit approved the *Roncker* test in *Devries v. Fairfax County Sch. Bd.*, 882 F.2d 876, 878-80 (4th Cir. 1989). See Oliver, *supra* note 89, at 768.

104. See *Daniel R.R. v. State Bd. of Educ.*, 874 F.2d 1036, 1048 (5th Cir. 1989). The Third Circuit was next to apply the *Daniel R.R.* test in *Oberti v. Bd. of Educ.*, 995 F.2d 1204, 1220-24 (3d Cir. 1993), the Eleventh Circuit also adopted the test in *Greer v. Rome City School District*, 950 F.2d 688, 696 (11th Cir. 1991), and though the Second Circuit has not formally adopted one test over others, the Northern District of New York used the reasoning of the *Daniel R.R.* test in *Mavis v. Sobol*, 839 F. Supp. 968, 987-92 (N.D.N.Y. 1993). See Oliver, *supra* note 89, at 770-71.

105. See *Sacramento City Unified Sch. Dist., Bd. of Educ. v. Rachel H. ex rel. Holland*, 14 F.3d 1398, 1404 (9th Cir. 1994). One district court in the Seventh Circuit applied but did not adopt the *Rachel H.* test in *D.F. v. Western Sch. Corp.*, 921 F. Supp. 559 (S.D. Ind. 1996). See Oliver, *supra* note 89, at 771-72.

106. Kickert, *supra* note 101, at 746 (citing *Roncker*, 700 F.2d at 1063).

107. *Id.* (citing, *inter alia*, Anne P. Dupre, *Disability, Deference, and the Integrity of the Academic Enterprise*, 32 GA. L. REV. 393, 451 (1998) ("Once the requirements of the Act have been met, courts plainly have no business intruding further into questions of educational methodology.")).



classroom.<sup>108</sup> Finally, the *Rachel H.* test analyzes the same question of whether education can be “satisfactorily achieved,” but uses different criteria.<sup>109</sup>

The process of battling a school district to change a child’s IEP can be arduous, lasting several years.<sup>110</sup> This is particularly unfortunate because the nature of autism necessitates immediate therapy upon diagnosis to facilitate a child’s social and verbal development at critical stages in infancy and childhood.<sup>111</sup>

The federal government has attempted to provide the necessary support for preschool children with autism. Pursuant to Part H of the IDEA,<sup>112</sup> compliant states receive funding to implement Early Intervention Programs to provide education and additional therapy for children before the age of three.<sup>113</sup> For example, in its implementation of the program, the New Jersey Legislature recognized the need for comprehensive and multidisciplinary early intervention.<sup>114</sup> In addition, the U.S. Department of Health and Human Services oversees the “Head Start”<sup>115</sup> program that provides preschool education and services.<sup>116</sup> However, like the IDEA, the primary purpose of Head Start and Early Intervention Programs is

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108. *Id.* Part one of the test examines whether the education can be achieved satisfactorily in a regular classroom, and if not, part two removes the child from the regular classroom while still attempting to “mainstream[] the child to the maximum extent appropriate.” *Id.* at 746 n.1 (quoting *Daniel R.R.*, 874 F.2d at 1048).

109. *Id.* at 746 n.93 (“Four factors are considered: (1) educational benefits; (2) non-academic benefits; (3) effect on the teacher and children in the regular class; and 4) cost.” (citing *Rachel H.*, 14 F.3d at 1401)).

110. See Seligmann, *supra* note 2, at 278 (citing Bd. of Educ. of County of Kanawha v. Michael M., 95 F. Supp. 2d 600, 602-04 (S.D.W. Va. 2000)).

111. See AUTISM PREVALENCE REPORT, *supra* note 2, at 35; NIMH REPORT, *supra* note 19, at 4, 11-12.

112. 20 U.S.C. § 1471 *et. seq.* (2006); see also 34 C.F.R. § 303.1 (2007).

113. See, e.g., California Department of Developmental Services, California Early Start, <http://www.dds.cahwnet.gov/EarlyStart> (last visited Oct. 12, 2008); Department of Health and Senior Services, New Jersey Early Intervention System, <http://www.state.nj.us/health/fhs/eis/index.shtml> (last visited Oct. 12, 2008); New York State Department of Health, New York State Early Intervention Program, [http://www.health.state.ny.us/community/infants\\_children/early\\_intervention](http://www.health.state.ny.us/community/infants_children/early_intervention) (last visited Oct. 12, 2008).

114. N.J. STAT. ANN. § 26:1A-36.6(e) (West 2007) (“The [New Jersey] Legislature finds and declares that: . . . services to infants and toddlers with disabilities must be comprehensive and multi-disciplinary and must be coordinated so as to assure access . . .”). Furthermore, New Jersey’s Early Intervention Program is required to “refer[] affected children who are identified as having autism . . . to schools and agencies . . .” *Id.* § 26:1A-36.7a.

115. Head Start Act, 42 U.S.C. § 9831 (2006).

116. U.S. Department of Health and Human Services, HHS What We Do, <http://www.hhs.gov/about/whatwedo.html/> (last visited Oct. 12, 2008).

to promote preschool children's educational development and readiness for school rather than their medical needs.<sup>117</sup>

Thus, while Head Start and state early intervention services provide some relief to parents seeking help for their children with autism, many parents committed to following intensive behavioral therapy programs are compelled to pursue additional therapy for their children.<sup>118</sup> However, such programs are initially paid for by the children's parents, thereby limiting this option to select families who possess the requisite means.<sup>119</sup> This option is also risky because it effectively defers the reimbursement battle while offering parents no money-back guarantee.<sup>120</sup> As one commentator explains:

If the child is never placed under a school-based IEP, it may be far more difficult to show the IEP would not have benefited him than it would be to show, after trying it, that the proposed program would continue failed approaches. On the other hand, most parents with both the desire and the means to pursue the more intensive program would not delay the child's entry into the program in order to bolster their claim for reimbursement. If the child is placed under the IEP and makes some progress, that may be enough to meet the educational benefit test, although the benefits may not be as good as those available from the program the parents are seeking.<sup>121</sup>

Federal appellate courts are also currently divided over the issue of whether parents are able to seek private school tuition reimbursement without first giving the public school system a chance to meet their child's needs.<sup>122</sup> The First Circuit, in *Greenland School District v. Amy N. ex rel. Katie C.*,<sup>123</sup> held that a parent who unilaterally places a child with autism in a private school without first raising the issue before public school officials is ineligible for

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117. See Office of Head Start, Head Start Program Description, [http://www.acf.hhs.gov/programs/hsb/about/index.html#prog\\_desc](http://www.acf.hhs.gov/programs/hsb/about/index.html#prog_desc) (last visited Mar. 9, 2008). For example, during the 2005-2006 Program Year, only 12.2% of the Head Start enrollment consisted of children with disabilities. Office of Head Start, Head Start Program Fact Sheet, <http://www.acf.hhs.gov/programs/ohs/about/fy2008.html> (last visited Oct. 12, 2008).

118. See Seligmann, *supra* note 2, at 279-80.

119. See *id.*

120. The IDEA provides for an award of "reasonable attorneys' fees" to prevailing parents. 20 U.S.C. § 1415(i)(3)(B)-(G) (2006). However, prevailing parents "may not recover the costs of experts or consultants." *Arlington Cent. Sch. Dist. Bd. of Educ. v. Murphy*, 548 U.S. 291, 300 (2006).

121. Seligmann, *supra* note 2, at 279-80.

122. Mark Fass, *NYC Loses Round Before Supreme Court on Tuition Payback Policy for Learning-Disabled Students*, N.Y.L.J., Oct. 11, 2007, at A1.

123. 358 F.3d 150 (2004).

tuition reimbursement.<sup>124</sup> However, in *Board of Education v. Tom F. ex rel. Gilbert F.*,<sup>125</sup> the United States Supreme Court affirmed this issue in favor of the parents.<sup>126</sup> Nevertheless, because this issue was affirmed by an equally divided Court,<sup>127</sup> it has no precedential value outside the Second Circuit, where the appeal was initially brought.<sup>128</sup> Five days after the *Tom F.* decision, the United States Supreme Court declined to settle this issue in *Board of Education v. Frank G. ex rel. Anthony G.*<sup>129</sup>

The most secure means of guaranteeing treatment coverage for children with autism is through legislatively mandated health insurance coverage. The tests used to interpret the LRE requirements and other portions of the IDEA differ by federal circuit.<sup>130</sup> The distinction between special educational and medical needs for children with autism is also a matter of significant debate.<sup>131</sup> Thus, specific mandatory coverage of behavioral therapy is a nondiscriminatory way to resolve the inconsistencies in IDEA coverage provided to children with autism.

### *B. The Implementation of Mental Health Parity in New Jersey*

Mental Health Parity is a movement that gained popular support beginning in the early 1990s, and aims to achieve equal coverage of mental health services and physical health services.<sup>132</sup>

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124. *Id.* at 160-61; *cf. id.* at 162 (“As the Supreme Court warned almost twenty years ago, ‘parents who unilaterally change their child’s placement . . . without the consent of state or local school officials, do so at their own financial risk.’” (quoting *Burlington v. Dep’t of Educ.*, 471 U.S. 359, 373-74 (1985))).

125. 128 S. Ct. 1 (2007), *aff’g by an equally divided court*, 193 F. Appx 26 (2d Cir. 2006) *vacating*, No. 01 Civ. 6845, 2005 U.S. Dist. LEXIS 49 (S.D.N.Y. Jan. 3, 2005).

126. *Id.*

127. *Id.* (“Justice Kennedy took no part in the decision of this case.”).

128. Fass, *supra* note 122. For a discussion of IDEA implementation in Connecticut, see Luretha R. McClendon, *The Representation of Children with Disabilities in Connecticut Under The Individuals with Disabilities Education Act*, 5 QUINNIPIAC HEALTH L.J. 85 (2001).

129. 128 S. Ct. 436 (2007), *denying cert. to* 459 F.3d 356 (2d Cir. 2006).

130. See discussion *supra* Part II.A.

131. See discussion *supra* Part I.D.

132. See Dana L. Kaplan, *Can Legislation Alone Solve America’s Mental Health Dilemma? Current State Legislative Schemes Cannot Achieve Mental Health Parity*, 8 QUINNIPIAC HEALTH L.J. 325, 328 (2005). Because more women suffer from mental illnesses, mental health parity is also a movement that stands for eliminating gender bias in healthcare. Vicki Lawrence MacDougall, *Medical Gender Bias and Managed Care*, 27 OKLA. CITY U. L. Rev. 781, 900 (2002) (citing LESLIE LAURENCE & BETH WEINHOUSE, OUTRAGEOUS PRACTICES: HOW GENDER BIAS THREATENS WOMEN’S HEALTH, at xv (1997)).

Mental health parity legislation is provided in a limited form on the federal level, and in varying degrees of strength in state statutes.<sup>133</sup>

### 1. Federal Mental Health Parity Statutes

The federal Mental Health Parity Act (MHPA) of 1996 was originally passed as a compromise piece of legislation, with the expectation that Congress would reach a more comprehensive agreement within six years.<sup>134</sup> Yet, despite several proposals for new legislation and amendments, Congress has merely extended the sunset provision of the 1996 Act each year since 2001.<sup>135</sup> Under the 1996 Act, insured individuals with autism would only be covered if they went to an “in-network provider,” and only if their plan offered benefits for a network of providers.<sup>136</sup> Furthermore, “[t]he Act is a ‘mandated if offered’ statute, which means that employers are not required to provide mental health benefits, but must comply with the legislation if they do offer some type of mental health benefits.”<sup>137</sup>

As of this writing, a long-anticipated mental health parity statute, the Paul Wellstone and Pete Domenici Mental Health and Addiction Equity Act of 2008,<sup>138</sup> has recently been passed under the Senate’s October 2008 economic stimulus relief bill.<sup>139</sup> The bill was proposed to achieve equal health insurance coverage between physical illnesses and mental health illnesses and addictions.<sup>140</sup> The original House bill, which proposed parity for all categories of mental health conditions listed in the DSM-IV and sought to significantly expand mental health coverage,<sup>141</sup> passed in the House of

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133. See Kaplan, *supra* note 132, at 344. An estimated 39 states have enacted mental health parity legislation. See *id.* at 344-45 for a summary of various examples of state legislation before and after the Federal MHPA. Connecticut, the birthplace of the parity movement, has one of the strongest parity laws in the country. *Id.* at 347-48. Due to strong lobbying on behalf of insurance company interests, New York is an example of a state without a mental parity law. *Id.* at 349-50.

134. *Id.* at 342-43.

135. *Id.* at 343 n.141 (“Public Law 107-116, § 701(a) extended the sunset to December 31, 2002. Public Law 107-313, § 2(a) extended the sunset to December 31, 2003. Public Law 108-197, § 2(a) extended the sunset to December 31, 2004. Public Law 108-311, § 302(c) extended the sunset to December 31, 2005.”).

136. John V. Jacobi, *Parity and Difference: The Value of Parity Legislation for the Seriously Mentally Ill*, 29 AM. J.L. & MED. 185, 192-93 (2003) (noting various exclusions and exemptions in the Federal Mental Health Parity Act).

137. Kaplan, *supra* note 132, at 343 n.139.

138. H.R. 1424, 110th Cong. § 512 (2008) (enacted).

139. Emergency Economic Stabilization Act of 2008, H.R. 1424, 110th Cong. (2008) (enacted).

140. Associated Press, *House Approves Mental Health Bill*, March 5, 2008, [http://wellstone.org/news/news\\_detail.aspx?itemID=11995&catID=6](http://wellstone.org/news/news_detail.aspx?itemID=11995&catID=6) (last visited October 29, 2008).

141. See *id.*

Representatives on March 5, 2008.<sup>142</sup> A similar version of the bill, the Mental Health Parity Act of 2007,<sup>143</sup> passed in the Senate in September 2007.<sup>144</sup> The House bill, which was broader than the Senate bill,<sup>145</sup> would have provided comprehensive parity for 87 million Americans covered by self-insured plans and another 31 million covered by insured plans that are subject to state regulation.<sup>146</sup> After negotiations between the House and the Senate, sponsors of the House bill abandoned the section requiring coverage of all conditions listed in the DSM-IV.<sup>147</sup> The enacted bill requires insurers to publish criteria for determining medical necessity and to provide reasons when denying claims for mental health services.<sup>148</sup> Furthermore, the bill will likely “encourage insurers to integrate coverage for mental health care with medical and surgical benefits.”<sup>149</sup> The Wellstone bill, as enacted, represents the culmination of an improved federal mental health parity act that has been in consideration for several years.<sup>150</sup>

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142. *Id.*

143. S. 558, 110th Cong. (2007).

144. *Id.*

145. Associated Press, *supra* note 140.

146. Mental Health America, House of Representatives Schedules Historic Vote on Mental Health Equity Legislation, March 5, 2008, <http://mentalhealthamerica.com/index.cfm?objectid=7F5E7CB9-1372-4D20-C8923C842B403AD9> (last visited Mar. 11, 2008).

147. Frederic J. Frommer, *Wellstone Son Launches Push on Mental Health Bill*, BOSTON.COM, July 9, 2008, [http://www.boston.com/news/local/rhode\\_island/articles/2008/07/09/wellstone\\_son\\_launches\\_push\\_on\\_mental\\_health\\_bill](http://www.boston.com/news/local/rhode_island/articles/2008/07/09/wellstone_son_launches_push_on_mental_health_bill) (noting that the Senate also made concessions during the negotiations, including expanded parity for out-of-network coverage).

148. See Robert Pear, *Bailout Provides More Mental Health Coverage*, N.Y. TIMES, Oct. 5, 2008, [http://www.nytimes.com/2008/10/06/washington/06mental.html?\\_r=1](http://www.nytimes.com/2008/10/06/washington/06mental.html?_r=1) (last visited Oct. 29, 2008).

149. *Id.*

150. Cf. Kaplan, *supra* note 132, at 343-44 (commenting that the 2003 version of the Wellstone Act would “provide all insured Americans with coverage comparable to the mental health coverage in the Federal Employees Health Benefit Plan, prohibit[] insurers from imposing treatment limitations or financial requirements on mental health services that differ from medical or surgical benefits, [and] lower[] the small business exception to 25 from 50.”). But cf. Jacobi, *supra* note 136, at 186 (“[P]arity legislation focuses on private insurance coverage. Since most Americans have private coverage, usually through their workplace, this focus is sensible. Many people with mental disabilities, however, and those most socially isolated, are unlikely to have access to private coverage.”).

## 2. New Jersey's Mental Health Parity Statutes

New Jersey's mental health parity statute,<sup>151</sup> like the federal MHPA, provides limited coverage for mental health services. New Jersey's statute provides parity in coverage only for "biologically-based mental illnesses"<sup>152</sup> (BBMI). Because autism is defined as a BBMI,<sup>153</sup> individuals with autism in New Jersey may have legal access to the same coverage for physical therapy, occupational therapy, and speech therapy as they would for any non-mental-health illness.<sup>154</sup> Behavioral therapy is notably absent from the above list, and "despite the BBMI mandate, claims for ABA do not appear to be routinely reimbursed by commercial carriers."<sup>155</sup>

New Jersey's BBMI statute contains other significant exclusions. It does not apply if the individual with autism is insured under a self-insured plan.<sup>156</sup> This may lead to considerable gaps in coverage, considering that "[o]ver 30% of firms offering insurance coverage in

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151. Act of May 13, 1999, ch. 1-8, 1999 N.J. Laws 106 (codified as amended at N.J. STAT. ANN. §§ 17:48-6v, 17:48A-7u, 17:48E-35.20, 17B:26-2.1s, 17B:27-46.1v, 17B:27A-7.5, 17B:27A-19.7 (West 2007)).

152. N.J. STAT. ANN. § 52:14-17.29d-e (West 2007).

153. *Id.* § 17:48-6v.

154. See *id.*; A-999 STUDY, *supra* note 30, at 5, 7. See NIMH REPORT, *supra* note 19, at 28-31, for a description of biological and genetic bases for autism spectrum disorders. Though autism's classification as a BBMI is certainly accurate and is beneficial to individuals with autism in New Jersey, the N.J. statute's restriction to "biologically-based" mental illnesses unfortunately excludes many conditions in the DSM-IV. For example, certain developmental disorders, post-traumatic stress disorder, and eating disorders are not covered by the N.J. statute. Kaplan, *supra* note 132, at 349 (citation omitted). And "most New Jersey children and adolescents are not covered under the present bill because they are often too young to be diagnosed with severe conditions." *Id.* (citation omitted); cf. Elizabeth S. Boison, Comment, *Mental Health Parity for Children and Adolescents: How Private Insurance Discrimination and ERISA Have Kept American Youth from Getting the Treatment They Need*, 13 AM. U. J. GENDER SOC. POL'Y & L. 187, 191 n.23 (2005) ("defining diagnosable psychiatric disorders to include anxiety, mood, disruptive, and substance abuse disorders" (citing U.S. PUB. HEALTH SERV., DEPT OF HEALTH AND HUMAN SERVS., REPORT OF THE SURGEON GENERAL'S CONFERENCE ON CHILDREN'S MENTAL HEALTH: A NATIONAL ACTION AGENDA 123 (2000))). However, some experts believe that certain DSM-IV definitions, such as Oppositional Defiant Disorder, should not be covered because they may be "so broad and malleable that nearly every juvenile may qualify as 'disordered' at some point, depending on the evaluator's personal values and beliefs." Dennis E. Cichon, *Developing a Mental Health Code For Minors*, 13 T.M. COOLEY L. REV. 529, 534 (1996).

155. A-999 STUDY, *supra* note 30, at 7.

156. See Kaplan, *supra* note 132, at 345 n.159 ("The Employee Retirement Income Security Act of 1974 (ERISA) bars states from regulating self-insured firms. Many large multistate corporations and some smaller corporations self-insure. A small employer may choose to self-insure to avoid the costly burden of complying with the prolific state mandates.").

the United States self-insure at least one offered health plan.”<sup>157</sup> In New Jersey, the self-insured health plan exception would also exclude 88% of all state and local employees.<sup>158</sup> This also leaves open the possibility that firms will self-insure to exempt themselves from compliance with the statute. For example, in Vermont, which also has a self-insured exclusion from its mental parity law, 8% of Vermont employees suffered because their firms switched from fully-insured to self-insured coverage.<sup>159</sup>

New Jersey’s mental health parity coverage is broken into two statutes, which creates another potential area of exclusion. One mental health parity statute governs private health insurance company policies, and the other regulates the State Health Benefits Program policies. For example, until 2007, there was a split between the interpretations of the New Jersey mental health parity statute concerning “non-restorative therapies.”<sup>160</sup>

### 3. Impact of Mental Health Parity

The fact that parity legislation exists will not in itself increase usage of mental health services. In two separate studies, researchers concluded that the existence of parity legislation neither had a measurable effect on the use of mental health services,<sup>161</sup> nor did it predict lower usage of mental health services compared to states that have not enacted legislation.<sup>162</sup> These results could mean either that parity does not increase usage rates, or that states with lower usage rates of mental health services are more likely to enact parity legislation due to lower opposition.<sup>163</sup> The lack of increase in usage rates could also be due to failure to adequately promote the increased access, which is a necessary step to implementing parity.

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157. *Id.*

158. *Id.* (citing *New Jersey Legislative Fiscal Estimate*, S. 208-86, 208th Leg., 2d Sess. (N.J. 1999)). Kaplan also notes that “[t]wo-thirds of employees in state, local, and tribal governments are enrolled in self-insured health plans.” Kaplan, *supra* note 132, at 345 n.159.

159. Kaplan, *supra* note 132, at 341 (citing SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., PUBL’N NO. (SMA) 03-3822, EFFECTS OF THE VERMONT MENTAL HEALTH AND SUBSTANCE ABUSE PARITY LAW 49 (2003), <http://mimh200.mimh.edu/PieDb/04988.pdf>).

160. See discussion *infra* Part II.E.

161. Kaplan, *supra* note 132, at 346 (citing Mari C. Kjorstad, *The Current and Future State of Mental Health Insurance Parity Legislation*, 27 PSYCHIATRIC REHAB. J. 34, 38 (2003)).

162. *Id.* (citing Roland Sturm & Rosalie Liccardo Pacula, *State Mental Health Parity Laws: Cause or Consequence of Differences in Use*, 18 HEALTH AFFAIRS 182, 189 (1999)).

163. *Id.*

### C. Medicaid

Medicaid is the largest children's health program in the country,<sup>164</sup> created to cover primarily low-income individuals and families.<sup>165</sup> In New Jersey, Medicaid covers healthcare costs for over 900,000 people,<sup>166</sup> including 24% of New Jersey's children.<sup>167</sup>

Medicaid requires states to provide coverage for "chronic diseases and congenital conditions" often unavailable through private insurance.<sup>168</sup> In contrast, private insurance typically limits coverage to services necessary to "restore normal functioning" following an "illness or injury," thereby excluding treatments for cerebral palsy and other developmental conditions.<sup>169</sup> The "restore normal functioning" clause further denies coverage for therapies "that improve quality of life, but do not correct the underlying condition, such as occupational or speech therapy for a child with autism."<sup>170</sup>

Despite Medicaid's successes, another significant flaw in Medicaid is that it only provides coverage for people with mental retardation, not for those with mental illness, who seek certain services. These critical services include community-supported living arrangements<sup>171</sup> and home and community-based services (HCBS) waivers.<sup>172</sup> Furthermore, states can receive federal funding for Medicaid even if they opt to not include services such as "rehabilitative care, personal care, and case management services."<sup>173</sup>

Unfortunately, the average middle-class family exceeds the income cap to qualify for Medicaid, even under state expanded

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164. AM. ACAD. OF PEDIATRICS, MEDICAID FACTS: NEW JERSEY (2007), <http://www.aap.org/advocacy/washing/elections/AAP%20New%20Jersey.pdf> [hereinafter NJ MEDICAID FACTS].

165. Centers for Medicare & Medicaid Services, Medicaid Program - General Information: Overview, [http://www.cms.hhs.gov/MedicaidGenInfo/01\\_Overview.asp](http://www.cms.hhs.gov/MedicaidGenInfo/01_Overview.asp) (last visited Oct. 12, 2008).

166. BRAIN INJURY ASS'N OF NEW JERSEY, INC., MEDICAID IN NEW JERSEY, <http://www.bianj.org/websites/bianj/images/pdfs/njmedicaidfactsheet.pdf>.

167. NJ MEDICAID FACTS, *supra*, note 164.

168. Sidney D. Watson, *Health Law Symposium: The View From the Bottom: Consumer-Directed Medicaid and Cost-Shifting to Patients*, 51 ST. LOUIS U. L.J. 403, 407 (2007).

169. *Id.* at 407-08; see discussion *infra* Part II.E.

170. Watson, *supra* note 168, at 407-08.

171. Jacobi, *supra* note 136, at 199 (citing 42 U.S.C. §§ 1396d(a)(23), 1396u(b)).

172. *Id.* ("HCBS waivers are of almost no use in preventing the unnecessary institutionalization of the non-mentally retarded mentally ill." (citations omitted)).

173. *Id.* at 200; see also Goodman, *supra* note 59, at 308 (arguing that state plans carve out very specific populations who are qualified to receive waivers for Medicaid services).



coverage programs.<sup>174</sup> Moreover, Medicaid has a particularly low reimbursement rate for pediatric services, paying “less than 30% of the Medicare value for over one-third of the most common pediatric services.”<sup>175</sup> This decreases pediatricians’ ability to participate in Medicaid and reduces available medical care for low-income children.

#### D. *The State Children’s Health Insurance Program*

The State Children’s Health Insurance Program (SCHIP), enacted in 1997, insures five million children of families who are ineligible for Medicaid, but who earn less than 200% of the poverty level.<sup>176</sup> President Bush vetoed a proposed bill that would expand funding by \$35 billion to \$60 billion over five years, which was estimated to increase SCHIP coverage to ten million children.<sup>177</sup> The House failed to override the veto in October,<sup>178</sup> and President Bush signed an extension of SCHIP to cover current enrollment levels through March 2009.<sup>179</sup>

The SCHIP is administered by the Centers for Medicare and Medicaid Services in a similar fashion as Medicaid, allowing states to set their own guidelines regarding eligibility and services.<sup>180</sup> States are required to provide mental healthcare under SCHIP, but are free to charge “higher premiums, deductibles, and co-payments for [mental health] services than for medical or surgical benefits.”<sup>181</sup> These higher costs may render state-funded mental healthcare too

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174. See Goodman, *supra* note 59, at 303 & n.16 (citing, *inter alia*, New York State Department of Health, Need Help Paying for Medical Care?, <http://www.health.state.ny.us/nysdoh/medicaid/mainmedicaid.htm> (last visited Aug. 2, 2008) (referencing chart of higher maximum monthly income levels for receiving New York Medicaid for children and pregnant women, ranging from \$867 to \$2967 for one person and eight person families, respectively)); Jacobi, *supra* note 136, at 200.

175. NJ MEDICAID FACTS, *supra* note 164; AMERICAN ACADEMY OF PEDIATRICS, MEDICAID REIMBURSEMENT SURVEY, 2004/05, NEW JERSEY, <http://www.aap.org/research/medreimpdf0405/nj.pdf> (comparing the reimbursement in 2004-2005 for a new toddler visit under New Jersey Medicaid (\$32.30) and Medicare (\$117.79 to \$124.03)).

176. State Children’s Health Insurance Program Summary, [http://www.cms.hhs.gov/MedicaidGenInfo/05\\_SCHIP%20Information.asp](http://www.cms.hhs.gov/MedicaidGenInfo/05_SCHIP%20Information.asp) (last visited Oct. 12, 2008) [hereinafter SCHIP Summary]; Boison, *supra* note 154, at 195 (citation omitted).

177. Sean Lenggell, *SCHIP Veto in House Upheld; Democrats Vow to Expand Plan*, WASHINGTON TIMES, Oct. 19, 2007, at A1.

178. *Id.*

179. Press Release, The White House, President Bush Signs H.R. 4839 and S. 2499 (Dec. 29, 2007), <http://www.whitehouse.gov/news/releases/2007/12/20071229-1.html>.

180. SCHIP Summary, *supra* note 176.

181. Boison, *supra* note 154, at 195 (citing Judy Greenwald, *Mental Health Parity Not as Costly as Feared*, BUS. OF INS., Jul. 31, 2000, at 1).

expensive for families otherwise eligible for SCHIP,<sup>182</sup> leading some critics to describe SCHIP as “woefully inadequate.”<sup>183</sup> This is especially unfortunate because children of families who earn less than 200% of the national poverty level experience the highest rate of emotional and behavioral disorders.<sup>184</sup>

### *E. Discussion of New Jersey Case Law*

Two recent New Jersey appellate cases serve to illustrate the difficulty of achieving mental health parity for children with autism in the case of “non-restorative therapies.”

#### 1. The *Micheletti* Case

In a recent New Jersey Supreme Court case, *Micheletti v. State Health Benefits Commission*, the Court clarified the interpretation of the New Jersey Mental Health Parity statute regarding non-restorative health benefits for children with autism.<sup>185</sup> This case involved Jake, the six-year-old child of a state employee, who was diagnosed with autism at the age of three.<sup>186</sup> Since Jake’s father was employed by the State of New Jersey, Jake was covered under the State Health Benefits Program (SHBP).<sup>187</sup> Following his diagnosis, Jake was evaluated at Hunterdon Medical Center, where it was determined that speech therapy and occupational therapy were “imperative and medically necessary to his treatment plan.”<sup>188</sup> However, the SHBP declined to provide the occupational therapy because it was not restorative in nature.<sup>189</sup>

New Jersey’s Mental Health Parity Act, enacted in 1999, requires “health insurers and health maintenance organizations, denoted as carriers under supervision of the Department of Banking

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182. *Id.*

183. Goodman, *supra* note 59, at 303 n.16 (citing MARY GILBERTI & RHODA SCHULZINGER, RELINQUISHING CUSTODY: THE TRAGIC RESULT OF FAILURE TO MEET CHILDREN’S MENTAL HEALTH NEEDS 7 (2000)).

184. Boison, *supra* note 154, at 195 n.50 (citation omitted).

185. 913 A.2d 842 (N.J. Super. Ct. App. Div. 2007), *enforced*, 934 A.2d 633 (N.J. 2007).

186. *Id.* at 845.

187. *Id.*

188. *Id.*

189. *Id.* The New Jersey Plus Members Handbook distributed by the SHBP stated: The plan does not cover services [for:]

Training in the activities of daily living [except for] services directly related to treatment of an illness or injury that resulted in a loss of a previously demonstrated ability to perform those activities[, and] promotion of development beyond any level of function previously demonstrated.

*Id.* at 845-46.

and Insurance (DOBI),” to provide coverage for BBMIs.<sup>190</sup> Because the SHBP is not a “carrier,” seven months later, a companion statute required the SHBP to provide the same coverage.<sup>191</sup> However, the State Health Benefits Commission, not the DOBI, has the requirement of administering the SHBP.<sup>192</sup>

In May 2003, the DOBI proposed the following rule regarding the Mental Health Parity Act: “[C]arriers may not apply exclusions to deny or limit benefits and services, including speech and occupational therapy, that are non-restorative to persons with BBMIs.”<sup>193</sup> The court recognized that all therapies for autism by definition go beyond mere restoration to promote healthy development of the child with autism.<sup>194</sup> It concluded that it would be against the spirit of the Mental Health Parity Act to deny coverage for children with autism based on “hidden or unfair reservation[s].”<sup>195</sup> In addition, the court noted that “restorative” is an ambiguous term.<sup>196</sup> The court therefore held that the SHBP’s refusal to provide therapy coverage violated the New Jersey Mental Health Parity statute, and ordered the SHBP to provide immediate coverage for speech and occupational therapy for the child.<sup>197</sup>

## 2. The *Markiewicz* Case

In *Markiewicz v. State Health Benefits Commission*,<sup>198</sup> decided on the same day as *Micheletti*,<sup>199</sup> a New Jersey appellate court applied

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190. *Id.* at 846.

191. *Id.*

192. *Id.* at 847.

193. *Id.* at 848. DOBI clarified this rule in May 2005 in response to an industry question: “[t]o allow carriers to exclude the primary mode of treatment for autism and pervasive development disorder (speech, occupational and physical therapy) would render the statutory directive meaningless and, therefore, it cannot be permitted. Interpretations that render a statute void are to be avoided.” *Id.*

194. *Id.* at 850-51.

195. *Id.* (“By undertaking that very consequential role in the financial security of public employees and their families, the State also undertakes to play fair with them.” (citing *Heaton v. State Health Benefits Comm’n*, 624 A.2d 69, 74 (N.J. Super. Ct. App. Div. 1993))).

196. *Id.* at 852 (“Every child is born with the potential to develop those skills necessary to life in society. Autistic children and other children afflicted with BBMIs are hindered from achieving that potential. The treatment for Jake can restore some of his potential. . . . [T]o some degree, he will share the skills and functions of more fortunate children, including his siblings.”); see also Mark Traynor, Comment, *Kunin v. Benefit Trust Life Insurance Co.: Protecting Employees Under ERISA by Construing Ambiguous Plan Terms Against the Insurer*, 77 MINN. L. REV. 1219 (arguing that ambiguous terms should be construed against the insurer).

197. *Micheletti*, 913 A.2d at 853.

198. 915 A.2d 553 (N.J. Super. Ct. App. Div. 2007).

199. *Micheletti*, 913 A.2d at 842. Both cases were decided on January 17, 2007. *Id.*

the same reasoning to require that the SHBP provide occupational and speech therapy for a child with “pervasive developmental disorder, not otherwise specified” (PDD-NOS).<sup>200</sup> This case was decided using identical reasoning to *Micheletti*, differing only in that it was applied to a child with PDD-NOS, and that it mandated additional coverage for physical therapy.<sup>201</sup>

Because the court “offer[ed] no opinion whether the exclusion at issue can be implemented legitimately in contexts other than those presented,”<sup>202</sup> it is uncertain whether such coverage would extend to ABA therapy. The New Jersey Mandated Health Benefits Advisory Commission (MHBAC), an expert review panel that advises the legislature on mandatory health benefits,<sup>203</sup> reported that it is possible to interpret the statute as requiring that “all services insured under the contract be covered to the same extent as any other disease; this would apply specifically to physical therapy, occupational therapy, speech therapy, and applied behavioral analysis and related therapies.”<sup>204</sup> In any event, “coverage by the SHBC may provide [families with their] ‘only source of protection from [such] catastrophic medical expenses.’”<sup>205</sup>

### 3. Implementation of the *Micheletti* and *Markiewicz* Holdings

Some New Jersey insurance plans have yet to reflect this requirement in their official policies. For example, Aetna’s Policy reads: “Most Aetna HMO-based plans cover short-term rehabilitation for non-chronic conditions and acute illnesses and injuries, subject to applicable terms and limitations. Rehabilitation for [Pervasive Developmental Disorders, including Autistic Disorder], a chronic condition, would be excluded under these plans.”<sup>206</sup> This sort of exclusion, if left unchanged, will continue to deny speech services and physical and occupational therapies to children with autism.

## III. THE CLASSIFICATION CONUNDRUM

Several loopholes exist between both the mandatory health insurance coverage of children with disabilities under the federal and

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200. *Markiewicz*, 915 A.2d at 555, 561.

201. *Id.* at 555.

202. *Id.* at 561 (agreeing with the DOBI’s interpretations of the New Jersey Mental Health Parity Law as set forth in N.J. ADMIN. CODE §11:4-57.1 to 57.4 (2008)).

203. New Jersey Mandated Health Benefits Advisory Commission, <http://www.state.nj.us/dobi/mandated.htm> (last visited Oct. 12, 2008).

204. A-999 STUDY, *supra* note 30, at 4-5.

205. *Markiewicz*, 915 A.2d at 561 (quoting *Heaton v. State Health Benefits Comm’n*, 624 A.2d 69, 74 (N.J. Super. Ct. App. Div. 1993)).

206. AETNA POLICY, *supra* note 60, at pt. I.O. n.2.

state mental health parity acts, Medicaid, and SCHIP, and the mandatory special education coverage of children with disabilities under the IDEA. Closing these loopholes, by providing specific mandatory coverage for medically necessary therapies, would greatly benefit these children.

IDEA primarily targets funding for special education, but not healthcare needs, for children with disabilities.<sup>207</sup> In general, a child with a mental disability may only receive services “that allow for an educational benefit.”<sup>208</sup> Because academic education is not the same as psychosocial development, one author argues that IDEA should promote social development in children with disabilities to a greater extent.<sup>209</sup> However, the responsibility to facilitate social development also falls upon healthcare carriers, who have an obligation to provide for the health and wellness of the children they insure. As noted above, insurance companies often refuse coverage for behavioral therapy evaluations and treatment for special needs.<sup>210</sup> Thus, the partially overlapping coverage between IDEA and health insurance creates a gray zone that often results in children being denied coverage by both their school districts and their insurance companies.

The IDEA narrowly defines a child with a disability, requiring not only that a child have one of the listed disabilities, but also that the child need special education.<sup>211</sup> If the child “only needs a related service,” he is not considered a child with a disability under the IDEA.<sup>212</sup> The IDEA provides for certain “medical services for

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207. See 20 U.S.C. § 1400(d)(1)(A) (2006).

208. Goodman, *supra* note 59, at 321 (“Although a school district is required to fund an entire residential program when placement is necessary for the child’s educational advancement, the district need only do so when the child’s IEP fails to provide appropriate educational advancement.”). A parent who decides unilaterally to place her child in a more effective placement will only be reimbursed if the school district caused the child to regress. See *Walczak v. Fla. Union Free Sch. Dist.*, 142 F.3d 119, 129 (2d Cir. 1998).

209. Kickert, *supra* note 101, at 741-42 (“Children with autism often do not imitate others, thus, they do not learn from imitation in the way that non-autistic children do. For children whose disabilities affects [sic] social learning, special education and related services directed toward social learning are thus an essential element of education.”). Analysts disagree on whether IDEA should be expanded to cover additional therapies for children with autism. Compare Oliver, *supra* note 89, at 787-90 (arguing for a standard to promote cost containment in special education) with Womack, *supra* note 30, at 192-93 (seeking to define and expand “the instances in which parents can implement Lovaas treatment for their autistic children under the IDEA”).

210. See discussion *supra* Parts I.D, II.E.

211. § 1401(3)(A) (2006).

212. McClendon, *supra* note 128, at 92.

diagnostic or evaluation purposes,”<sup>213</sup> as well as related “school health services,” which it defines as “health services that are designed to enable a child with a disability to receive FAPE as described in the child’s IEP.”<sup>214</sup> Under the regulations, school districts must “appropriately monitor and maintain medical devices that are needed to maintain the health and safety of the child, including breathing, nutrition, or operation of other bodily functions, while the child is transported to and from school or is at school.”<sup>215</sup>

School districts should not have the exclusive burden of covering autism treatments. Autism is a biologically-based medical illness<sup>216</sup> that demands its “fair share” of coverage by private and public health insurance.<sup>217</sup> Though schools should contribute to special education costs, there is a conflict of interest in requiring school districts to bear the majority of the burden for healthcare needs because school districts have a financial incentive to focus on special education.<sup>218</sup> Schools may have difficulty keeping up with the special education costs for children with autism, let alone their medical costs. During academic year 1999-2000, schools spent \$50.0 billion on special education, compared to only \$27.3 billion for regular education.<sup>219</sup>

In certain cases, schools have been required to cover evaluations, treatment, and outside placement services for children with autism. In *J.B. v. Killingly Board of Education*,<sup>220</sup> the court required the school district to pay for a “psychiatric evaluation . . . to specifically determine the type and the extent of psychological and counseling services” to enable a child to benefit from special education.<sup>221</sup> In *Mrs. B. v. Milford Board of Education*,<sup>222</sup> the court directed another district to place a child who suffered from emotional, psychological,

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213. 34 C.F.R. § 300.34(a) (2007).

214. *Id.* § 300.34(c)(13). Physical therapy and psychological services are also provided towards this end. *Id.* §§ 300.34(c)(9)-(10).

215. *Id.* § 300.34(b)(2)(ii).

216. N.J. STAT. ANN. § 52:14-17.29d (West 2007).

217. *Arguments for Private Insurance Coverage*, *supra* note 71, at 20 (“Across the nation, children with autism are routinely denied insurance benefits for treatment of their disorder. We believe that private insurance companies must contribute their fair share and partner in the financial burdens with these families.”).

218. See Oliver, *supra* note 89, at 781 (noting that the incentive is for “schools to place students in more restrictive environment[s]” because special education placement allows the district to qualify for supplemental IDEA funding).

219. U.S. DEP’T OF EDUC., TWENTY-FIFTH ANNUAL REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT 62 (2003), <http://www.ed.gov/about/reports/annual/osep/2003/index.html>.

220. 990 F. Supp. 57 (D. Conn. 1997).

221. *Id.* at 80.

222. 103 F.3d 1114 (2d Cir. 1997).

and educational disabilities into a private residential treatment facility because it was necessary for educational progress.<sup>223</sup>

Though school districts are able to apply for reimbursement from Medicaid, they often fail to do so, or submit improper or unverifiable claims for reimbursement.<sup>224</sup> School districts are sometimes unaware that they have the option of applying for Medicaid reimbursement for healthcare costs,<sup>225</sup> and should be encouraged to apply to increase available healthcare funding for children with special needs. However, even for school districts that properly apply for and receive Medicaid reimbursement, such funding is only partial at best. In particular, New Jersey school districts receive the lowest rate of Medicaid reimbursement dollars in the nation because the state retains 85% of the reimbursements.<sup>226</sup> And because state funds may support other educational services besides Medicaid-reimbursable services, school districts have little incentive to apply for Medicaid reimbursement.<sup>227</sup>

#### IV. PROPOSALS

##### A. *Mandate Health Insurance Coverage of Behavioral Therapies*

###### 1. New Jersey Assembly Bill 2238

New Jersey Assembly Bill 2238<sup>228</sup> (Assembly Bill 2238), currently before the 213th Legislature, is a direct and effective solution that promises to close the loopholes in autism therapy

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223. *Id.* at 1121.

224. See U.S. GEN. ACCOUNTING OFFICE, MEDICAID IN SCHOOLS: IMPROPER PAYMENT DEMAND IMPROVEMENTS IN HCFA OVERSIGHT 21-22 (2000), <http://www.gao.gov/archive/2000/h600069.pdf>; U.S. GEN. ACCOUNTING OFFICE, MEDICAID IN SCHOOLS: POOR OVERSIGHT AND IMPROPER PAYMENTS COMPROMISE POTENTIAL BENEFIT 1-3 (2000), <http://www.gao.gov/archive/2000/h600087t.pdf> [hereinafter GAO TESTIMONY].

225. Interview with Esther Canty-Barnes, Assoc. Clinical Professor of Law and Dir. of the Special Educ. Clinic, Rutgers Univ. School of Law, in Newark, N.J. (Nov. 15, 2007).

226. GAO TESTIMONY, *supra* note 224, at 15 tbl.3. “[A] school district may receive as much as \$100 in Minnesota to as little as \$7.50 in New Jersey in federal Medicaid reimbursement for every \$100 spent to pay for services and activities performed in support of Medicaid-eligible children.” *Id.* at 16.

227. *Id.* at 14. State officials justify the practice of retaining Medicaid reimbursements because states fund a portion of local education activities. *Id.* However, “such a practice severs the direct link between Medicaid payment and services delivered, increases the potential for the diversion of Medicaid funds to purposes other than those intended, and is inconsistent with the program’s fundamental tenet that federal dollars are provided to match state or local dollars to provide services to eligible individuals.” *Id.*

228. Gen. Assem. 2238, 213th Leg., 1st Sess. (N.J. 2008).

coverage. The bill mandates coverage under private health insurance plans and the State Health Benefits Program for “physical therapy; speech therapy; occupational therapy; and evidence-based behavioral interventions” for Pervasive Developmental Disorders, including Autistic Disorder.<sup>229</sup> According to the New Jersey Mandated Health Benefits Advisory Commission (MHBAC), which issued a report to the Legislature on the 2006 version of Assembly Bill 2238, the main effect of Assembly Bill 2238 would be to mandate coverage for behavioral therapies, since coverage for physical, speech, and occupational therapies are already covered by the New Jersey mental health parity statute.<sup>230</sup>

The MHBAC noted that adoption of this bill would increase access and utilization of the necessary behavioral therapy.<sup>231</sup> In addition, the MHBAC observed that “the number of licensed practitioners to provide ABA is limited. One positive effect of this mandate may be to draw additional people into the field, and to provide incentives for upgraded training and certification. Supervision and evaluation of techniques may also improve.”<sup>232</sup>

On February 2, 2008, the date of the bill’s introduction, the Assembly Health and Senior Services Committee “report[ed] favorably [on Assembly Bill 2238]”.<sup>233</sup> Yet, despite the potential benefits of mandated behavioral therapy for autism, the New Jersey Pension and Health Benefits Review Commission had recommended not to enact prior versions of this bill on December 10, 2004<sup>234</sup> and June 23, 2006.<sup>235</sup> The Commission reasoned in 2004 that “few states offer these types of services in their health benefits coverage.”<sup>236</sup> In 2006, perhaps in response to the increasing acceptance of mandated

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229. *Id.*; cf. Gen. Assem. 999, 212th Leg., 1st Sess. (N.J. 2006) (covering “behavioral interventions based on the principles of applied behavioral analysis and related structured behavioral programs” specifically).

230. A-999 STUDY, *supra* note 30, at 7 (commenting on Gen. Assem. 999, 212th Leg., 1st Sess. (N.J. 2006), the 2006 version of Assembly Bill 2238).

231. *Id.* at 9.

232. *Id.*

233. ASSEM. HEALTH AND SENIOR SERV. COMM., STATEMENT TO ASSEM. NO. 2238, Gen. Assem. 213-2238, 1st Sess., at 1 (N.J. 2008), [http://www.njleg.state.nj.us/2008/Bills/A2500/2238\\_S1.PDF](http://www.njleg.state.nj.us/2008/Bills/A2500/2238_S1.PDF) [hereinafter ASSEM. HEALTH STATEMENT].

234. PENSION & HEALTH BENEFITS REVIEW COMM’N, PENSION AND HEALTH BENEFITS REVIEW COMMISSION VOTE RESULTS DECEMBER 10, 2004, [http://www.state.nj.us/treasury/pensions/pension\\_hb\\_review\\_commission.htm](http://www.state.nj.us/treasury/pensions/pension_hb_review_commission.htm) (last visited Aug. 17, 2008) [hereinafter HEALTH BENEFITS COMM’N 2004].

235. PENSION & HEALTH BENEFITS REVIEW COMM’N, PENSION AND HEALTH BENEFITS REVIEW COMMISSION VOTE RESULTS JUNE 23, 2006, at 2, [http://www.njstatelib.org/digit/905/p417/Pension\\_Health\\_Review\\_062306.pdf](http://www.njstatelib.org/digit/905/p417/Pension_Health_Review_062306.pdf) [hereinafter HEALTH BENEFITS COMM’N 2006].

236. HEALTH BENEFITS COMM’N 2004, *supra* note 234.



autism therapy coverage,<sup>237</sup> the Commission gave a different explanation for their recommendation. They stated that “the bill does not address the overall issue of providing coverage for developmental disorders,” issues that must be “addressed during the next labor contract negotiations.”<sup>238</sup> The Commission reiterated that autism is covered under the New Jersey mental health parity statute,<sup>239</sup> but failed to address the key benefit to the bill, namely, specific coverage for behavioral therapies not currently provided for under the mental health parity statute.<sup>240</sup>

Finally, the commission cited economic concerns, stating that the New Jersey SHBP “does not cover developmental therapies.”<sup>241</sup> The Office of Legislative Services estimated that this bill would cost the SHBP \$36.7 million in fiscal year 2008 and \$40.3 million in 2009.<sup>242</sup> However, the Pension and Health Benefits Review Commission estimated in 2006 that the program would only increase costs by a modest \$15 million in 2007.<sup>243</sup>

One of the shortcomings of Assembly Bill 2238 is that it only provides coverage for private health insurance.<sup>244</sup> Though employer-sponsored welfare plans are the most common form of health coverage,<sup>245</sup> public sources are more likely to cover mental health expenditures.<sup>246</sup> However, this shortcoming is somewhat alleviated

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237. See discussion *infra* notes 248-51 and accompanying text.

238. HEALTH BENEFITS COMM’N 2006, *supra* note 235, at 2.

239. See *id.* (finding that Autism “treatment is currently provided at the same level as other medical conditions”).

240. A-999 STUDY, *supra* note 30, at 7.

241. HEALTH BENEFITS COMM’N 2006, *supra* note 235, at 2.

242. ASSEM. HEALTH STATEMENT, *supra* note 233, at 1-2. Cf. OFFICE OF LEGISLATIVE SERV., FISCAL NOTE, Gen. Assem. 210-2578, 2d Sess., at 1 (N.J. 2003) (containing the Office of Legislative Services 2003 estimate that the bill would cost the state \$28.9 million in Fiscal Year 2004 and \$34.9 million in 2006). The 2004 estimate assumed an estimated 1155 children would receive coverage under the State Health Benefits Program at \$25,000 for each child). *Id.*

243. See HEALTH BENEFITS COMM’N 2006, *supra* note 235, at 2.

244. See Gen. Assem. 2238, 213th Leg., 1st Sess. (N.J. 2008).

245. Boison, *supra* note 154, at 193-94 (citing Press Release, Employee Benefit Research Institute, EBRI Survey Examines Americans’ Confidence in the Health Care System (Sept. 9, 1999) (reporting that more two thirds of all Americans under age 65 have employer-sponsored health insurance)).

246. Jacobi, *supra* note 136, at 198 (citing SURGEON GENERAL’S REPORT, *supra* note 70, at 414) (explaining that public sources including Medicare and Medicaid account for about 53% of mental health expenditures, whereas private insurance accounts for only 27% of the total). See also Boison, *supra* note 154, at 194 n.44 (“giving statistics on the various types of public healthcare” (citing Alcohol, Drug Abuse, and Mental Health Administration Reorganization Act, 42 U.S.C. 290aa (2006))); *id.* at 194 n.45 (discussing the “Katie Beckett opinion” (quoting U.S. GEN. ACCOUNTING OFFICE, CHILD WELFARE & JUVENILE JUSTICE 4, 5 (2003))).

by New Jersey's FamilyCare program, which increases access to HMO insurance coverage for "uninsured children and certain low-income parents and guardians."<sup>247</sup>

Despite insurance industry opposition, mandated health benefits have been legislated in a number of cases in recent years as a means of providing otherwise excluded coverage of specific medical therapies.<sup>248</sup> In 2007, the Council for Affordable Health Insurance (CAHI), a research and advocacy association of insurance carriers, reported that ten states, including New Jersey, have mandates requiring coverage of autism therapies.<sup>249</sup> CAHI assessed the

247. See NJ FamilyCare Home Page, <http://www.njfamilycare.org/pages/whatitis.html> (last visited Oct. 12, 2008); see also NAT'L CTR. FOR CHILDREN IN POVERTY, COLUMBIA UNIVERSITY MAILMAN SCHOOL OF PUBLIC HEALTH, NEW JERSEY EARLY CHILDHOOD PROFILE 1 (Oct. 24, 2007), [http://www.nccp.org/profiles/pdf/profile\\_early\\_childhood\\_NJ.pdf](http://www.nccp.org/profiles/pdf/profile_early_childhood_NJ.pdf) ("New Jersey has been a leader among states in maintaining access to public health insurance for children in families earning up to 350 percent of the federal poverty level."). The report also notes that New Jersey's Abbott Preschool Program is a leader in funding state prekindergarten, providing "\$11,000 to serve any 3- or 4-year-old living in one of the 31 designated school districts." *Id.*

248. See generally Nicole M. Bellows et al., *State-Mandated Benefit Review Laws*, 41 HEALTH SERVICES RESEARCH 1104 (2006) (explaining the various state review laws and their criteria for evaluation and passage of mandated health benefits); Glen Cheng & William E. Halperin, *A Comparative Analysis of the Determinants and Impact of Mandated Health Benefit Review Laws and Commissions* (forthcoming 2009) (manuscript on file with author) (describing the overall effect that state review laws have had on the passage rates of different types of mandated health benefits); Miriam J. Laugesen et al., *A Comparative Analysis of Mandated Benefit Laws, 1949-2002*, 41 HEALTH SERVICES RESEARCH 1081, (2006) (describing the growth of mandated health benefits over the last five decades); Sara B. McMenamin et al., *Assessing the Public Health Impact of State Health Benefit Mandates*, 41 HEALTH SERVICES RESEARCH 1045 (2006) (analyzing the collective impact of mandated health benefits on public health); Thomas R. Oliver & Rachel Friedman Singer, *Health Services Research as a Source of Legislative Analysis and Input: The Role of the California Health Benefits Review Program*, 41 HEALTH SERVICES RESEARCH 1124 (2006) (reporting the results of California's university-based review program and explaining the effect of the political process on the passage of mandated health benefits).

249. VICTORIA CRAIG BUNCE ET AL., COUNCIL FOR AFFORDABLE HEALTH INSURANCE, HEALTH INSURANCE MANDATES IN THE STATES 2007 (2007), [http://www.cahi.org/cahi\\_contents/resources/pdf/MandatesInTheStates2007.pdf](http://www.cahi.org/cahi_contents/resources/pdf/MandatesInTheStates2007.pdf) [hereinafter CAHI STUDY] (listing the following ten states: Colorado, Delaware, Georgia, Iowa, Indiana, Kentucky, Maryland, New Jersey, New York, and Tennessee); see A-999 STUDY, *supra* note 30, at 3 n.1 (including California and Connecticut for a total of twelve states); cf. BLUE CROSS AND BLUE SHIELD ASSOCIATION, STATE LEGISLATIVE HEALTH CARE AND INSURANCE ISSUES (Dec. 2006) (on file with author). Rhode Island recently passed an "early intervention services" mandate, which covers such services as "speech and language therapy, occupational therapy, physical therapy, evaluation, management, nutrition, service plan development and review, nursing services, and assisted technology services from birth to three years of age." Victoria Craig Bunce, *Trends in State Mandated Benefits*, TRENDS & ENDS, Dec. 2005, [http://www.cahi.org/cahi\\_contents/resources/pdf/TrendsEndsDec2005.pdf](http://www.cahi.org/cahi_contents/resources/pdf/TrendsEndsDec2005.pdf).

incremental cost of state-mandated benefits for autism in these ten states as less than one percent.<sup>250</sup> In the coming years, as more mandated health benefits are passed both in New Jersey and in neighboring states,<sup>251</sup> the legislature should face diminishing industry resistance against Assembly Bill 2238.

The following subsections outline recent developments in federal and state proposals mandating coverage for autism therapies.

## 2. Recently Passed 2007 Acts

In 2007 alone, South Carolina,<sup>252</sup> Texas,<sup>253</sup> and Colorado<sup>254</sup> each passed laws mandating increased autism coverage. South Carolina just passed a comprehensive autism coverage act<sup>255</sup> that mandates health insurance coverage up to \$50,000 per year for behavioral therapy for individuals with autism under sixteen years of age.<sup>256</sup> Though the act was vetoed by the Governor of South Carolina on June 6, 2007, the veto was overridden by the Senate and the House the following day.<sup>257</sup>

Texas passed an autism coverage act<sup>258</sup> that mandates specific coverage, including evaluation services; applied behavioral analysis; speech, occupational, and physical therapy; and medication or nutritional supplements for children with autism ages three to five.<sup>259</sup>

Colorado passed an early intervention act<sup>260</sup> to facilitate the coordination of payment for early intervention services from federal,

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250. CAHI STUDY, *supra* note 249, at 3; *see also* AUTISM SPEAKS, SUBMISSION TO THE PENNSYLVANIA HEALTH CARE COST CONTAINMENT COUNCIL, ARGUMENTS IN SUPPORT OF PENNSYLVANIA HOUSE BILL 1150 at 15 (Oct. 4, 2007), [http://www.autismspeaks.org/docs/gr/HC4\\_testimony.pdf](http://www.autismspeaks.org/docs/gr/HC4_testimony.pdf) [hereinafter PENNSYLVANIA H.B. 1150 SUBMISSION].

251. *See, e.g.*, PENNSYLVANIA H.B. 1150 SUBMISSION, *supra* note 250, at 14-15. Autism Speaks, the nation's largest autism advocacy organization, recently announced its multi-state insurance legislation campaign. Press Release, Autism Speaks, Autism Speaks Announces Multi-State Insurance Legislation Campaign (Dec. 27, 2007), [http://www.autismspeaks.org/press/insurance\\_legislation\\_campaign.php](http://www.autismspeaks.org/press/insurance_legislation_campaign.php) [hereinafter Autism Speaks Press Release]. The campaign plans to expand Autism Speaks' ongoing advocacy work in Pennsylvania, focusing especially on Florida, California, and Michigan in 2008. *Id.*

252. S.C. CODE ANN. § 38-71-280 (2007).

253. TEX. INS. CODE ANN. §§ 1355.001-.015 (Vernon 2007).

254. COLO. REV. STAT. §§ 27-10.5-701 to -707 (2007).

255. S.C. CODE ANN. § 38-71-280 (2007).

256. *See id.*

257. *Id.*

258. TEX. INS. CODE ANN. §§ 1355.001-.015 (Vernon 2007).

259. *See id.*

260. COLO. REV. STAT. §§ 27-10.5-701 to -707 (2007).

state, local, and private sources.<sup>261</sup> The act streamlines the funding process and defines the responsibility of private health insurers in providing payment for early intervention services.<sup>262</sup> The purpose of the statute is to ensure that public and private funds are utilized in a manner such that children with developmental disabilities, including autism, have increased access to early intervention therapies.<sup>263</sup>

### 3. Minnesota's Recently Repealed Autism Statute

In 2001, Minnesota enacted a comprehensive autism coverage law.<sup>264</sup> Though this law would have provided significant coverage for home-based, "intensive early intervention behavior therapy,"<sup>265</sup> it was rescinded before it could demonstrate its benefit to society. Four months after its original effective date of January 1, 2003,<sup>266</sup> it was delayed until July 2007,<sup>267</sup> at which time it was repealed.<sup>268</sup> The statute would have provided comprehensive coverage, including ample caps on annual receivable hours of autism therapy.<sup>269</sup> Though this law was halted within months of becoming effective, it was an

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261. See *id.* § 27-10.5-701.

262. See *id.* § 27-10.5-703.

263. See *id.* § 27-10.5-702.

264. Law of June 30, 2001, ch. 9, sec. 31, 2001 Minn. Laws 9, *amended by* Law of June 5, 2003, ch. 14, sec. 33, 2003 Minn. Laws 14, *repealed by* Law of May 25, 2007, ch. 147, sec. 41, 2007 Minn. Laws 147 (codified as amended at MINN. STAT. § 256B.0625 (2007)) (repealing subdivisions 5a-5k, which would have provided "intensive early intervention behavior therapy services for children with autism spectrum disorders").

265. ERIC LARSSON, LOVAAS INSTITUTE MIDWEST, SUMMARY OF THE NEW AUTISM LAW IN MINNESOTA (2001), <http://rsaffran.tripod.com/MNautismlaw.doc> (last visited Aug. 22, 2008). The therapies were specifically required to be based on applied behavior analysis, consistently applied throughout the seven-day week, and capable of being delivered in the child's home. See Law of June 30, 2001, ch. 9, sec. 31, § 5e-5f, 2001 Minn. Laws 9 (repealed 2007).

266. Law of June 30, 2001, ch. 9, sec. 31, 2001 Minn. Laws 9 (repealed 2007).

267. Law of June 5, 2003, ch. 14, sec. 33, 2003 Minn. Laws 14 (repealed 2007); see MINN. DEP'T OF HUMAN SERVS., SUMMARY OF 2007 LAWS RELATED TO CHEMICAL & MENTAL HEALTH SERVS. 2 (2007), [http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs16\\_138674.pdf](http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs16_138674.pdf). Cf. Milt Freudenheim, *Battling Insurers Over Autism Treatment; Most Resist Big Payments, Challenging Therapists and Disorder's Nature*, N.Y. TIMES, Dec. 21, 2004, at A1 (stating that "some insurers have paid in varying degrees for autism therapy" under the Minnesota autism coverage law).

268. Law of May 25, 2007, ch. 147, sec. 41, 2007 Minn. Laws 147 (codified as amended at MINN. STAT. ANN. § 256B.0625, subdvs. 5a-5k).

269. See Law of June 30, 2001, ch. 9, sec. 31, § 5a, 2001 Minn. Laws 9 (repealed 2007) (stating that the statute would have enabled children with autism spectrum disorders, except Rett Syndrome, to receive up to 1800 billable hours per year of direct behavior therapist services, in addition to senior behavior therapist and clinical supervisor services).

ambitious attempt to provide children with autism with comprehensive behavioral therapy coverage.

#### 4. Pennsylvania's Autism Bill

In July 2007, the Pennsylvania House of Representatives passed House Bill 1150, the Autism Spectrum Disorders Coverage Bill.<sup>270</sup> The bill, which would allow children with autism to access applied behavior analysis therapy,<sup>271</sup> is awaiting the Pennsylvania Senate's vote.<sup>272</sup> The bill would require health insurance companies to reimburse up to \$36,000 per year for autism therapies.<sup>273</sup> This bill promises to be the most comprehensive piece of mandated autism coverage legislation in the country.<sup>274</sup>

#### 5. Federal Autism Bill

The Fairness in Autism Treatment Act of 2007,<sup>275</sup> a federal House bill, would amend the Employee Retirement Income Security Act of 1974 and the Internal Revenue Code of 1986 to require group health plans to provide coverage of autism therapy.<sup>276</sup> The coverage provided would include "therapeutic, respite, and rehabilitative care for participants or beneficiaries who have not attained twenty-two years of age."<sup>277</sup> The bill would work similarly to other health parity statutes, applying to any group health plan that provides both medical and surgical benefits.<sup>278</sup> Another measure of parity in the bill provides that health insurers "may not impose any annual or lifetime dollar limitation on benefits for pervasive developmental disorders unless such limitation applies to all medical and surgical benefits."<sup>279</sup>

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270. H.R. 1150, 191st Leg., Reg. Sess. (Pa. 2007); cf. Christina Gostonski, *Besides Advocacy of House Speaker, Agency Changes Planned*, 1 TRANSITIONMAP 19, Feb. 2007 (e-newsletter), [http://www.transitionmap.org/enews/enews19\\_full.htm](http://www.transitionmap.org/enews/enews19_full.htm) (reporting in early 2007 that House Speaker Dennis O'Brien was planning to introduce the bill).

271. PENNSYLVANIA H.B. 1150 SUBMISSION, *supra* note 250, at 10.

272. Liz Hayes, *Pa. Families Want Autism Covered by Health Plans*, PITTSBURGH TRIBUNE-REVIEW, Aug. 5, 2007, [http://www.pittsburghlive.com/x/pittsburghtrib/news/cityregion/s\\_520710.html](http://www.pittsburghlive.com/x/pittsburghtrib/news/cityregion/s_520710.html).

273. H.R. 1150, 191st Leg., Reg. Sess. (Pa. 2007).

274. Bob Wright, Address at the Introduction of the Pennsylvania Autism Bill (Apr. 18, 2007), [http://www.autismspeaks.org/press/pennsylvania\\_autism\\_bill.php](http://www.autismspeaks.org/press/pennsylvania_autism_bill.php).

275. H.R. 5028, 110th Cong. (2008).

276. *Id.*

277. *Id.* § 714(a).

278. *See id.*

279. *Id.* § 714(c)(1).

*B. Apply for Federal Medicaid Waivers*

The “Katie Beckett Waiver” Program,<sup>280</sup> named after the child who first received Medicaid funds to pay for the costs of in-home care, enables states to expand use of federal Medicaid funds to cover health care services in non-institutional settings such as the home and community.<sup>281</sup> This program has helped to increase the number of children who are able to receive autism treatment while residing in their homes and participating in their home communities.<sup>282</sup>

Maryland is an example of a state that has applied for and received a Medicaid waiver to cover services for children with autism.<sup>283</sup> This waiver allows children with autism up to twenty-one years of age to receive specific waiver services to support them in their homes and communities, including supported employment, residential habilitation, and “[i]ntensive [i]ndividual [s]upport [s]ervices.”<sup>284</sup>

A more recent example is an Arkansas act passed in 2007<sup>285</sup> that requires the state Medicaid program to seek a special waiver from the federal government to pay for autism therapies, including applied behavioral analysis.<sup>286</sup> The program promises to provide good coverage for children with autism, including one-on-one therapy for children ages three through ten at a limit of \$50,000 per child.<sup>287</sup>

*C. Give Tax Credits for Training and Educational Expenses for Autism*

The TEACH Act of 2007,<sup>288</sup> a federal House bill, would amend the Internal Revenue Code of 1986 to provide a refundable tax credit up to \$10,000 per year for “education and training expenses relating to autism spectrum disorders.”<sup>289</sup> The bill aims to expand the number

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280. Tax Equity and Fiscal Responsibility Act of 1982, Pub. L. No. 97-248, § 134, 96 Stat. 324, 375 (1982).

281. Donna H. Lehr & Jill Greene, *Educating Students with Complex Health Care Needs in Public Schools: The Intersection of Health Care, Education, and the Law*, 5 J. HEALTH CARE L. & POL’Y 68, 71 (2002) (citing 42 U.S.C. § 1396 (2006)).

282. See *id.* (citations omitted).

283. See MD. DEP’T OF HEALTH AND MENTAL HYGIENE, MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER FOR CHILDREN WITH AUTISM SPECTRUM DISORDER FACT SHEET (2007), <http://www.dhmh.state.md.us/mma/waiverprograms/pdf/AutismWaiverFactSheet92906.pdf>.

284. *Id.*

285. ARK. CODE ANN. § 20-77-124 (2008).

286. See *id.*; Nell Smith, *Autism Bill Offers Hope for More Treatments*, ARK. DEMOCRAT-GAZETTE, Mar. 18, 2007, at 19, 24.

287. ARK. CODE ANN. § 20-77-124(b)(1)-(2) (2008).

288. H.R. 2390, 110th Cong. (2007) (enacted).

289. *Id.*

of teachers proficient in handling the needs of children with autism.<sup>290</sup>

Other initiatives advocate for support of autism services on a global scale. A 2008 federal House bill<sup>291</sup> would provide support for activities of advocacy groups and training for health and education professionals working with children with autism in developing countries.<sup>292</sup>

#### *D. Create Special Task Forces*

Another 2007 federal House bill, the Empowering Children with Autism through Education Act of 2007,<sup>293</sup> would require the federal government to establish “a task force to identify and disseminate evidence-based educational strategies and promising best practices to improve the quality of learning for individuals with autism grades K-12.”<sup>294</sup> If passed, the bill would require the task force, composed of autism experts and individuals affected by autism, to submit a report detailing its findings within twenty-seven months.<sup>295</sup>

States have also proposed similar bills. Arkansas, one of the leaders in autism services research, recently introduced House Bill 2739, “[a]n act to create the legislative task force on autism.”<sup>296</sup> This task force would “examine how Arkansas responds to autism spectrum disorders,” determine the best treatment practices for autism, “recommend how to obtain more federal funds for treating autism,” and recommend changes to the Arkansas “law that would improve treatment of autism.”<sup>297</sup>

As noted, New Jersey has the highest prevalence of autism in the country.<sup>298</sup> Therefore, creation of a similar legislative task force in New Jersey would be particularly effective for achieving parity for children with autism.

#### *E. Increase Special Education Coverage under the IDEA*

In addition to mandating insurance coverage of autism therapies, the federal IDEA could be bolstered to improve access to education and behavioral therapy for children with autism.

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290. *Id.* § 2(b).

291. Global Autism Assistance Act of 2008, H.R. 5446, 110th Cong. (2008).

292. *Id.*

293. H.R. 2609, 110th Cong. (2007).

294. *Id.*

295. *Id.* §§ 5-6.

296. H.B. 2739, 86th Gen. Assem., Reg. Sess. (Ark. 2007).

297. *Id.*

298. See discussion *supra* note 2 and accompanying text.

## 1. Universal Preschool

IDEA provides a federal right to a "free appropriate public education" for three- to five-year-old preschool children with disabilities.<sup>299</sup> However, because most school districts do not have public preschools, children with disabilities are being denied preschool special education.<sup>300</sup> To correct this, advocates have proposed implementation of public preschool under the IDEA to benefit children with developmental disorders, including autism.<sup>301</sup> With increased special education coverage, children with autism will likely be able to receive additional education-related behavioral therapy through the IDEA.

## 2. Increase Federal Funding for IDEA up to Forty Percent

The IDEA Funding Coalition states: "Part B of IDEA originally authorized Congress to contribute up to forty percent of the national average per pupil expenditure (APPE) for each special education student."<sup>302</sup> Currently, the federal government only provides funding to cover no more than seventeen percent of IDEA's costs.<sup>303</sup> If federal funding were increased to the originally authorized forty percent, school districts would be able to cover many more therapies for children with autism.<sup>304</sup>

## CONCLUSION

Autism is a heartrending condition whose impact reaches beyond families to affect schools, workplaces, and communities.<sup>305</sup> The rapidly increasing incidence of autism in our society pleads for a timely response.<sup>306</sup> As Cardinal Trujillo stated to the United Nations General Assembly on Children, "[t]he true measure of a society's greatness is the extent to which it recognize[s] and protects human

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299. Mithaiwala, *supra* note 83, at 373.

300. *See id.* at 373-74 (explaining that because Congress explicitly applied the LRE requirements of the IDEA to preschool-aged children, "preschoolers with disabilities must be educated in a 'regular classroom' in a school that they would normally attend if not disabled. However, because most school districts do not have public preschools, 'regular' preschool classrooms are non-existent.").

301. *See id.* at 386-87.

302. IDEA FUNDING COALITION, *supra* note 15, at 3.

303. *Id.* at 2; Parrish & Wolman, *supra* note 16, at 203.

304. *See* IDEA FUNDING COALITION, *supra* note 15. *See generally* Parrish & Wolman, *supra* note 16.

305. AUTISM PREVALENCE REPORT, *supra* note 2, at 36 ("The impact of having a developmental disability is immense for the families affected and for the community services that provide intervention and support for these families.").

306. *Id.*



dignity and human rights and truly ensure[s] the well-being of all its members, especially the children.”<sup>307</sup>

New Jersey, because of its singularly high population of children with autism, is perhaps the state with greatest need in this area. New Jersey also has a unique opportunity to set an example of compassionate and effective care for its children with autism. Early intervention behavioral therapies, such as ABA, have consistently been shown to be effective in facilitating normal social and verbal development in children with autism. Unfortunately, such behavioral therapies are often refused coverage by insurance companies and inadequately covered under the IDEA. Consequently, there is a pressing need for specific mandatory coverage of behavioral therapy for these children.<sup>308</sup> Whether it is provided through bolstering IDEA provisions or through mandating health insurance coverage, early intervention is urgently needed. Assembly Bill 2238,<sup>309</sup> currently before the New Jersey Legislature, is an effective answer that will ensure the provision of appropriate early interventions for children with autism.

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307. Press Release, General Assembly, At UN Special Session, High Commissioner Calls for Human Rights Approach to Ensure Well-Being of Children, U.N. Doc. GA/10020 (Sept. 5, 2002), <http://www.un.org/News/Press/docs/2002/ga10020.doc.htm>.

308. The 2008 U.S. Presidential Election has brought into focus the need to provide adequate healthcare for every American, and autism has received prime coverage. *See, e.g.*, BarackObama.com, Plan for a Healthy America, <http://www.barackobama.com/issues/healthcare/> (last visited Oct. 12, 2008); JohnMcCain.com, Combating Autism in America, <http://www.johnmccain.com/content/?guid=24dc9c37-e739-4aa3-8a88-ebae650a2f11> (last visited Oct. 12, 2008); HillaryClinton.com, Hillary Clinton's Plan to Help Children And Families Affected by Autism, <http://www.hillaryclinton.com/news/release/view/?id=4342> (last visited Oct. 12, 2008).

309. Assem. B. 2238, 213th Leg. (N.J. 2008).

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