

NOTE

AUTISM, INSURANCE, AND THE IDEA: PROVIDING A COMPREHENSIVE LEGAL FRAMEWORK

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INTRODUCTION

Public awareness of and concern about the incidence of autism among children is growing. Autism is “now thought to be second only to mental retardation among the most common serious developmental disabilities in the United States.”¹ As public awareness has grown and autism rates have risen, the provision of therapeutic services for

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¹ Craig J. Newschaffer et al., *The Epidemiology of Autism Spectrum Disorders*, 28 ANN. REV. PUB. HEALTH 235, 236 (2007).

children with autism spectrum disorders (ASDs)² has become an extremely significant societal issue. As parents struggle to obtain the often costly therapies that they believe represent their child's only hope for a "normal" life, they have turned to both schools and insurance companies for support, with mixed results. In response to lobbying from parents and advocacy groups, many state legislatures have passed statutes requiring private insurance companies to cover the cost of applied behavioral analysis (ABA) for children with ASDs.³ Other parents have accessed ABA through their local schools via the Individuals with Disabilities Education Act (IDEA),⁴ which provides that all disabled children receive a publicly supported education suited to their needs. The struggle to obtain therapeutic services for autistic children can be complicated, long, and frustrating; both the insurance companies and the schools may have their own ideas about what constitutes appropriate therapy, and those ideas do not necessarily align. More importantly, however, the struggle simply to obtain services may overshadow the larger issue of what services truly promote the best interests of the child.

A conceptual divide begins to emerge in considering therapeutic services for children with ASDs. On the one hand, the schools provide such services, thereby giving them an educational quality. Insurance companies eagerly endorse this educational conception, as it would seemingly alleviate their responsibility to pay for such services. On the other hand is the medical conception, supporters of which posit that autism is a disease and that the therapeutic services are treatments. Between these two conceptions lies a plethora of questions about the interactions between autistic individuals and society as a whole.

Though it is perhaps not as well known, one can view autism and societal interaction through another conception—the neurodiversity conception. Autism, such advocates argue, is not a disorder but is sim-

² Autism spectrum disorders include "[a]utistic disorder (also called 'classic' autism)," "Asperger syndrome," and "Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism)." Nat'l Inst. of Child Health & Human Dev., Autism Spectrum Disorders (ASDs), <http://www.nichd.nih.gov/health/topics/asd.cfm> (last visited July 18, 2010).

³ See, e.g., TEX. INS. CODE ANN. § 1355.015 (Vernon 2009) (requiring a health benefit plan to cover those treatments, including ABA, that a child's primary physician recommends for a child between the age of two and six who is diagnosed with ASD); MD. CODE ANN., INS. § 15-835 (LexisNexis 2006) (requiring insurers to cover habilitative services for children under the age of nineteen who are diagnosed with ASD but excluding those habilitative services provided through early intervention or school services).

⁴ 20 U.S.C. §§ 1400–1501 (2006); Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, § 101(a)(1), 104 Stat. 1103, 1103.

ply an alternative wiring of the brain.⁵ To summarize the philosophy of the neurodiversity movement, Andrew Solomon quotes Jim Sinclair's seminal essay, *Don't Mourn For Us*:

It is not possible to separate the autism from the person. Therefore, when parents say, "I wish my child did not have autism," what they're really saying is, "I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead." Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.⁶

The implications of this philosophy are clear and significant: autistics (the preferred term amongst neurodiversity advocates for individuals with ASDs) are not broken, and they do not require fixing. To advocate otherwise is to advocate extermination.

Having identified these three ideological conceptions of autistic individuals and societal interaction, two major questions remain: from which of these perspectives should we approach deciding what services are appropriate for children with ASDs, and how does our choice of a perspective impact the manner in which we think such services should be provided? In the discussion that follows, I attempt to answer these questions. Throughout this discussion, I operate on two basic assumptions: First, I assume that behavioral therapy benefits at least some autistic people in some cases. Second, I assume that one primary goal of a legal framework in this context is to respect and enhance the dignity of the individual. One could, of course, disagree with either or both of these assumptions, but I believe they are necessary for a productive discussion. I also focus on the provision of ABA rather than other therapies. My choice here stems from the two following realities: ABA has become an exceptionally popular therapy for children with ASDs, and many state insurance provisions deal specifically with payments for this particular therapy.

Part I of this Note more fully introduces the conceptions of ASDs, behavioral therapy, and society. In analyzing each, I focus on underlying assumptions of each conception as well as potential objections to each of them. Part II discusses the current law surrounding ASDs and ABA, which will serve as a reference point for how the law might be improved. Part III explores, through the lens of disability legal stud-

⁵ See Andrew Solomon, *The Autism Rights Movement*, N.Y. MAG., June 2, 2008, at 30, 32, available at <http://nymag.com/news/features/47225/> ("[Neurodiversity] activists argue that autism is not an illness but an alternative way of being.")

⁶ *Id.* at 32 (quoting Jim Sinclair, *Don't Mourn for Us*, 1 OUR VOICE (Autism Network Int'l, Syracuse, N.Y.) 1993, available at http://www.autreat.com/dont_mourn.html).

ies, which of the conceptions most fully integrates the best interests of children with ASDs. After considering the benefits and shortcomings of each conception, I conclude that none is fully satisfactory. Accordingly, I propose a new conception that integrates the educational and the neurodiversity models; I call this model the disability legal studies model. Finally, I propose possible ways to change the law to reflect the insights of this model.

I

EXPANSION OF THE CONCEPTIONS

A. The Medical Conception

The notion of understanding ASDs and ABA as disease and cure, respectively, may be initially attractive, particularly if one is most interested in straightforward “solutions” to the “problem” of autism. The legal field has increasingly been moving toward incorporating scientific understanding—including the neurological advances that have been growing by leaps and bounds in recent decades⁷—into law. For judges and school boards, a straightforward and “scientific” framing may be simpler to apply. Also, a certain common sense appeal is inherent in being able to clearly state that ABA is a medical cure for autism, as it could prevent insurance companies from denying therapies that parents seek. Unsurprisingly, reality is not quite so neat.

Before evaluating the medical conception of ASDs and ABA, it is necessary to understand at a basic level the meanings of those terms, beginning with ASDs themselves. According to the National Institute of Mental Health, children with ASDs exhibit impairments in “1) social interaction, 2) verbal and nonverbal communication, and 3) repetitive behaviors or interests.”⁸ Furthermore, children with ASDs may exhibit “unusual responses to sensory experiences.”⁹ ASDs are referred to as spectrum disorders because individuals may exhibit highly variant levels of the associated traits.¹⁰ Prevalence-rate esti-

⁷ LAURENCE R. TANCREDI, *HARDWIRED BEHAVIOR: WHAT NEUROSCIENCE REVEALS ABOUT MORALITY* 1 (2005) (“Neuroscience advances during the past few decades have been nothing short of astounding.”).

⁸ NAT’L INST. OF MENTAL HEALTH, *AUTISM SPECTRUM DISORDERS: PERSVASIVE DEVELOPMENTAL DISORDERS* 5 (2008), <http://www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf>; *see also* 34 C.F.R. § 300.8(c)(1)(i) (2009) (“*Autism* means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.”).

⁹ NAT’L INST. OF MENTAL HEALTH, *supra* note 8, at 5.

¹⁰ *See id.* (“Each of these symptoms runs the gamut from mild to severe. They will present in each individual child differently.”). This Note will address these differences in the context of evaluating the shortcomings of various conceptions of ASDs and ABA.

mates for ASDs range from two to six per one thousand children,¹¹ and according to the Centers for Disease Control and Prevention (CDC), in 2007, 258,305 children ages six through twenty-one and 39,434 children ages three through five were “served under the ‘autism’ classification for special education services.”¹²

Within the last few decades, ABA has generally become the most favored therapy for children with ASDs. ABA is “the process of applying sometimes tentative principles of behavior to the improvement of specific behaviors, and simultaneously evaluating whether or not any changes noted are indeed attributable to the process of application—and if so, to what parts of that process.”¹³ Although the therapy was developed as early as the 1960s, Dr. O. Ivar Lovaas is widely credited with having pioneered the use of ABA to treat children with ASDs.¹⁴ In 1987, he published a paper showing significantly improved educational outcomes for children with ASDs who were treated with ABA as compared to untreated control groups.¹⁵ Critics alleged a number of flaws in this study,¹⁶ but it has since been replicated.¹⁷ Many consider ABA the most effective therapy for children with ASDs; the fact that parents are pushing to have insurance cover this therapy reflects this consideration.¹⁸

The scientific understanding of ASDs is, as virtually all those in the neuroscience field would recognize, convoluted and incomplete.¹⁹

¹¹ *Id.* at 3.

¹² Centers for Disease Control and Prevention, Autism Spectrum Disorders, <http://www.cdc.gov/ncbddd/autism/topics.html> (last visited July 18, 2010).

¹³ Donald M. Baer et al., *Some Current Dimensions of Applied Behavioral Analysis*, 1 J. APPLIED BEHAV. ANALYSIS 91, 91 (1968) (footnote omitted).

¹⁴ See, e.g., Susan Faja & Geraldine Dawson, *Early Intervention for Autism*, in HANDBOOK OF PRESCHOOL MENTAL HEALTH: DEVELOPMENT, DISORDERS, AND TREATMENT 388, 390, 393 (Joan L. Luby ed., 2006) (“The work of Lovaas and colleagues . . . was groundbreaking in its comprehensive exploration of intervention with autism.”).

¹⁵ O. Ivar Lovaas, *Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children*, 55 J. CONSULTING & CLINICAL PSYCHOL. 3, 3 (1987).

¹⁶ See, e.g., Faja & Dawson, *supra* note 14, at 393–94.

¹⁷ See Glen O. Sallows & Tamlynn D. Graupner, *Intensive Behavioral Treatment for Children with Autism: Four-Year Outcome and Predictors*, 110 AM. J. ON MENTAL RETARDATION 417, 419 (2005).

¹⁸ See Larry Abramson, *Family Wins Suit for Autistic Son’s Health Care*, NAT’L PUB. RADIO, Sept. 26, 2007, <http://www.npr.org/templates/story/story.php?storyId=14577821>.

¹⁹ Nat’l Inst. of Neurological Disorders & Stroke, Autism Fact Sheet, http://www.ninds.nih.gov/disorders/autism/detail_autism.htm [hereinafter Autism Fact Sheet] (last visited July 18, 2010):

Scientists aren’t certain about what causes ASD, but it’s likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that

As evidenced by the ongoing debate over the effects of vaccination on autism rates,²⁰ no consensus exists about the underlying causes of ASDs. Some believe that the recent explosion of autism rates is attributable to environmental factors; others believe that autism is a genetic phenomenon. Neurodiversity proponents believe that autism is genetic but object to attempts to cure it through genomic manipulation.²¹

The underlying uncertainties about the causes of autism pose a significant obstacle for proponents of the medical conception. First, it is exceedingly difficult for doctors to offer an accurate and conclusive diagnosis of autism. The American Academy of Pediatrics has articulated the difficulty, noting that

[e]arly diagnosis of ASD is challenging in the context of primary care visits, because there is no pathognomonic sign or laboratory test to detect it. Thus, the physician must make the diagnosis on the basis of the presence or absence of a constellation of symptoms. ASD is a phenomenologic rather than an etiologic disorder . . . , making the diagnosis more challenging. Pediatricians must rely on parent report, clinical judgment, and the ability to recognize criteria-based behaviors that define ASD.²²

This difficulty for doctors contributes to trouble in identifying appropriate treatment and obtaining insurance coverage thereafter. Insurance companies have seized upon the uncertainty surrounding autism and its treatment, refusing to cover ABA and other therapies (including occupational therapy) because they deem such treatments “experimental.”²³

The medical conception would solve such difficulties by requiring insurance companies to cover what the powerful advocacy group Autism Speaks describes as “the most effective forms of treatment

regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study.

²⁰ This controversy is, again, outside the scope of this Note.

²¹ See Solomon, *supra* note 5, at 33 (“There are in reality three sides in this debate: those who believe autism is caused by environmental toxins (especially vaccines) and should be cured by addressing those pollutants; those who believe it is genetic and should be addressed through the genome; and the neurodiverse, who believe that it is genetic and should be left alone. These camps are blatantly hostile to one another.”).

²² Comm. on Children with Disabilities, Am. Acad. of Pediatrics, *The Pediatrician’s Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children*, 107 PEDIATRICS 1221, 1221 (2001).

²³ See *Micheletti v. State Health Benefits Comm’n*, 913 A.2d 842, 845–46 (N.J. Super. Ct. App. Div. 2007); NPR Radio Broadcast, *supra* note 18 (“Many insurance companies say they will not cover ABA because they view it as experimental and unproven.”).

[with] . . . the best outcomes” for ASDs.²⁴ Despite what insurance companies may claim, advocates argue that these mandates would result in very little additional cost to policyholders.²⁵ As such, advocates see little downside and a significant upside to such mandates.

B. The Educational Conception

The educational conception can perhaps be seen as a more careful version of the medical conception. Its proponents do not quibble with the classification of autism as a disorder, nor do they claim that ameliorating the outward manifestations of autism is an illegitimate goal. Rather, they propose that because science, as of yet, has been unable to positively identify the concrete cause or causes of autism (not to mention the underlying mechanisms by which it affects its manifestations), it is premature to consider ABA a “cure.”²⁶ Instead, ABA should be viewed as a therapy that may help children achieve academically, like speech-language pathology and occupational therapy. Speech-language pathology is a particularly apt analogy for ABA because it is one of the many therapies that may be incorporated into an ABA program.²⁷

One concern that many have about ABA is its cost. ABA can be extremely expensive, thereby limiting the ability of some families to access the therapy.²⁸ Cost concerns may affect school districts as well. In 2002, public schools provided services for almost 120,000 children with ASDs.²⁹ This number represents a large increase from 1993, when public schools served fewer than 20,000 children with ASDs.³⁰

²⁴ Press Release, Autism Speaks, Autism Speaks Announces Multi-State Insurance Legislation Campaign (Dec. 27, 2007) (available at http://www.autismspeaks.org/press/insurance_legislation_campaign.php).

²⁵ AUTISM SPEAKS, ARGUMENTS IN SUPPORT OF PRIVATE INSURANCE COVERAGE OF AUTISM-RELATED SERVICES 15 (2007), http://www.autismspeaks.org/docs/arguments_for_private_insurance_coverage.pdf (noting that in a survey of ten states that have mandates for insurance coverage of behavioral therapy, the estimated cost increase was less than one percent).

²⁶ See Abramson, *supra* note 18 (“Pamela Greenberg of the Association for Behavioral Health and Wellness says there just is not enough data on the effectiveness of ABA therapy. ‘Yes, there are examples of where ABA has been very effective. And there are other examples of situations where it has been very harmful,’ Greenberg says.”).

²⁷ See Mark R. Hammond, *Applied Behavior Analysis in Speech-Language Therapy*, SCI. AUTISM TREATMENT (Ass’n for Sci. Autism Treatment, Crosswicks, N.J.), Spring 2000, at 5, 6, http://www.asatonline.org/forum/articles/speech-language_therapy.htm (noting that “there can be an almost symbiotic relationship between speech therapy and applied behavior analysis”).

²⁸ See Rachel Ratcliff Womack, *Autism and the Individuals with Disabilities Education Act: Are Autistic Children Receiving Appropriate Treatment in Our Schools?*, 34 TEX. TECH L. REV. 189, 191 (2002) (estimating the cost to be between \$12,000 and \$20,000 per year for the Lovaas ABA method).

²⁹ U.S. GOV’T ACCOUNTABILITY OFFICE, SPECIAL EDUCATION: CHILDREN WITH AUTISM 17 (2005).

³⁰ *Id.*

Providing services to children with ASDs may come with a stiff price tag: in 1999–2000, school districts spent over \$18,500 on each autistic pupil. By contrast, a regular-education pupil cost the school district around \$6,500.³¹ Thus, when discussing the optimal arrangement for the provision of ABA to children with ASDs, one must always keep in mind the cost of the therapy.

The issue of cost also becomes important when deciding if ABA falls within the coverage of the IDEA, which requires that participating states—currently all fifty—provide children with certain disabilities, including ASDs, a “free appropriate public education” (FAPE).³² As part of FAPE, school districts must provide for “related services,” which the IDEA defines as “transportation, and such developmental, corrective, and other supportive services . . . as may be required to assist a child with a disability to benefit from special education.”³³ Because the IDEA covers all children with recognized disabilities, its reach will necessarily be broader than insurance laws, which by definition only provide for those children who have insurance coverage.

As the IDEA becomes the preferred mechanism to cover the costs of therapies for children with ASDs, the educational conception necessarily implicates ABA. This proposal somewhat contradicts the notion of ABA as a medical treatment because the IDEA specifically excludes coverage for medical services (except to the extent that such services are necessary for diagnosis or evaluation).³⁴ However, the definition of “medical services” in the context of the IDEA is very narrow—the term refers only to those services “provided by a licensed physician.”³⁵ Because nobody, including proponents of the medical conception, argues that ABA needs to be performed by a licensed physician, the two conceptions are not necessarily mutually exclusive.

³¹ *Id.* at 27.

³² See 20 U.S.C. § 1401(9) (2006) (defining FAPE as “special education and related services that—(A) have been provided at public expense, under public supervision and direction, and without charge; (B) meet the standards of the State educational agency; (C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and (D) are provided in conformity with the individualized education program required under [20 U.S.C. § 1414(d)]”); see also *id.* § 1412(a)(1)(A) (including as one of the requirements for participating states that “[a] free appropriate public education is available to all children with disabilities residing in the State between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from school”). The IDEA first recognized autism as a covered disability in 1990. Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, § 101(a)(1), 104 Stat. 1103, 1103 (defining children with disabilities).

³³ 20 U.S.C. § 1401(26)(A).

³⁴ *Id.*

³⁵ 34 C.F.R. § 300.34(c)(5) (2009). This regulation encompasses psychiatric services but does not include psychological services. See *Darlene L. v. Ill. State Bd. of Educ.*, 568 F. Supp. 1340, 1344 (N.D. Ill. 1983).

The IDEA requires that “related services” be provided for children with disabilities if those services are “required to assist a child with a disability to benefit from special education.”³⁶ The IDEA specifically identifies a number of services that may be considered related services, including

speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, [and] counseling services, including rehabilitation counseling, orientation and mobility services.³⁷

Notably, behavioral therapy does not appear in this list. However, a number of cases exist in which an individualized education program (IEP)—the document that sets forth the program for an individual student’s FAPE³⁸—has included some form of behavioral therapy.³⁹

The educational conception, then, argues that schools should provide ABA to children with ASDs who require it to reap the benefits of the education to which they are entitled. This position is somewhat complicated, however, by the fact that the IDEA does not require that children with disabilities be provided with the services they need to achieve their maximum potential; instead, it ensures that disabled children be provided with a “basic floor of opportunity.”⁴⁰ Furthermore, states and school districts may consider economics in deciding what constitutes that floor. The Fourth Circuit has explained that “Congress intended the states to balance the competing interests of economic necessity, on the one hand, and the special needs of a handicapped child, on the other, when making education placement decisions.”⁴¹ A state, the court said, is not required to disregard costs in deciding what constitutes a FAPE: “Although . . . [the school board] should not make placement decisions on the basis of financial consid-

³⁶ 34 C.F.R. § 300.34(a).

³⁷ 20 U.S.C. § 1401(26)(A).

³⁸ See *id.* § 1414(d)(1)(A)(i) (describing the required content of an IEP).

³⁹ See, e.g., *County Sch. Bd. v. Z.P.*, 399 F.3d 298, 308–09 (4th Cir. 2005); *L.B. ex rel. K.B. v. Nebo Sch. Dist.*, 379 F.3d 966, 968 (10th Cir. 2004); *Wikel v. Birmingham Pub. Sch. Bd. of Educ.*, 360 F.3d 604, 606 (6th Cir. 2004) (discussing a Lovaas model of ABA).

⁴⁰ *Bd. of Educ. v. Rowley*, 458 U.S. 176, 200 (1982). This seminal Supreme Court case introduced the language “reasonably calculated to enable the child to receive educational benefits,” a test that lower courts have adopted to gauge whether a school district complies with the IDEA. See *id.* at 207; *infra* note 98 (citing lower-court cases applying the *Rowley* test).

⁴¹ *Barnett v. Fairfax County Sch. Bd.*, 927 F.2d 146, 154 (4th Cir. 1991).

erations alone, 'appropriate' does not mean the best possible education that a school could provide if given access to unlimited funds."⁴²

This struggle to weigh the costs and benefits of a given program for the disabled is not unique to the educational context. Now-Judge Robert Katzmann has touched on this issue in the context of transportation law and the disabled, noting that where an issue is cast as one of "rights," it takes the debate to a more sensitive place than a simple discussion of costs and benefits.⁴³ This observation certainly resonates in the educational context, where parents most assuredly view the issues as involving rights. The ability of school districts to perform cost-benefit analyses in determining what therapies to provide may then raise significant doubts as to whether the educational conception can, on its own, provide access to therapy for all children with ASDs who might reasonably benefit from ABA.

To further understand the meaning of the educational conception, it is necessary to ask what, precisely, is meant by "educational." This task is difficult because although education is often identified as a critical human right, it is not often defined. For example, the International Covenant on Economic, Social and Cultural Rights requires that signatories provide free education to their citizens, but it does not define education beyond requiring that

education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. . . . [E]ducation shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.⁴⁴

These are lofty and admirable goals, and they illustrate the important role that education can play in cultural understanding; the Covenant, however, explains neither *what* education is nor *how* it will achieve these goals.

The IDEA also utilizes the term "education" without offering a definition; the federal regulations relevant to the IDEA likewise provide no definition.⁴⁵ The regulations do, however, define "special education."⁴⁶ That definition is helpful in exploring what advocates of the educational conception may mean when they contemplate educational benefits. For example, special education is defined to include

⁴² *Id.*

⁴³ ROBERT A. KATZMANN, INSTITUTIONAL DISABILITY: THE SAGA OF TRANSPORTATION POLICY FOR THE DISABLED 74-75 (1986).

⁴⁴ International Covenant on Economic, Social and Cultural Rights, G.A. Res. 2200A (XXI), art. 13, U.N. Doc. A/6316 (Dec. 16, 1966).

⁴⁵ 34 C.F.R. §§ 300.4-.45 (2009).

⁴⁶ *Id.* § 300.39.

“[t]ravel training,” which is instruction that allows children with disabilities to “[d]evelop an awareness of the environment in which they live” and “[l]earn the skills necessary to move effectively and safely from place to place within that environment (e.g., in school, in the home, at work, and in the community).”⁴⁷

This definition suggests that educational benefits primarily seek to allow the disabled child to adapt to society. The regulations further illustrate this idea through the definition of physical education as the development of “(A) [p]hysical and motor fitness; (B) [f]undamental motor skills and patterns; and (C) [s]kills in aquatics, dance, and individual and group games and sports (including intramural and lifetime sports).”⁴⁸ Although this definition does not *explicitly* embrace societal norms, the norm-based focus becomes clearer when one considers that the regulations identify dance (presumably in the form of organized dance), games, and sports as equally important as “[f]undamental motor skills and patterns.”⁴⁹ The IDEA’s notion of education, then, is perhaps best understood as training that will best enable a child with disabilities to integrate into the dominant society.

C. The Neurodiversity Conception

The neurodiversity conception stands for the proposition that it is impossible to separate the individual from the autism; autism is simply an intrinsic and equally acceptable way of being. This idea is clearly incompatible with the medical conception of autism as a disease and ABA as a cure. Furthermore, even if ABA did “cure” autism, neurodiversity advocates would reject it because they would see it as displacing the original, autistic self. The educational conception, on the other hand, is perhaps less axiomatically incompatible with the neurodiversity conception because, although it views autism as an obstacle to be overcome, it at least does not suggest that autism can be cured.

The neurodiversity movement counts amongst its members both parents of autistic children and individuals who themselves have ASDs,⁵⁰ and it is an attractive movement in many ways. First, the movement offers hope in the present, not at some elusive point in the future when a “cure” can be found. Second, it offers an opportunity to listen to the voices of those who have ASDs—a group that other forms of autism advocacy often silences. There is arguably, however, a

⁴⁷ *Id.* § 300.39(b)(4).

⁴⁸ *Id.* § 300.39(b)(2)(i).

⁴⁹ *Id.* § 300.39(b)(2)(i)(B).

⁵⁰ See Solomon, *supra* note 5, at 33 (“The neurodiversity activists include both people on the spectrum and their parents; their opponents likewise include both groups, with a heavy concentration of parents.”).

downside to the movement. Although neurodiversity proponents claim to eschew labels such as high- and low-functioning autism,⁵¹ it is clear that only those who have the ability to communicate (be it through speech or some other form of aided communication, such as a computer) and organize are able to become neurodiversity advocates. Those who are more severely autistic do not have that opportunity, and this observation may lead some to question the ability of the neurodiversity movement to speak for those whom the movement purports to serve. As one neurodiversity advocate has observed, “When you know a person on the spectrum, you know *one* person on the spectrum.”⁵² Although neurodiversity advocates often utilize this expression in support of their position, it also cuts the other way; the fact that one person is on the spectrum may not qualify him or her to speak for all persons on the spectrum.

The neurodiversity conception is easier to articulate than to fully understand. Some in the autism advocacy community have harshly criticized this conception.⁵³ This level of distaste is hard to understand, although the simplest explanation may be that parents of severely autistic children, already faced with many difficulties, cling to the idea that a cure may exist that will ease the suffering they believe their children will experience. The hardships parents see in their children’s futures may sadden them, or the parents may be in something of a state of mourning for the expected parent–child relationship that they believe they will no longer experience.⁵⁴ Perhaps, then, parents who are experiencing profound grief over a lost relationship are hostile to the suggestion that the relationship is indeed lost forever.

Another possible reason for the resistance to the neurodiversity movement is that our society is in many ways based on norms, loosely defined as “rules of behavior that are enforced not by courts but by

⁵¹ See NPR Radio Broadcast: Autism Movement Seeks Acceptance, Not Cures (June 26, 2006) (transcript available at <http://www.npr.org/templates/transcript/transcript.php?storyId=5488463>) (quoting a neurodiversity advocate as saying “I don’t believe in functioning levels. High functioning and low and all of that crud, that is really mostly illusions in people’s heads.”).

⁵² Solomon, *supra* note 5, at 34 (emphasis added).

⁵³ *Id.* (“‘Please don’t write about them,’ Lenny Schafer, editor of the prominent Schafer Autism Report, adoptive father of a severely autistic child, and a vaccine activist, said. ‘It’s a handful of noisy people who get a lot of media attention but do not represent a broad swath of the autism community. Best for them to be ignored. They want to redefine autism as something nice that Einstein and Bill Gates had. They’re trivializing what autism really is. It’s like stealing money from the tin cup of a blind man when you say that it’s not an illness.’ . . . John Best, parent of a child with autism and author of the Hating Autism blog, puts it most harshly: ‘It’s time to put an end to celebrating having brain damage.’”).

⁵⁴ See Sinclair, *supra* note 6.

other forces.”⁵⁵ Society enforces these norms because those that do not follow them are subject to punishment from bystanders.⁵⁶ Some scholars argue that these norms are intended to promote efficient behaviors and are therefore generally positive.⁵⁷ Autistics, almost by definition, do not typically express a high level of conformity with social norms. For many people, this lack of social compliance goes against everything they have been socialized to believe is necessary for society to function.

Despite the hostility, if one embraces the neurodiversity conception, it becomes clear that the imposition of ABA significantly implicates civil rights. On a very broad level, civil rights are “the general category of basic rights needed for free and equal citizenship.”⁵⁸ These rights can be viewed through the prism of the right to be free from discrimination.⁵⁹ Proponents of the neurodiversity conception often vehemently oppose the notion that behavioral therapy is appropriate for any autistic individual, much less for *everyone* with ASDs.⁶⁰ This opposition is logical if one considers it discrimination to force individuals to conform to social norms that do not speak to their own needs. As I will discuss in Part II, this conformity is largely what the current law seeks to achieve.

II

THE CURRENT STATE OF THE LAW

This Part will begin by considering how the IDEA, as a representative statute of the educational conception, encompasses the provision of ABA for autistic children. It will assess both the statutory language of the IDEA and the courts’ interpretation of that language.

⁵⁵ Lynn A. Stout, *Social Norms and Other-Regarding Preferences*, in *NORMS AND THE LAW* 13, 28 (John N. Drobak ed., 2006) (providing examples of social norms, such as the understanding that one should wear shoes in an office or ask permission before smoking in another person’s house).

⁵⁶ *See id.* at 31.

⁵⁷ *Id.* at 30.

⁵⁸ Andrew Altman, *Civil Rights*, in *STANFORD ENCYCLOPEDIA OF PHILOSOPHY* § 1.1 (rev. ed. 2007), <http://plato.stanford.edu/entries/civil-rights/>.

⁵⁹ *See id.* § 3 (“In liberal democracies, civil rights claims are typically conceptualized in terms of the idea of discrimination.” (citation omitted)).

⁶⁰ *See, e.g.*, Andrew Fenton & Tim Krahn, *Autism, Neurodiversity and Equality Beyond the “Normal,”* J. ETHICS MENTAL HEALTH, Nov. 2007, at 1, 4 (“[I]t is not acceptable to expect that an autistic individual undergo behavioral therapy that teaches them to suppress various physical or verbal ticks. An important criterion for whether they undergo treatment is whether it is in their interests, understood as a recognizable interest from their perspective”); Solomon, *supra* note 5, at 108 (“Many neurodiversity people also take exception to ABA. Camille Clark, who blogs as the Autism Diva, told me that she objected to the treatment’s goal, to render the autistic child ‘indistinguishable from his peers.’ ABA, she says, ‘may make a very neurotic simulacrum of a normal kid who can pull off a normal act in some narrow situations, but there is no way to train a kid to be “normal” inside using dog/dolphin/pigeon training methods.’”).

It will then consider the coverage provided by state insurance statutes as representative of the medical conception.

A. ABA Is a Related Service Within the Meaning of the IDEA

The IDEA defines “related services” and mandates that a child’s special education include them.⁶¹ By comparing ABA to two of the explicitly identified related services, namely speech pathology and occupational therapy, one can see that ABA is similar enough that the IDEA ought to—and does—cover its use in appropriate cases.

ABA is built on the notion that, through repetition and careful training methods, therapists can train individuals with ASDs to either implement or eliminate selected behaviors.⁶² ABA must be carefully designed to meet the needs of the individual child receiving the therapy; this tailoring is inherent, as therapists target specific behaviors that they identify through personalized evaluation. ABA practitioners may use a variety of methods in implementing the therapy.

One common method used by practitioners is discrete trial training (DTT), “a method of instruction in which tasks are broken down into small subtasks, instruction is given on each individual subtask, and positive reinforcement is given for correct answers. DTT entails frequent repetition of drills set up in a programmed sequence.”⁶³ Another representative therapy consists of

employing brief, standard instructions and tasks requiring only visual attending (e.g., matching), using familiar materials . . . , prompting success (physically assisting him or her to place a ring on the pole if a demonstration was not sufficient), presenting only two or three trials at a time, and reinforcing each response immediately with powerful reinforcers⁶⁴

By considering these two example therapies, one can conclude that a representative ABA method involves multiple trials of simple tasks where the therapist positively reinforces a successful outcome and gives physical assistance, if necessary.

The methods used by speech pathologists and occupational therapists resemble those of ABA therapists. Speech pathologists utilize a variety of techniques depending on the particular outcome they seek. These outcomes may include “reduc[ing] overall speaking rate,” im-

⁶¹ See 20 U.S.C. § 1400(d)(1)(A) (2006); *id.* § 1401(26)(A).

⁶² See Baer et al., *supra* note 13, at 92 (discussing the seven features that are essential to ABA).

⁶³ *J.P. v. W. Clark Cmty. Sch.*, 230 F. Supp. 2d 910, 928 (S.D. Ind. 2002) (internal citations omitted). The court goes on, however, to note that some experts have reservations regarding the efficacy of the discrete trial method; these reservations may include the “concern that children trained solely by the discrete trial format tend not to generalize very well and tend not to retain their skills well.” *Id.* at 929.

⁶⁴ Sallows & Graupner, *supra* note 17, at 422.

proving “overall speech performance,” and focusing on interactions between those with speech disabilities and listeners.⁶⁵ Speech-language pathologists choose an appropriate goal for each client by consulting with the client and with individuals close to the client and then by identifying primary and secondary deficits.⁶⁶ After the pathologist identifies relevant deficits and chooses an appropriate goal, the pathologist might use any of the following techniques: multiple readings of word lists,⁶⁷ modeling particular ways of using the organs or artificial organs of language production,⁶⁸ and providing positive reinforcement for successful attempts at appropriate speech production.⁶⁹

Occupational therapists begin their assessments in a manner similar to speech-language pathologists: “An assessment . . . should always be led by the needs of the person rather than by the resources available. . . . Identification of the individual’s needs provides the foundation for proposing solutions.”⁷⁰ After identifying the needs of the individual client, an occupational therapist then considers, with the client, possible solutions to those particular problems.⁷¹ The occupational therapist then implements the chosen solutions. For example, where the client has trouble standing up, the occupational therapist might provide physical assistance in performing the motions.⁷² Verbal prompts and encouragement may also be part of an occupational therapy regimen.⁷³ The goal, therefore, of occupational therapy is to allow the client to perform the necessary activities of living with greater ease.

After looking at these three types of therapies—ABA, speech-language pathology, and occupational therapy—some key similarities emerge. First, each therapy focuses on the needs of the individual client, and each therapy is tailored to meet those particular needs.

⁶⁵ David R. Beukelman et al., *Outcomes Measurement in Motor Speech Disorders*, in *MEASURING OUTCOMES IN SPEECH-LANGUAGE PATHOLOGY* 334, 335–36 (Carol M. Frattali ed., 1998).

⁶⁶ Keith Landis et al., *THE SPEECH-LANGUAGE PATHOLOGY TREATMENT PLANNER* 3–4 (2004) (describing a six-step process to develop an effective treatment plan). “[S]peech-language pathologists must focus the treatment process on the most significant problems. . . . It is important to consider the opinions of clients (as appropriate, depending on the client’s age and mental status) and significant others to prioritize communicative issues and other related disabilities.” *Id.*

⁶⁷ *Id.* at 10–11.

⁶⁸ *Id.* at 23–24.

⁶⁹ *Id.* at 30.

⁷⁰ Cath Doman, *Management of the Environment*, in *OCCUPATIONAL THERAPY AND PHYSICAL DYSFUNCTION: PRINCIPLES, SKILLS AND PRACTICE* 168, 170 (Annie Turner et al. eds., 5th ed., Harcourt Publishers Ltd. 2002) (1981).

⁷¹ *See id.*

⁷² Liz Tipping, *Moving and Handling*, in *OCCUPATIONAL THERAPY AND PHYSICAL DYSFUNCTION: PRINCIPLES, SKILLS AND PRACTICE*, *supra* note 70, at 181, 181, 185–87 (noting, however, that “where possible, the overall aim should be for [the client’s] independence”).

⁷³ *See id.* at 181.

Second, positive reinforcement plays a role in each therapy. Third, the therapist performing each therapy may actively assist and model behavior for the client. Fourth, a trained therapist—not a medical doctor—performs each therapy. Fifth, and perhaps most importantly, each therapy is an intensive, one-on-one method to help a client develop appropriate and necessary skills. Children with autism may often benefit from speech-language pathology and occupational therapy as well as ABA.⁷⁴ The similarities between ABA and these two related services strongly suggest that ABA also should be explicitly included as a “related service” under the IDEA.⁷⁵

B. Court Interpretations of the IDEA and Its Relationship to ABA

A few courts have specifically dealt with cases involving the IDEA and ABA. These cases generally indicate that ABA can, in appropriate cases, be part of an individual FAPE. Examining the reasoning and discussion in these cases provides additional evidence that ABA should be considered a “related service” pursuant to the IDEA.⁷⁶ There are no Supreme Court cases on point; however, a number of circuit courts of appeals have addressed ABA in conjunction with the IDEA.

In *G v. Fort Bragg Dependent Schools*,⁷⁷ the Fourth Circuit dealt with the implementation of a FAPE and the development of an IEP. G was a child with autism for whom the school district first developed an IEP in 1994.⁷⁸ His parents became dissatisfied with his progress, and in 1996 they requested that the school district add Lovaas-style ABA to G’s IEP. When the school district refused to honor this request, G’s parents sought out private therapy.⁷⁹ In 1997, the school district developed an IEP that included all the aspects of the Lovaas method except for the participation of a Lovaas-certified consultant. The Fourth Circuit ultimately held that it could not, on the record before it, determine whether the 1997 IEP, which excluded the assistance of the Lovaas-certified consultant, would satisfy the relevant standard of a plan “‘reasonably calculated to provide educational benefit’ to G.”⁸⁰ Notably, however, the court did not suggest that the 1997 IEP improperly included the Lovaas method, nor did the school district explicitly

⁷⁴ See, e.g., Autism Speaks, Your Child’s Rights, <http://www.autismspeaks.org/rights/index.php> (last visited July 18, 2010) (listing ABA, speech pathology, and occupational therapy as interventions for children with autism).

⁷⁵ 34 C.F.R. § 300.34(a) (2009).

⁷⁶ *Id.*

⁷⁷ 343 F.3d 295 (4th Cir. 2003).

⁷⁸ *Id.* at 299.

⁷⁹ *Id.* at 300.

⁸⁰ *Id.* at 307–08.

dispute the necessity of its inclusion.⁸¹ The court also left open the possibility of G's parents being compensated for their expenditures on private ABA therapy.⁸² This case, therefore, indicates that for some autistic children, Lovaas-method ABA may be an acceptable—and perhaps critical—part of the IEP.

The Third Circuit also considered at least one IDEA case involving ABA therapy. In an unpublished decision, that court considered the award of attorneys' fees in a case that involved whether a school board could reduce a child's ABA therapy from twelve hours per week to six.⁸³ In this case, the court did not consider the permissible amount of ABA therapy provided because an administrative law judge already had determined that the school could not reduce the hours of ABA therapy.⁸⁴ The issue before the Third Circuit instead dealt with an award of attorneys' fees, which the IDEA provides may be available to prevailing parties.⁸⁵ Although this case is somewhat attenuated, it provides further evidence that the IDEA may implicitly require ABA for those children who would benefit from the therapy.

One particularly significant case arose in the Sixth Circuit. In *Deal v. Hamilton County Board of Education*,⁸⁶ the court held that a school district refusing even to *consider* providing ABA to an autistic student, when the school did not take into account his particular educational needs, constituted a procedural violation of the IDEA.⁸⁷ Zachary Deal was an autistic child whose parents had implemented ABA therapy in the home, completely outside the school context.⁸⁸ According to the court, “[a]t a May 24, 1999, IEP meeting, [Zachary's parents] requested . . . 43 hours per week of one-on-one ABA therapy and 5 hours per week of speech therapy. The IEP team determined that it could not document any regression Zachary would suffer . . . , so the School System declined [to offer services].”⁸⁹ The court went on to state:

The evidence reveals that the School System, and its representatives, had pre-decided not to offer Zachary intensive ABA services regardless of any evidence concerning Zachary's individual needs and the effectiveness of his private program. This predetermination amounted to a procedural violation of the IDEA. Because it effectively deprived Zachary's parents of meaningful participation in the

⁸¹ See *id.* at 306–08.

⁸² See *id.* at 308–09.

⁸³ A.S. v. Colts Neck Bd. of Educ., 190 F. App'x 140, 141 (3d Cir. 2006).

⁸⁴ See *id.* at 142.

⁸⁵ See 20 U.S.C. § 1415(i)(3)(B) (2006); A.S., 190 F. App'x at 142.

⁸⁶ 392 F.3d 840 (6th Cir. 2004).

⁸⁷ See *id.* at 857.

⁸⁸ *Id.* at 845.

⁸⁹ *Id.* at 846.

IEP process, the predetermination caused substantive harm and therefore deprived Zachary of a FAPE.⁹⁰

The concept of a prohibition on predetermination—that is, deciding a child’s placement based on factors other than that child’s individual needs—is important in the IDEA context. At least in part, the regulations that require a school district to base placement decisions on the child’s IEP form the basis for this prohibition on predetermination.⁹¹ For proponents of ABA, it is a helpful doctrine because, at least in the Sixth Circuit, school districts may not simply disregard ABA therapy as a matter of course.

A few other cases have arisen in which a child’s FAPE included ABA.⁹² Taken together, these cases seem to indicate that (1) school districts, in at least some cases, include ABA as part of a child’s FAPE; and (2) in cases where ABA is not included in a child’s FAPE, the judiciary has, on at least some occasions, required the school district to include it. This evidence strongly suggests that ABA is a “related service” under the IDEA.⁹³

C. Limitations on the IDEA’s Provision of Services to Children with ASDs

The IDEA, although it *sometimes* covers provision of ABA, does not offer a complete solution to the problem of accessing the therapy. The primary reason for this defect is that the IDEA does not require school districts to provide disabled children with the tools to achieve their maximum level of personal accomplishment. Instead, the IDEA simply requires that students be provided with enough to achieve a *minimum* level of accomplishment. The seminal Supreme Court case *Board of Education v. Rowley*⁹⁴ elucidated this proposition, and it remains controlling precedent. In *Rowley*, the Court elaborated on the standard for evaluating an IEP for compliance with the IDEA:

Insofar as a State is required to provide a handicapped child with a “free appropriate public education,” we hold that it satisfies this requirement by providing personalized instruction with sufficient support services to permit the child to benefit educationally from that instruction. . . . In addition, the IEP, and therefore the personalized instruction, should be formulated in accordance with the requirements of the Act and, if the child is being educated in the regular classrooms of the public education system, should be rea-

⁹⁰ *Id.* at 857.

⁹¹ 34 C.F.R. § 300.116(b)(2) (2009).

⁹² See, e.g., *County Sch. Bd. v. Z.P.*, 399 F.3d 298, 313–14 (4th Cir. 2005); *L.B. ex rel. K.B. v. Nebo Sch. Dist.*, 379 F.3d 966, 968 (10th Cir. 2004); *Wikol v. Birmingham Pub. Sch. Bd. of Educ.*, 360 F.3d 604, 606 (6th Cir. 2004).

⁹³ 34 C.F.R. § 300.34(a).

⁹⁴ 458 U.S. 176 (1982).

sonably calculated to enable the child to achieve passing marks and advance from grade to grade.⁹⁵

Rowley also introduced the phrase “basic floor of opportunity” as it applies to the IDEA.⁹⁶ In other words, this case establishes that school districts are only required to provide as much as is necessary for a child to *pass* but not as much as is necessary for a child to *excel*. The *Rowley* Court established the test for determining compliance with the IDEA:

[A] court’s inquiry in suits brought under § 1415(e)(2) is twofold. First, has the State complied with the procedures set forth in the Act? And second, is the individualized educational program developed through the Act’s procedures reasonably calculated to enable the child to receive educational benefits? If these requirements are met, the State has complied with the obligations imposed by Congress and the courts can require no more.⁹⁷

As a result, a number of lower courts have adopted the test for IDEA compliance that an IEP must be “reasonably calculated to enable the child to receive educational benefits.”⁹⁸

The IDEA is further unable to provide ABA access to all children who would benefit from it because some courts have held that school districts are entitled to take economic considerations into account when deciding what constitutes a FAPE.⁹⁹ This limitation on the IDEA is critical because it could provide a reason for school districts to refuse ABA access to children with ASDs.

D. State Insurance Statute Coverage

In this subpart, I will consider several representative state insurance statutes and their coverage relative to the IDEA. The three statutes illustrate the diverse approaches among states and the variations in the amount of coverage these states have required insurance companies to provide for ABA.

The first law I will consider is the Pennsylvania provision requiring insurance companies to provide for ABA.¹⁰⁰ This law provides, in pertinent part, that “[a] health insurance policy or government program . . . shall provide to covered individuals or recipients under twenty-one (21) years of age coverage for the diagnostic assessment of autism spectrum disorders and for the treatment of autism spectrum

⁹⁵ *Id.* at 203–04.

⁹⁶ *Id.* at 200.

⁹⁷ *Id.* at 206–07 (footnotes omitted).

⁹⁸ See, e.g., *D.F. ex rel. N.F. v. Ramapo Cent. Sch. Dist.*, 430 F.3d 595, 598 (2d Cir. 2005); *Petersen v. Hastings Pub. Sch.*, 31 F.3d 705, 707 (8th Cir. 1994).

⁹⁹ See *supra* notes 42–43 and accompanying text.

¹⁰⁰ 40 PA. CONS. STAT. ANN. § 764h (West Supp. 2009).

disorders.”¹⁰¹ The law additionally defines treatment of ASDs as including rehabilitative care, which the statute defines as “professional services and treatment programs, including applied behavioral analysis, provided by an autism service provider to produce socially significant improvements in human behavior or to prevent loss of attained skill or function.”¹⁰² A significant difference in this coverage and the coverage of the IDEA is immediately noticeable: the IDEA standard ensures a “basic floor of opportunity,”¹⁰³ while the Pennsylvania statute strives “to produce socially significant improvements in human behavior.”¹⁰⁴

Looking next to the Texas law, one finds a much less detailed statute. The Texas law simply provides that “[a]t a minimum, a health benefit plan must provide coverage . . . to an enrollee older than two years of age and younger than six years of age who is diagnosed with autism spectrum disorder” and mandates coverage of all generally recognized services prescribed therein.¹⁰⁵ The Texas law then specifically includes ABA as a generally recognized service.¹⁰⁶ This statute may actually provide less coverage than the IDEA, however, because it only requires coverage up to age six; the IDEA requires coverage throughout the entire school career. Comparison of the requisite levels of coverage is difficult because the Texas statute provides so little detail. Thus, at least one state statute does not necessarily improve upon the coverage available through the IDEA, but it remains to be seen whether interpretation of this statute may provide more coverage than appears on its face.

The South Carolina statute provides another example of ABA coverage. To begin, it does not explicitly state that ABA must be covered. However, it does state that “[a] health insurance plan . . . must provide coverage for the treatment of autism spectrum disorder” and limit coverage to “treatment that is prescribed by the insured’s treating medical doctor in accordance with a treatment plan.”¹⁰⁷ The statute further provides a maximum benefit of \$50,000 per year for behavioral therapy for the treatment of autism.¹⁰⁸ Overall, two aspects of this statute are notable. First, it requires coverage for seemingly anything that the autistic child’s doctor may prescribe; this coverage is undoubtedly more expansive than the IDEA, which only requires edu-

101 *Id.* § 764h(a).

102 *Id.* § 764h(f)(12).

103 *See* Bd. of Educ. v. Rowley, 458 U.S. 176, 200 (1982).

104 *See* 40 PA. CONS. STAT. ANN. § 764h(f)(12).

105 TEX. INS. CODE ANN. § 1355.015 (Vernon 2009).

106 *See id.* § 1355.015(c)(2).

107 S.C. CODE ANN. § 38-71-280(B) (Supp. 2009).

108 *See id.* § 38-71-280(E) (providing that the cap will be adjusted annually for inflation).

ationally beneficial services. Second, it provides a monetary ceiling on the behavioral therapy that must be provided to an autistic child. However, \$50,000 per year is a comparatively large cap and would cover the required therapy in almost all circumstances.¹⁰⁹ Thus, the South Carolina statute likely offers coverage in excess of that which the IDEA offers.

Having reviewed the state of the law, it is possible to draw a few conclusions. First, the IDEA, as it exists, provides a path for at least some autistic children to receive services such as ABA. However, this pathway contains significant limitations. Furthermore, it is clear from my previous exploration of the ideological underpinnings of the IDEA that the understanding of what constitutes special education limits the provision of services under this approach. Second, the state insurance statutes may provide greater coverage than the IDEA in some circumstances. This discrepancy suggests that such statutes may be a useful stopgap. Nevertheless, the problematic aspects of the medical conception suggest that this route is not ideal. Below, I will consider what might be a more suitable method of provision of services that, unlike the current state of the law, integrates the neurodiversity conception.

III

AN ALTERNATIVE PROPOSAL: INTEGRATING THE CONCEPTIONS

A. Whose Voices Are Heard? Whose Are Silenced?

I now come to the heart of this Note's critique of the three identified conceptions—examining how each conception privileges various groups over others and how each values the voices of persons with ASDs. By asking these questions, it is possible to then assess the appropriateness and desirability of each conception from a disability legal studies perspective and examine the relative shortcomings and strengths of each conception. I will analyze each conception through the lens of disability legal studies, a theoretical perspective that “investigates issues such as the social construction of disability, ableism[,] and the power structure that supports and enhances the privileged status and conditions of nondisabled persons in relation to disabled persons, the genealogy of social categories such as normalcy, and the politics of bodily variations.”¹¹⁰

I will begin by examining the medical conception, which is perhaps the simplest to understand in terms of privileging. It corresponds closely with what the disability community has labeled the

¹⁰⁹ See Womack, *supra* note 28 (explaining that the cost of educating autistic children ranges from \$12,000 to \$20,000 per year).

¹¹⁰ Sagit Mor, *Between Charity, Welfare, and Warfare: A Disability Legal Studies Analysis of Privilege and Neglect in Israeli Disability Policy*, 18 *YALE J.L. & HUMAN.* 63, 64 (2006).

medical model of disability. Deborah Kaplan explains the medical model as follows:

Under this model, the problems that are associated with disability are deemed to reside within the individual. In other words, if the individual is “cured” then these problems will not exist. Society has no underlying responsibility to make a “place” for persons with disabilities, since they live in an outsider role waiting to be cured.¹¹¹

This articulation of the medical model of disability clarifies that it privileges the abled (“healthy”) over the disabled (“sick”). The medical conception of ASDs and ABA clearly applies the medical model of disability. It posits that those with ASDs are sick and that ABA must cure them. As such, it privileges being “neurotypical” over being “neurodiverse.” A disability legal studies conception rejects this premise and argues that “disability is socially constructed and not an inherent, objective, or fixed trait that resides within the disabled person.”¹¹² From a disability legal studies perspective, the medical conception fails because it assumes that the “problem” of ASDs can be “fixed” by removing the disability, which proponents of the medical conception understand as a sickness located within the autistic individual. The medical conception thus “assumes that the individual is a problem that should be fixed, adapted, rehabilitated, and ‘mainstreamed’ to fit social norms.”¹¹³

Furthermore, the most prominent voices advocating the medical conception are those of autism advocacy groups, many of which are primarily comprised of parents or other relatives of autistic children.¹¹⁴ This point raises questions regarding what role parents should play in the autism community: Should parents’ voices be heard at all? If so, to what degree? The disabled community in general has suffered from allowing *disability* to be constructed by others; as Kaplan notes, this construction leads to a situation where conditions may be considered “major social disabilities” even though “they cause little or no functional or physical difficulty for the person who has them.”¹¹⁵ Moreover, as Sinclair noted, parents of autistic children often suffer severe grief.¹¹⁶ This emotional investment suggests that parents of children with ASDs may be ill equipped to fairly and functionally articulate a proper conception of ASDs and ABA. However, for individuals

¹¹¹ Deborah Kaplan, *The Definition of Disability: Perspective of the Disability Community*, 3 J. HEALTH CARE L. & POL’Y 352, 353 (2000) (footnotes omitted).

¹¹² Mor, *supra* note 110, at 69.

¹¹³ *Id.* at 70.

¹¹⁴ See Autism Speaks, Autism Speaks History, http://www.autismspeaks.org/about_us.php (last visited July 18, 2010) (noting that autism speaks was founded by the grandparents of an autistic child); Solomon, *supra* note 5, at 108–09.

¹¹⁵ Kaplan, *supra* note 111, at 357.

¹¹⁶ Sinclair, *supra* note 6.

with ASDs who are unable to communicate for themselves, who will speak for them if not their parents, other close relatives, or friends? As I will demonstrate, this particular criticism applies to all three of the previously articulated conceptions and is perhaps the hardest to address satisfactorily.

The medical conception relates closely to the state insurance laws discussed above because they explicitly posit ABA as a medical treatment for autism. For example, the South Carolina statute explicitly states that to qualify for coverage, a medical doctor must order ABA therapy.¹¹⁷ Thus, the criticisms articulated for the medical conception apply with equal force to the state insurance laws. Nevertheless, these laws do have a potential role in an acceptable model of understanding ASDs and ABA, which I explore below.

The educational conception, like the medical conception, falls short from a disability legal studies perspective. Its failure is not as egregious as the medical conception, though, because it can at least arguably be understood as providing autistic individuals with the tools they need to function in a particular society rather than as an attempt to “cure” ASDs. This discussion, however, implicates a second model of disability—the social model. The social model, which some disability legal studies scholars embrace, explains that “the many daily activities and basic pleasures that people with disabilities cannot enjoy are rooted not in their own limitations, but in the way society was designed—by the nondisabled and for the nondisabled. And it is that design that *socially* burdens people with disabilities—not their biological impairments.”¹¹⁸ In other words, it is precisely the problem that people with ASDs are expected to conform to a society that does not even contemplate their unique needs or desires. This problem obviously cannot be solved by providing them with the tools to adapt to a hostile society that is unsuitable to their very way of being.

What can be made of the fact that the IDEA provides behavioral therapy only to those autistic children whose educational achievement it would aid? From a disability legal studies perspective, this provision has both negative and positive aspects. It is positive because it attempts to distinguish between disabilities that truly affect an individual’s ability to function and those that do not. As disability legal studies scholars have noted, an acceptable construction of disability need not—and ought not—discount the actual impact that a disability has on the disabled person’s life.¹¹⁹ However, a problem remains because the proffered solution to such disabilities remains therapy that

¹¹⁷ S.C. CODE ANN. § 38-71-280(B) (Supp. 2009)

¹¹⁸ MOF, *supra* note 110, at 70. See generally CLAIRE H. LIACHOWITZ, *DISABILITY AS A SOCIAL CONSTRUCT: LEGISLATIVE ROOTS* (1988).

¹¹⁹ See Kaplan, *supra* note 111, at 355.

will allow the individual to hew more closely to societal norms. Furthermore, introducing this distinction may create an unfortunate power dynamic: if only some autistic children are afforded access to ABA, someone must decide who receives access and who does not. Almost certainly, the decision maker will not be the autistic individual or even that individual's parents.

The educational conception also silences the voices of the autistic in other ways. First, some of the obvious beneficiaries of the educational conception are insurance companies, which would be relieved of the burden of providing ABA. Insurance companies, as businesses operating within a capitalist system, have few incentives to seek the solutions that best benefit the affected individuals. Insurance companies do not even have the built-in incentive that parents and close relatives have to seek the best interests of the autistic individual, however flawed that incentive may appear in practice.

Second, the educational conception itself may silence the autistic individuals it seeks to help. For example, the IDEA provides that the IEP team—those responsible for developing the child's individualized education program—shall include the child's parents, teachers, a representative of the local educational agency, and "*whenever appropriate, the child with a disability.*"¹²⁰ One is left to wonder, when is it appropriate *not* to include a child in determining what would best serve his or her needs? Perhaps more importantly, who decides whether or not inclusion is "appropriate?" If the parents and the school district must decide, the problem of silencing the voices of the disabled arises again.

Finally, it is necessary to address the most serious failing of the educational conception—the inability to articulate a disability-friendly definition of education. The IDEA, which is the paradigmatic legislation for understanding the educational conception, regards education as little more than a tool for functioning within the dominant, able-bodied society. This goal of conformity is part of a larger problem with the role of education and schools in American society. As H. Svi Shapiro and David E. Purpel explain, the true

purposes of education can only be grasped if we view schools as cultural and political sites that give legitimacy to the way social relations and cultural values are patterned in this society. . . . [P]owerful social and ideological interests seek to integrate schools into the system of hierarchy, social differentiation, and commodified human relationships.¹²¹

¹²⁰ 20 U.S.C. § 1414(d)(1)(B)(vii) (2006) (emphasis added).

¹²¹ *Part I: Social Justice and Democracy: Unmet Promises*, in *CRITICAL SOCIAL ISSUES IN AMERICAN EDUCATION: DEMOCRACY AND MEANING IN A GLOBALIZING WORLD* 1, 5 (H. Svi Shapiro & David E. Purpel eds., 3d. ed. 2005).

In a way, the educational conception is unacceptable because society has an objectionable perception of education. In the final subpart of this Note, I will explore what might constitute a more acceptable notion of education.

The neurodiversity conception appears to solve some of the problems perceived in the medical and educational conceptions. First, the neurodiversity conception does not privilege nondisabled over disabled persons. Neurodiversity proponents want society to accept autistic persons as they are rather than fighting to make them “normal.”¹²² By arguing that it is not the responsibility of an autistic person to conform to societal norms, neurodiversity proponents mirror the arguments of the social model of disability. It is only because society has labeled the characteristic behaviors of ASDs “abnormal” that they are widely viewed as unacceptable. The problem, as neurodiversity proponents see it, is with society, not the autistic.

The neurodiversity movement also clearly values the voices of the autistic, giving them a space in which they can be heard. Indeed, one of the neurodiversity movement’s most trenchant criticisms of “mainstream” autism advocacy groups is that they do not speak to the needs of the autistic. As one neurodiversity advocate states, “The organizations with the best connections were founded by parents of people with autism, who aren’t going to have the same priorities as autistic people, especially if those parents’ idea of success is to make their kid the same as themselves.”¹²³ The neurodiversity conception, thus, clearly gives a voice to those whom the medical and educational conceptions silence.

The neurodiversity conception, however, is not without its own problems. As discussed previously, autistic people without the ability to communicate clearly cannot join the neurodiversity movement, no matter how much the proponents of that movement would love for them to speak. One mother of an autistic child articulated this problem to Solomon:

I’d like nothing more than for [my autistic daughter] to develop the kind of consciousness that would allow her to join the neurodiversity movement If she decides to communicate without speech, that will be her choice, and I would love for her to be capable of such choices. It’s my fantasy that someday my daughter will go to

¹²² See, e.g., Amy Harmon, *Neurodiversity Forever: The Disability Movement Turns to Brains*, N.Y. TIMES, May 9, 2004, at WK1 (“[T]hose who deviate from the shrinking subset of neurologically ‘normal’ want tolerance, not just of their diagnoses, but of their behavioral quirks. They say brain differences, like body differences, should be embraced, and argue for an acceptance of ‘neurodiversity.’”).

¹²³ Solomon, *supra* note 5, at 108.

her therapist to say what a terrible mother I was forcing her to do all this ABA. When that happens, I'll know I succeeded.¹²⁴

The ability to make meaningful decisions is not the only benefit that may result from treatment with behavioral therapy. Children with autism may engage in behaviors that are not just socially unacceptable but also pose real physical threats, both to themselves and others.¹²⁵ If ABA therapy can help to eliminate self-injurious behaviors,¹²⁶ is it fair to deny that to autistic individuals who, if they could communicate, might express a desire *not* to engage in those behaviors? It is notable, though, that Solomon interviewed at least one autistic individual who was more interested in a cure than in acceptance:

Jonathan Mitchell, an autistic who blogs against neurodiversity, says, "Most persons with an autism-spectrum disorder have never expressed their opinions on someone's blog and never will. The neurodiverse often reach a vulnerable audience, as many persons on the spectrum have low self-esteem. Neurodiversity provides a tempting escape valve."¹²⁷

Are the voices of people like Jonathan, or those who lack his ability to speak against neurodiversity, less valuable than those who speak for it?

There are downsides, then, with each of the three identified conceptions. Looking at these shortcomings, it becomes clear that a significant number are based on the fallacious concept of "autistic people" as a monolithic group and the general failure to fully appreciate the reason for the terminology "autism *spectrum* disorders." The medical conception fails to account for autistic individuals whose perceived shortcomings do not act as a burden. Despite the fact that many autistics lead happy, fulfilling lives with families and successful careers, the medical conception categorizes them as "sick" and tells them that they must be "cured." This treatment is an insult to human dignity and further illustrates why it is problematic to impose traditional measures of happiness and success onto individuals who may have completely different measures of such attributes.

The educational conception also fails to account for particular individuals with ASDs in two ways. First, if one accepts the notion that for certain individuals with autism, ABA may be useful in eliminating

¹²⁴ *Id.*

¹²⁵ See Autism Fact Sheet, *supra* note 19 ("Many children with [autism] engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-banging."). This is not a suggestion that autistic people are prone to violence towards others, which is a common stereotype employed against the autistic. It is merely an acknowledgement that an autistic person might, while engaging in self-injurious behaviors, inadvertently injure another person.

¹²⁶ See Solomon, *supra* note 5, at 108 (noting that since beginning ABA therapy, one child "no longer engages in self-injurious behavior and has few tantrums").

¹²⁷ *Id.*

self-injurious or otherwise truly objectionable behaviors, the educational conception alone cannot suffice. This conception is insufficient because, as the name suggests, it is concerned with educational benefits, which may not be what an autistic individual really needs (especially considering the narrow and somewhat suspect view of education that the federal regulations promote). The educational conception fails from the other side as well because it ignores the voices of the autistic in conceiving of appropriate educational benefits. One could argue, however, that the IDEA makes an effort to include these voices by stipulating that the disabled child could possibly be part of the IEP team.

B. The Disability Legal Studies Conception

As I have discussed, significant limitations are inherent in each of the medical, educational, and neurodiversity conceptions; one significant problem is that each conception silences the voices of some members of the autistic population. Any solution, then, must account for the fact that autism is a spectrum, and the needs of the various people on that spectrum will vary dramatically. The educational conception may provide the best starting point to articulate a disability legal studies conception of ASDs and ABA. Although the medical and neurodiversity conceptions are, in many ways, fundamentally incompatible, a conception rooted in the educational conception could appropriately bridge the gap between them.

A disability legal studies conception must be built on two key principles. First, it must be understood that disability is a social construct, created by a society not attuned to the needs of the disabled. Second, one must be careful not to erase the real “pain, suffering, dependency, and other bodily and functional limitations that impairments entail, or . . . the multifaceted relations between impairment and disability, and between the social and the biological experiences of impairment/disability.”¹²⁸ It is necessary to keep these critical insights in mind as we try to envision a viable and respectful relationship between the autistic population and ABA therapy.

The educational conception’s strength lies in its recognition of the fact that not all people with autism require the same therapy (if any at all). Both the medical and the neurodiversity conceptions falter in this regard—the former because it perceives behavioral therapy as appropriate for all individuals with autism and the latter because it perceives behavioral therapy as appropriate for no one. Even so, the biggest failure of the educational conception lies in its understanding of education as simply an application of the unfortunate notion that

¹²⁸ Mor, *supra* note 110, at 71.

the primary purpose of schools is indoctrination into the dominant societal structure. As Jane Roland Martin states, a person who receives such an education “will be provided with knowledge about others[] but will not be taught to care about their welfare or act kindly toward them. That person will be given some understanding of society[] but will not be taught to feel its injustices or even to be concerned over its fate.”¹²⁹ A disability legal studies conception based on the educational model must first explicate a more responsible understanding of education.

One alternate form of education is known as multicultural education. Christine E. Sleeter and Carl Grant describe multicultural education as an approach that “links race, language, culture, gender, disability, and, to a lesser extent, social class, working toward making the entire school celebrate human diversity and equal opportunity.”¹³⁰ Sleeter and Grant provide little description of how such an educational approach would be implemented; however, they do mention that “many special educators . . . argue that disabled students’ differences should be accepted and built on.”¹³¹ In the context of autism and ABA, then, the relevant inquiry is whether ABA can be a part of accepting and building on the differences that autistic students exhibit. This task is difficult without delving into the mechanics of autism, which is outside the scope of this Note; however, we can set forth a basic paradigm.

In sum, an education-based disability legal studies conception of the relationship between autistic individuals would resemble the following: an individualized evaluation would be made to determine the ways in which autism was negatively impacting the life and abilities of the autistic child. This evaluation would involve significant and decisive input from the autistic child. If the autistic child is unable to communicate, his or her relatives, friends, and teachers should be involved in the evaluation; each participant should focus on the needs of the autistic child and not his or her own personal preferences. The members of the evaluation team should be familiar with the arguments of the neurodiversity movement and should consider how best to amplify the autistic child’s inherent abilities.

After the evaluation team has determined what aspects of the autistic child’s disability truly impact his or her quality of life negatively, the team should ask whether ABA is an appropriate therapy for miti-

¹²⁹ Jane Roland Martin, *Becoming Educated: A Journey of Alienation or Integration?*, in CRITICAL SOCIAL ISSUES IN AMERICAN EDUCATION: DEMOCRACY AND MEANING IN A GLOBALIZING WORLD, *supra* note 121, at 197, 199.

¹³⁰ Christine E. Sleeter & Carl Grant, *Illusions of Progress: Business as Usual*, in CRITICAL SOCIAL ISSUES IN AMERICAN EDUCATION: DEMOCRACY AND MEANING IN A GLOBALIZING WORLD, *supra* note 121, at 89, 104.

¹³¹ *Id.* at 103.

gating those negative impacts. For example, if self-injurious behaviors are a concern, ABA might be appropriate. The autistic child should have as much input as possible in developing the therapeutic program and choosing the instructors. These instructors should be trained to build on the autistic child's strengths and to refrain from forcing the child to conform to social norms that do not benefit that particular child.

Finally, there should be periodic evaluations to determine whether the therapy is still necessary or helpful. This step is critical because it should prevent inappropriate uses of the therapy, such as imposition of unnecessary or unsuitable social conventions. As with all steps of the therapy process, the input of the autistic child should be the focus of this inquiry: does the child feel that the therapy is helping him or her to live more easily?

Insurance statutes that autism advocacy groups promote are potentially problematic within this new scheme because insurance is perhaps inextricably linked to the medical conception. Nevertheless, these statutes could be a useful stopgap measure when local schools are unable to bear the entire cost of therapy. As illustrated above, cases exist in which, because of the narrow understanding given to "education," children who might benefit from ABA are not given access to it; the state insurance statutes might also be useful in these situations. Eventually and ideally, however, such laws would become unnecessary as the understanding of education broadens and the best interests of the autistic child control the decision-making process.

This new conception would perhaps be expensive but likely no more so than the existing methods used under the IDEA. The biggest change from the status quo would be a shift in focus of the various inquiries, which would change from a society-based focus (can this child function in the dominant society?) to a child-based focus (is this child being helped to live in a way that is functional for him or her?). By changing the focus, the process can be retooled to introduce elements of human dignity and avoid imposing therapy on those who neither want nor need it.

CONCLUSION

Having identified three conceptions of autism and ABA (the medical conception, the educational conception, and the neurodiversity conception), this Note examined the shortcomings of each from the perspective of disability legal studies. Each conception failed in a variety of ways, but the overarching problem was that each conception silenced the voices of at least some members of the autistic community. On this front, the neurodiversity conception silenced the fewest

voices, but it ultimately failed because it ignored the voices of autistics who did not share its underlying goals.

I then articulated a new conception, which in many ways combines the educational and neurodiversity conceptions. This new conception starts from the disability legal studies notion that it is not the responsibility of a disabled person to conform him or herself to the dictates of a society that is hostile to his or her way of being. However, this understanding does not mean that we must pretend that a disability never negatively impacts a person's life or that accommodations are never necessary or helpful. Proceeding from this starting point, I articulated a conception that focuses, whenever possible, on the actual, expressed needs of the autistic individual. Where the autistic individual cannot provide meaningful input, necessity compels us to rely on the input of others. However, to make sure that this input is as valuable as possible, the other person's interactions with and knowledge of the autistic individual, as well as his or her understanding of the neurodiversity conception, should inform his or her input. By integrating these two perspectives, we are able to envision a legal framework that best serves the needs of the autistic individual and his or her community.