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## American Law, Global Norms: The Challenge of Enforcing Children with Disabilities' Right to a Free and Appropriate Education

**Abstract:** This essay critically analyzes the legal interpretation of the Supreme Court of the United States of what constitutes a “free and appropriate public education”<sup>1</sup> for children with disabilities. Through the lens of a case study of an American child with communication disabilities, this essay examines why US law should instead be informed by a social model of disability embraced by the Convention of the Rights of Persons with Disabilities (CRPD).<sup>2</sup> Related, the essay argues that American courts’ current interpretation of whether a student with disabilities has received an “appropriate education” relies too heavily on a medical model of disability, which requires a child first to demonstrate sufficient competence to merit related supports. Were the Supreme Court to adopt instead a social model of disability, however, it might advise public schools to presume the competence of students with disabilities. One implication of this essay is that even within the relatively robust legal framework for disability rights that presently exists in the US, judicial interpretation and enforcement of the law is too-often guided by judges’ ableist<sup>3</sup>

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1 Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2018). Domestically, disability law has continued to expand over the decades leading up to and following the passage of the Americans with Disabilities Act in 1990.

2 G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (May 3, 2008). Although the United States has not ratified the CRPD, as of October 2016, 168 countries had ratified the CRPD. Laurence R. Helfer, Professor of Law, Duke University, A Human Rights Approach to Implementing the Marrakesh VIP Treaty: Statement on behalf of the World Blind Union (Aug. 14, 2017). Thus, over 85% of UN member states are States Parties to the CRPD. See *Convention on the Rights of Persons with Disabilities (CRPD)*, Dep’t of Econ. and Soc. Affairs, Div. For Inclusive Soc. Dev., <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> (access 25.05.2018).

3 For purposes of this Essay, Thomas Hehir’s definition of ableism applies. Hehir defines ableism as “the devaluation of disability” that “results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell

assumptions. For CRPD States Parties, the implication of this argument is that members of the judiciary should be trained not only in existing legal standards, but also in disability history and theory that can guide the interpretation of the legal standards.

This essay critically analyzes the legal interpretation of the Supreme Court of the United States of what constitutes a “free and appropriate public education”<sup>4</sup> for children with disabilities. Through the lens of a case study of an American child with communication disabilities, the essay examines why US law should instead be informed by a social model of disability embraced by the Convention of the Rights of Persons with Disabilities (CRPD).<sup>5</sup> Related, the essay argues that American courts’ current interpretation of whether a student with disabilities has received an “appropriate education” relies too heavily on a medical model of disability, which requires a child first to demonstrate sufficient competence to merit related supports. Were the Supreme Court to adopt instead a social model of disability, however, it might advise public schools to presume the competence of students with disabilities. One implication of this essay is that even within the relatively robust legal framework for disability rights that presently exists in the US, judicial interpretation and enforcement of the law is too-often guided by judges’ ableist<sup>6</sup> assumptions. For CRPD States Parties, the implication of this argument is that members of the judiciary should be trained not only in existing legal standards, but also in disability history and theory that can guide the interpretation of the legal standards.

This brief essay proceeds in five parts. The first part sets forth a case study of a young American child’s attempts to secure an education despite his communication and physical disabilities. The second part sketches the legal framework, defining the standard for a “free and appropriate public education” in the United States.<sup>7</sup> The third part elaborates the inherently illogical inconsistencies embedded in the current judicial standard in part by focusing on the case of pre-literate children with significant communication disabilities. The fourth part argues that a social model of disability would invite schools to presume the competence of students with disabilities and offer them related supports. The fifth part unpacks an implication of this case study for States Parties to the CRPD.

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7 20 U.S.C. §§ 1400, 1401(9) (2018).

Ensuring access to a quality education for children with disabilities matters. For the 15% of the world's population with disabilities,<sup>8</sup> the issue implicates nothing less than the core of pluralist democracies' claim to legally accommodate and realize the needs, preferences and rights of diverse individuals.

**Keywords:** children with disabilities, CRPD, education

## 1. Graham, an American Child with Disabilities

Four-year old Graham is a social, happy, loving American child. Graham requires assistive technology ("AT") in order to speak using alternative communication ("AAC").<sup>9</sup> Examining Graham's brain scans at birth, neurologists predicted that Graham would have at least an average, if not better, IQ. The nerve damage that Graham sustained at birth, however, prevents him from moving his mouth to speak, and requires him to receive his nutrition through a small port directly into his belly. He is a power wheelchair user. At age four, youth, inexperience, and illiteracy are also real limitations for Graham, as they are for any four-year old. In terms of inexperience, however, even after the best efforts of his family to offer him stimulation, he has likely experienced 1/1000<sup>th</sup> of the physical stimulation of a typically developing child as he begins his pre-school experience.

After his family's significant exertions,<sup>10</sup> Graham's "individualized education plan"<sup>11</sup> for his public education system includes limited AT supports. Luckily for

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8 World Health Org., Summary Report on Disability 7 (2011), [http://apps.who.int/iris/bitstream/handle/10665/70670/WHO\\_NMH\\_VIP\\_11.01\\_eng.pdf;jsessionid=07B144A83058FD47F3830EE1C47B7802?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/70670/WHO_NMH_VIP_11.01_eng.pdf;jsessionid=07B144A83058FD47F3830EE1C47B7802?sequence=1).

9 Augmentative and alternative communication" is "an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language." *Augmentative and Alternative Communication*, Wikipedia, [https://en.wikipedia.org/wiki/Augmentative\\_and\\_alternative\\_communication](https://en.wikipedia.org/wiki/Augmentative_and_alternative_communication) (last visited May 20, 2018); see e.g. *Augmentative and Alternative Communication* (AAC), Am. Speech-Language-Hearing Ass'n, <https://www.asha.org/public/speech/disorders/AAC/> (access 25.05.2018).

10 Graham's Special Education Director (SPED) protests including AT services in his individualized education plan. Although AT is a federally mandated service, the SPED tells Graham's mother and father that the District does not provide AT supports for children in preschool. Indeed, like many districts, the District does not employ an AT provider on a full-time basis, the SPED says, and she further claims she cannot locate one. Graham's family searches for a speech-trained, AT/AAC provider in the broader community, and presents this professional to the District as a candidate to provide Graham's necessary supports. After much bureaucracy, the SPED begrudgingly agrees to secure the necessary administrative approval to allow Graham's supports for his first year of preschool.

11 In 2013-14, 13.5% of students had IEPs. Laura McKenna, *How a New Supreme Court Ruling Could Affect Special Education*, The Atlantic (Mar. 23, 2017), <https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/> (access 25.05.2018).

Graham, AT is a federally-mandated service under the IDEA.<sup>12</sup> Yet at the conclusion of Graham's first year of preschool, when Graham is five, the School District attempts to withdraw all of Graham's AT services. The school district attempts to withdraw these supports despite the fact that Graham's "mean length of utterance" is woefully behind his peers, he has only a handful of vocabulary words available in his device, and his grammar is far from age-appropriate. The Special Ed Director argues that a "free and appropriate public education" (FAPE) only requires Graham to be presented with "yes/no" questions that he can answer, not to have a programmed device and be taught to use it to speak. After a long battle that year, the District reduces his previous 60 hours of AT services by ten valuable hours to 50.

The next year, Graham's AT provider, along with his school's educational team,<sup>13</sup> recommends to the District that Graham's supports remain steady at 50 hours a year. As Graham prepares to head to elementary school, Graham's mean length of utterance is falling even further behind his peers with each passing year. Although the team notes many ways that Graham is behind his peers socially and in his communication,<sup>14</sup> and the team knows that in elementary school Graham's curricular needs will increase, the team is unwilling to consider an increase in AT and speech supports for Graham.

In first grade, Graham struggles to participate in class, communicate his thoughts, and succeed in school. The school, however, says he is making sufficient progress to move to the next grade. In second grade, Graham's parents bring him to a private Speech Language Pathologist (SLP), who recommends for Graham an AAC device designed by a linguist that enables the user to communicate much more quickly and automatically, removing much of the fine motor burden required to spell out every word he utters. After Graham learns the system, the device will allow him to utter up to 50 words a minute instead of 12-15 words per minute he might if he had to spell each word himself (and assuming total accuracy in spelling).<sup>15</sup> The District,

12 20 U.S.C. § 1401(1)-(2). (Effective Oct. 1, 2016).

13 This AT provider is a different consultant from the previous year. She was hired by the District as an independent consultant and her child attends the District and receives special education services from the Special Education Director, arguably creating significant conflicts of interest for her in delivering her services. (Case study on file with author).

14 Two weeks later, however, in a meeting at the elementary school with the SPED, the same AT provider changes her position, saying that just 20 hours of AT support for Graham's first year of elementary school is sufficient. The AT provider later discloses to Graham's mother that the District would require her to be a full-time employee were she to continue to provide this level of service for Graham, and she already supports children with communication needs in over 14 districts, so it will not work for her to become a provider. She also breaks confidentiality and discloses to a parent in another district that Graham has more AT services than any other child in the area. (Case study on file with author).

15 Graham's parents locate relatively recent US Department of Justice guidance stating that the presumption is for schools to defer to the families and medical experts' advice of the appropriate

however, says it will not support Graham's new device at school, that he can continue to spell out each word he wants to say, which is sufficient for him to make "some progress." Graham's parents purchase the device with Graham's private insurance, letting the District know that his SLP and neurologist have recommended it. After a protracted battle, the District reluctantly concedes to "allow" Graham to use his SLP-recommended device at school.

At the end of his second-grade year, Graham's school reports that he has made just one month's progress in reading over the course of the whole school year, yet the school wants to keep him at the same level of services and pass him to the next grade. Each year, rather than increase Graham's in-class supports, the School District has argued to reduce them or reluctantly agreed to hold them steady. As long as he makes one month's progress in a year, he is making sufficient progress, the School District claims. That is all the law requires, they say.

## 2. American Law

Is the School District correct? What law or laws apply to Graham's education? As an American child, Graham lives in a federal political system in a country that embraces so-called negative rights, lacks a federal constitutional right to education,<sup>16</sup> and leaves the delivery and funding of education primarily to the local and state levels.<sup>17</sup>

Federal congressional legislation Title II of the ADA and Section 504<sup>18</sup> requires schools to offer students with disabilities to "receive to the full benefit of public services"<sup>19</sup> such as education and aspires to protect such students' right to "effective communication." The 1975 Individuals with Disabilities Education Act ("IDEA"), as amended in 1997 and in 2004, governs whether a child with one or more disabilities, like Graham, is receiving a "free and appropriate public education," (FAPE) even as he progressively slips academically and socially further and further behind his classmates.<sup>20</sup> The interrelationship between the ADA and the IDEA is complex and

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device for the student in order to procure the necessary support for his device. 28 C.F.R. §§ 35.130, 35.160 DOJ/OCR FAQ Nov. 2014 at p. 9.

16 See, e.g. *San Antonio Indep. Sch. Dist. v. Rodriguez*, 411 U.S. 1, 35 (1973).

17 *Id.*

18 34 C.F.R. § 104.33 (2018). Section 504 provides, "No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . ." 29 U.S.C. § 701 (2018). The ADAA amended the ADA. 81 C.F.R. § 53204-01 (2016).

19 20 U.S.C. § 1411 (2018); 20 U.S.C. § 1401(1) (2) (2018) (defining assistive technology device and differentiating it from a medical device).

20 20 U.S.C. §§ 1400, 1401(9) (2018).

evolving.<sup>21</sup> Indeed, in dealing with inexperienced parents, school districts frequently conflate IDEA compliance with ADA compliance, neglecting to mention to parents like Graham's that the School District has "effective communication" obligations under the ADA, focusing instead on the "FAPE" standard of the IDEA. Therefore, as a practical matter, this essay focuses its analysis on concerns arising from the Supreme Court's interpretation of what constitutes "free and appropriate public education" under the IDEA (only).

In 2017 in the *Endrew* case, the Supreme Court of the United States held that a FAPE requires schools to provide children with disabilities the opportunity to make more than *de minimis* educational progress, but the Court otherwise left the standard largely unspecified.<sup>22</sup> In the earlier *Rowley* case, the Court had held that excellence in education for children with disabilities is not required.<sup>23</sup> The *Endrew* Court did not reject that conclusion, but Chief Justice John Roberts stated, in this unanimous decision, that a child's "educational program must be *appropriately* ambitious in light of his circumstances" and that "every child should have the chance to meet challenging objectives."<sup>24</sup>

The *Endrew* Court rejected the plaintiff's argument that students with disabilities are entitled to a "substantially equal" standard of education. Rather, the majority opinion tied the level of education a child with disabilities should receive to whether that child is "showing educational progress in light of their disabilities."<sup>25</sup> In other words, the child is entitled to more supports only if the child is able to demonstrate his or her capacity to do more. In the United States, enforcement of these laws are therefore left to the often-overwhelmed parents of children with disabilities.<sup>26</sup>

So is the School District right – is Graham's progress sufficient to conform to the requirement of "a free, appropriate public education?" As a practical matter, few lawyers in the United States would be willing to press forward with FAPE cases, in order to challenge how much progress is enough progress for a child like Graham. As a result, school districts know that they are unlikely to be challenged as long as they

21 The *Frye* case may be altering the relationship between the ADA and the IDEA, and lower courts are currently untangling the related consequences. Although the ADA is beyond the scope of this Article, Professor Kanter has helpfully analyzed the limitations of both the ADA's theoretical orientation and its predominant focus on discrimination. See Kanter, Arlene, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 Drake L. Rev. 821 (2015).

22 *Endrew F. v. Douglas Cty. Sch. Dist.*, 137 S.Ct. 988 (2017).

23 *Bd. of Educ. Hendrick Hudson Cent. Sch. Dist., Westchester Cty. v. Rowley*, 458 U.S. 176, 187 (1982).

24 *Endrew F.*, 137 S. Ct. at 1000-01.

25 L. McKenna, *How a New Supreme Court Ruling Could Affect Special Education*, The Atlantic (Mar. 23, 2017), <https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/> (access 25.05.2018).

26 For some challenges associated with this policy, see, e.g. Eloise Pasachoff, *Special Education, Poverty, and the Limits of Private Enforcement*, 86 Notre Dame L. Rev. 1413 (2011).

provide some services, and children like Graham may never reach even a fraction of their full potential.

### **3. The Supreme Court's current review standard for a free and appropriate public education creates a presumption of (in)competence for children with disabilities.**

Whether a child with disabilities is receiving an appropriate education under United States law, then, turns on what that child can demonstrate he/she is capable of learning.<sup>27</sup> Despite the seeming logical symmetry of this standard, cases like Graham's highlight a number of urgent concerns the Court's interpretation raises.

First, with Graham in mind, the Court's standard raises a critical logical and epistemological concern: how do courts or school districts know of what the child is capable? If the standard is tied to the child's capacity, then it is critical to know that capacity. The conventional answer is that a developmental neurologist will test the child to determine his/her capacity. But that is simply not possible in many cases. Take the case of the non-verbal, preliterate child with severe physical disabilities, as is Graham in our case study. At present, there simply is not an appropriate intelligence test for a preliterate young child with disabilities like Graham. With existing intelligence tests, his capacity is largely unknowable. Developmental psychologists agree that existing intelligence tests are neither norm-tested nor appropriate for children with severe physical disabilities.<sup>28</sup> To offer one illustration of the ineptitude of standardized tests for preliterate, physically disabled children: the classic exam, the Bayley exam, requires the psychologist to hand the very young child a bell or some similar object and observe what the child does with the object. Tests such as these are simply absurd for children like Graham, who lack the motor control to reach for, grasp, or maintain a hold on a bell. Nevertheless, these norm-tested scales remain the currency of competence-markers.<sup>29</sup> Administrative courts and appellate courts are certainly no better prepared than are cognitive psychologists to ascertain the intelligence or capacity of a particular child, nor can they rely on existing tests.

Careful readers may object that while it may not be possible to gather accurate or precise assessments of a child's intelligence, a general baseline can be developed from

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27 Typically developing children, by contrast, are presumptively enrolled in grade-level classes.

28 J.F. Fagan, A Theory of Intelligence as Processing Implications for Society, 6 Psychol. Pub. Pol'y & L. 168, 170-176 (2000).

29 Indeed, at great expense and investment of time, Graham has been subjected to over four of these tests in his short life. When he consistently scores low, the psychologist administering the test explains in writing that the results are not accurate, and elaborates the many ways the test does not measure his aptitude. She adds then that in fact he appears to be quite bright, listing many of her *ad hoc* perceptions of his intelligence.

these tests, and it is therefore most efficient for the school to proceed in distributing limited resources based on this approximate baseline.<sup>30</sup> Yet such a definition of efficiency prizes the District's resources in the short-term of the academic school year, failing to take into consideration the wasted cognitive potential of the child over the long-term, and the value for society of ensuring that the student has a strong educational foundation in order to pursue employment and be as independent as possible later in life. Indeed, state-run Early Intervention programs already recognize the need for resources to be offered to children with disabilities early in their development, before school age.

A related second concern, then, relates to the burden of proof. The Court's interpretation of the "appropriate" standard effectively places on the child the burden to prove that she is worthy of the supports in order to receive them. Thus a child with communication disabilities like Graham must first demonstrate that he is capable of reading at grade-level in order to secure the very supports he requires to read at grade-level. For a child like Graham, whose physical limitations prevent him from accessing the curriculum without extensive supports, the futility of such a standard is clear. Graham cannot read aloud or demonstrate his comprehension of text he has read without assistive technology. Yet Graham requires services and supports as well as modifications to the curriculum to be able to meet and keep up with the grade level. Each year that the system does not offer Graham these necessary supports to reach grade level, he slips further behind and becomes less and less capable of demonstrating that he is capable of functioning at grade level. Indeed, under the Court's current standard, it is likely that with each passing year, what is deemed to be "appropriately ambitious for him in light of the challenging circumstances"<sup>31</sup> will only minimally advance what he is already achieving.

The third concern is the perverse incentives these policies create for schools. The Court's standard offers school districts tremendous leeway, possibly even incentivizing schools not to discover the child's capacities, lest they need to provide supports for him to adequately access the curriculum. In this way, placing the impetus on the child to demonstrate capacity before offering him supports, even in unprovable circumstances, may effectively incentivize schools to have consistently low expectations for students like Graham. Even in the child's earliest developmental periods, schools are not required to "presume competency"<sup>32</sup> and allocate resources accordingly. Low expectations need not only be of concern to disability rights advocates and people with disabilities. Taxpayers, too, may well be worried that the

30 D. Grissmer, K. Grimm, S. Aiyer, W. Murrah, J. Steele, *Fine motor skills and early comprehension of the world: Two new school readiness indicators*, 46(5) *Developmental Psychology* 1008-1017 (2010).

31 *Andrew F. ex rel. Joseph F. v. Douglas Cnty. Sch. Dist. RE-1*, 137 S.Ct. 988, 1000 (2017).

32 D. Biklen, J. Burke, *Presuming Competence*, 39 *Equity & Excellence in Education* 166 (2006).



Court's present legal interpretation of the "appropriate" standard is problematic. The concern is that the present interpretation creates the near-certain risk that a child like Graham will be far less likely to achieve independent employment. With an education that presumed his competence and sought to support him accordingly from an early age, however, he would not face as many obstacles to securing employment.

The next section explores the bias that the current standard perpetuates. In short, although children with disabilities are now provided with a free, appropriate public education in the United States, too often, educators, lawmakers, and the public still do not hold disabled children to a standard that would allow them to achieve their full potential.

#### **4. Global Norms: By Embracing a Social Model of Disability, US Courts Could Help Students with Disabilities by Requiring Schools to Presume Competence**

Some disability rights advocates might ask, why should a child be required to demonstrate ability in order to receive supports? Indeed, even a child who might not ever succeed academically at the same level as her peers deserves to have adequate supports to be included with her peers and to achieve her potential.

Although the United States has famously refused to ratify the CRPD,<sup>33</sup> disabled children in America could benefit from the social view of disability that the CRPD embraces. The current *Endrew* standard arguably derives from a medical model of disability. This model, under which, as Professor Liz Emens says, "a disability is a lack that requires costly filling"<sup>34</sup> predominates in American disability law. The *Endrew* standard implies that capacity is predetermined and that it must be proven in order for a person to receive supports. By contrast, under the CRPD, a disability refers "to a limitation which results in particular from long-term physical, mental or psychological impairments *which in interaction with various barriers* may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers."<sup>35</sup>

Adopting a social model of disability,<sup>36</sup> and examining impediments to an individual's ability to function, would uniquely assist American children like Graham

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33 J. Lord and M. Stein, *The Law and Politics of U.S. Participation in the UN Convention on the Rights of Persons with Disabilities*, in S. Hertel and K. Libal (eds.), *Human Rights in the United States. Beyond Exceptionalism* 119 (Cambridge: University Press, 2011).

34 Elizabeth F. Emens, *Integrating Accommodation*, 156 U. Pa. L. Rev. 839, 840 (2008).

35 For an explanation of the background of the definition of disability in the CRPD, see A. Kanter, *The Development of Disability Rights Under International Law: From Charity to Human Rights* (Routledge: 2015, 2017).

36 For a discussion of the social model of disability and how it differs from other models of disability, see A. Kanter, *The Law: What's Disability Studies Got to Do with It or An Introduction to Disability*

in achieving their potential in education. Were the Supreme Court of the US to embrace the theoretical approach which guided the drafting of the CRPD, American case law might well require a presumption of the young child's competence and an exhortation to the school to provide students with disabilities with the necessary resources to achieve *their full potential*.

## **5. Implication of this US Case Study for CRPD States Parties: Working to Overcome Judges' Theoretical Limitations**

In order to ensure that lawmakers in countries that have ratified the CRPD accurately and thoroughly embrace the social model of disability in the CRPD, judges will need to be trained not only on the legal provisions of the treaty, but also in the social theories of disability that frame those provisions. If judges are made aware of and bear in mind the history of extensive legal and social discrimination against people with disabilities,<sup>37</sup> their interpretation of the CRPD's provisions will necessarily be more empowering. Armed with this background information and faced with a child like Graham and language perhaps requiring a "free and appropriate public education," a judge might require the School District to intensify supports for the child as he initially learns to read and speak.

In short, this analysis demonstrates one way that, in the absence of more specific legislation, judicial interpretation of existing law can be determinative for children with disabilities seeking to realize their educational rights – this can be true in both civil and common law systems. In order for provisions of the CRPD, for example, on accessibility, inclusive education, and communication, among others, to be interpreted progressively to realize the rights of children with disabilities, judges who have limited experience with disability, need to be trained on how social obstacles create and reify experiences of disability. Only once judges and lawmakers, most of whom are able-bodied and products of segregated educational systems themselves, are introduced to and begin to understand the comprehensive manner that social policies and societal attitudes create and reify lived experiences of disability will the law begin to change.

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37 In fact, judges have frequently perpetuated the discrimination. See, e.g. *Buck v. Bell*, 274 U.S. 200 (1927).

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