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WHAT A DIFFERENCE THIRTY YEARS—1978 TO 2008—MAKES IN THE TRANSFORMATION OF DISABILITY LAW

Ruth O'Brien*

FRED PELKA, *WHAT WE HAVE DONE: AN ORAL HISTORY OF THE DISABILITY RIGHTS MOVEMENT* (2012). Pp. 656. Hardcover \$ 90.00.

RUTH COLKER, *DISABLED EDUCATION: A CRITICAL ANALYSIS OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT* (2013). Pp. 293. Hardcover \$ 47.00.

Almost a decade ago, this reviewer published *Bodies in Revolt*, a utopian tract on disability rights, after having previously written about the reality of disability rights in the workplace. Arguing that the word *disability* did not capture our physical, mental, intellectual, developmental, and/or cognitive limitations well, this reviewer suggested that what it best conveys is the human condition.¹

Given what neuroscientists would call our organic or genomic structure, in combination with preventative, degenerative, and regenerative medicine, the idea of describing disability solely on the basis of limitations falls short.² Throw in time and perspective, making possible a broad definition of disability—be it permanent or temporary—and the definition grows wider, becoming so expansive that it suits the entire life cycle. Whether mental, physical, developmental, intellectual, or cognitive, the word *disability* represents a non-essential, ever-evolving or mutable, socially constructed category.

Put differently, the term *persons with disabilities*, no matter how cumbersome, describes “the lives of others,” or at least the lives of the lucky others in wealthy nations who have access to preventative and regenerative medicine.³ Increased longevity exists,

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1. RUTH O'BRIEN, *BODIES IN REVOLT: GENDER, DISABILITY, AND A WORKPLACE ETHIC OF CARE* (2005) (with a foreword by Martha Fineman). Fineman's notion of an ethic of care particularly helped me extend the ethic of care to minds and bodies. See also ROSEMARIE GARLAND THOMSON, *EXTRAORDINARY BODIES: FIGURING PHYSICAL DISABILITY IN AMERICAN CULTURE AND LITERATURE* (1996); Fedwa Malti-Douglas *The Interplay between Disability and Sexuality: Legal Cross-Dressing: Sexuality and the Americans With Disabilities Act*, 15 COLUM. J. GENDER & L. 114 (2006).

2. *BIOMATERIALS AND REGENERATIVE MEDICINE* (Peter Ma, ed., 2014).

3. Rabia Belt, *And Then Comes Life: The Intersection of Race, Poverty, and Disability in HBO's The Wire*, 13 RUTGERS RACE & L. REV. 1 (2012); Samuel R. Bagenstos, *The Concept of Disability: United States: Comparative Disability Employment Law From an American Perspective*, 24 COMP. LAB. L. & POL'Y J. 649 (2003).

whether or not these persons acknowledge, accept, or eschew this legal category of having a permanent or temporary disability—or, as Fred Pelka describes it in his excellent book *What We Have Done: An Oral History of the Disability Rights Movement*, being part of the “open minority.”⁴ Less than 20 percent of all persons with disabilities were born with physical, mental, intellectual, cognitive, or developmental limitations.⁵ In other words, eighty percent of all disabilities are acquired during our increasingly long lifespans.

To be sure, the term “temporarily able-bodied” (TAB) has long existed.⁶ All those who are not persons with disabilities are temporarily able-bodied. Babies born with limitations account for such a small fraction of persons with disabilities that this idea no longer reflects the reality of demographics in affluent nations. The disability-rights community and the field of disability studies have long tried to debunk this misunderstanding.

Despite its pointed accuracy, the acronym TAB gained little foothold in the 1970s or thereafter; and, as critics contested, why should it have? We are but temporarily alive. What is more, today’s teenagers have for years had health teachers trying to “prepare” them for a 200-year lifespan based upon preventative care. This is not to say the medical community has caught up. Experts such as actuaries who rely on cost-benefit or cost-per-averted-death types of risk analysis in some states suggest that the over-fifty crowd should not undergo knee surgery, since it often is less effective for them than for those under that threshold age.⁷

So although we are all TAB, knowing this makes few folks more likely to link arms in solidarity and fight for disability rights. If it was this easy, why did the American Association of Retired People (AARP) fail to throw in its lobbying lot with the disability-rights movement and the parents’ movement a long time ago? What a powerful voting bloc that would be. One explanation: The category of persons with disabilities increases our fear, dread, and anxiety about the one fact that remains unknown about the eighty percent (i.e. all those who are or will be persons with disabilities during their lifetimes)—when and how they will discover that they have a disability.

Perhaps this lack of unity is because *schadenfreude* does not create solidarity within any civil or human rights movement—particularly one that includes independent-living, self-advocacy, and parents’ rights movements, some of which are prone to balkanization that cuts along injury and/or genetic predisposition to chronic-illness or disease lines.

4. FRED PELKA, *WHAT WE HAVE DONE: AN ORAL HISTORY OF THE DISABILITY RIGHTS MOVEMENT* (2012).

5. On May 11, 1999, Sen. Edward M. Kennedy said on the U.S. Senate floor: “When we think of citizens with disabilities, we tend to think of men and women and children who are disabled from birth. But fewer than 15 percent of all people with disabilities are born with their disabilities.” 145 Cong. Rec. S5001 (1996). Five years later, Kennedy stated that “fewer than 10 percent of all children with disabilities are born with their disabilities.” 150 Cong. Rec. 8644 (2004). Among all disabled Americans, “3 in 10 were disabled at birth or childhood, 4 in 10 were disabled in their 20’s, 30’s or 40’s, 3 in 10 were disabled later in life.” See John Patrick Evans, *Americans with Disabilities Act*, Western Region Outreach Center and Consortia, Western Oregon University (2004), available at http://www.wou.edu/education/sped/wrocc/training_federal_law_ADAIntro.htm. In addition to the employment of different statistical methodologies, the greatest variance in rates of disability from birth is by country, particularly wealthy nations versus poor nations.

6. Irving K. Zola, *Disability Statistics: What We Count and What it Tells Us: A Personal and Political Analysis*, 4 J. OF DISABILITY POL’Y STUD. 9 (1993).

7. Taimie L. Bryant, *Similarity or Difference as a Basis for Justice: Must Animals be like Humans to be Legally Protected from Humans?* 70 LAW & CONTEMP. PROBS. 207 (2007).

Yet who knew in the mid-2000s that the Americans with Disabilities Act Amendments Act (“ADAAA”) was right around the legislative corner.⁸ President George W. Bush signed the ADAAA “just as his father,” President George Herbert Walker Bush, “signed the original Americans with Disabilities Act in 1990.”⁹ Who knew that viable legislation undoing the Supreme Court’s gutting of the Americans with Disabilities Act in 1990 on the basis of this first threshold Catch-22 question would occur within less than two decades?¹⁰

What we did know was that in the six pivotal cases about the ADA’s workplace provisions, the Rehnquist Court kept ruling that persons with disabilities had limitations significant enough to disqualify them from work, but not significant enough to warrant statutory protection or freedom from discrimination.¹¹ Had this reviewer had such foresight, more thought would have been given to social-movement realities rather than a utopian or idealistic tract.

Moreover, the ADAAA was signed in September 2008, leaving the regulations to fall into newly elected President Barack Obama’s administrative lap.¹² The well-documented five-year battle for federal regulations under Section 504 of the Rehabilitation Act taught disability-rights scholars and advocates only too well how meaningless statutory rights are on paper unless coupled with executive action, in the form of regulations, to enforce them.¹³

It is the regulations that give the ADAAA its bite, though it remains the federal judiciary’s role to determine how deep that bite will go in any given case. And by 2011, unbeknownst to all but insiders, it turned out that Obama administration’s Equal Employment Opportunity Commission (EEOC) had planned on issuing final regulations fast (anything less than the usual two-year public comment period is considered speedy). By 2011 Obama’s EEOC, moreover, had gone after the “largest number of affirmative-action violations in at least nine years . . . as it sought to boost the hiring of veterans and people with disabilities,” explained a reporter.¹⁴

Two strong women with multiple intersecting identities helped run the EEOC. Intersectionality ruled, as Obama nominated an expansive set of civil-rights advocates to run this agency. Jacqueline Berrien, who had worked at the NAACP Legal Defense and Education Fund, the Ford Foundation’s Peace and Social Justice Program, the American Civil Liberties Union (ACLU), and the Lawyers’ Committee for Civil Rights, was named chair

8. Robert Pear, *Congress Passes Bill With Protections for Disabled*, N.Y. TIMES (Sept. 17, 2008), <http://www.nytimes.com/2008/09/18/washington/18rights.html>.

9. *Bush Eager to Sign Bill Opening Doors for 43 Million Disabled*, ORLANDO SENTINEL TRIB., July 14, 1990, at A1.

10. Ruth Colker, *The ADA: A Windfall for Defendants*, 34 HARV. C.R.-C.L. L. REV. 99 (1999).

11. RUTH O’BRIEN, *CRIPPLED JUSTICE: THE HISTORY OF MODERN DISABILITY POLICY IN THE WORKPLACE* (2001).

12. Reuters, *Senate Measure Would Expand Disabilities Act*, N.Y. TIMES, Sept. 12, 2008, at A16. *See also The Path to Equality*, ARCHIVE ADA, <https://www.law.georgetown.edu/archiveada/>.

13. SHARON N. BARNARTT & RICHARD K. SCOTCH, *DISABILITY PROTESTS: CONTENTIOUS POLITICS 1970 - 1999* (2001); RICHARD K. SCOTCH, *FROM GOOD WILL TO CIVIL RIGHTS: TRANSFORMING FEDERAL DISABILITY POLICY* (1984).

14. Kathleen Miller, *Uncle Sam Wants You . . . to Hire More Vets, Women, and Minorities*, BUSINESSWEEK (July 19, 2012), <http://www.businessweek.com/articles/2012-07-19/uncle-sam-wants-you-dot-dot-dot-to-hire-more-vets-women-and-minorities>.

of the EEOC. While the political Right expressed outrage over Berrien's appointment, Obama installed Chai Feldblum, who had been at the forefront of legal activism on behalf of expanding civil rights to include disability rights as well as LGBTQ rights, as an EEOC commissioner.¹⁵

What was so radical about the new regulations? First, by redefining disability broadly along functional grounds, these EEOC intersectionality leaders made disability rights so strong and so expansive that, as one group predicted, "most individuals over fifty years old seem likely to be covered by the ADA."¹⁶ Disability is an open minority that anyone can fall into, regardless of social or economic standing. There is nothing constructive about describing it as a category about our "being"; it is about our doing, involving ethics based on functionality. A functional definition of the human mind and body is necessary. Unlike racial discrimination, it is not immutable; nor is it necessarily visible, nor can it be left alone. Disability requires more than an open attitude about this open minority. It is about needs, though not one-size-fits-all needs, and certainly not traditional needs dictated by experts, in light of the self-advocacy and independent-living movements that preceded the disability-rights movement.¹⁷ Instead it is about needs that fit the individual. It is about individualized assessment of each person's situation that often defies white male Anglo-American cultural supremacy inherent in neotribalism.¹⁸

And second, the ADAAA shifts the burden from the individual—the person with a disability—to the entity or institution that that should accommodate this individual. Accommodation law is more akin to that of sexual harassment law than to civil rights based upon intention.¹⁹ With one fell swoop, the ADAAA humanized capitalism and opened up higher education as a public accommodation, as well as other public accommodations open for services, such as a private physician's office, or a business.²⁰

This legal categorization of disability mandates rethinking. Whether we rethink the utility of stairwells, the public purpose of higher education, or our basic assumptions about humanity, and whether it is done in terms of genetics, the genome, longevity, the human life cycle, or the balancing of human, animal, and inanimate bodies or systems, is less material.

What we know for sure is that individual identity is not staid or static. It must take into account our individuality, and this legal category is reciprocal or interactive. Accommodations can take many forms—they can be goods or products, or also special environments or conditions.

15. RUTH O'BRIEN, *OUT OF MANY, ONE: OBAMA AND THE THIRD AMERICAN POLITICAL TRADITION* 144 (2013).

16. Rebecca R. Hastings, *New ADAAA Rules Focus on Rights of Workers with Disabilities*, HR NEWS (SHRM, Society for Human Resource Management) (March 31, 2011), available at <http://www.shrm.org/publications/hrnews/pages/newadaaarules.aspx>.

17. Ruth O'Brien, *Other Voices at the Workplace: Gender, Disability and An Alternative Ethic of Care* 30 SIGNS: JOURNAL OF WOMEN IN CULTURE AND SOCIETY 1529 (2005). See also GERARD GOGGIN & CHRISTOPHER NEWELL, *DIGITAL DISABILITY: THE SOCIAL CONSTRUCTION OF DISABILITY IN NEW MEDIA* (2002).

18. O'BRIEN, *supra* note 11, at 73-75.

19. Ruth O'Brien, *Heretical Thought Oxford University Press Book Series*, <http://ruthobrien.org/new-oxford-university-press-book-series/heretical-thought-mission-statement/>.

20. O'BRIEN, *supra* note 11, at 144-46.

Finally, despite their being tailored to the individual, the precedent set is collective. Is a collective the public/private/social sphere or the division between the three spheres? The 2014 Supreme Court decision in *Burwell v. Hobby Lobby* might start rebalancing what is meant by *collective*.²¹

In other words, one person profits from the open door created by this open minority. And this open door does not just involve goods and products but also rules and regulations; and now, given *Hobby Lobby*, possibly faith, as long as this faith is “sincere,” as opposed to dogmatic faith articulated in specific religions, such as the dominant three within neotribalism (e.g. Christian, Judaic, Islamic).²²

To be sure, there are alternative ways of doing different things. One standard size does not fit all, nor can our workplaces or public accommodations be standardized; however, individuals do decide where to work, where to be educated, and where to live and shop. An expansive notion of disability, therefore, questions the rationale behind the private, public, and social spheres.

It requires not only the *acceptance* of difference, but also an *accommodation* of difference. It is a positive right, not just a negative right, like civil rights. It accepts the identity of the individual, and how it must be assessed individually, according to what one can or cannot do. It is a functional definition. It is a fluid concept of an individual’s corporeality, undermining the idea that identities are static or fixed. Every mind and every body is unique. Indeed, many inventions have been born of rethinking how to do things. Questioning the primary assumptions underlying how we function, or what apparatus we need to function, is very productive, most critical thinkers claim. Thomas Edison, for example, invented the phonograph for people with visual problems.

The interactive process also helps provide a different view. The onus is put on society, not the individual, not because it is only good for the individual, but because it is good for society, the polity, the market or the public and private spheres. It is cultural, and can stem from one strain of Christianity that triggered a social transformation, reflecting Martin Luther King’s notion of a dream as Vincent Harding describes it.²³

The best test of the regulations is the tenacity with which not only private industry, but also state and local governments and their subsidiaries, prepared to frame the fight in 2011. The final regulations created a firestorm. Employer associations as well as public universities called in expert consultants and lawyers for workshops seeking ways to protect themselves from the lawsuit onslaught. A near panic ensued. “Strangulation by regulation” was what one blogger called it. Others simply called the regulations “dangerous.”²⁴

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Disability law, policy, and history, particularly accounts that are not separated into physical, mental, developmental, and parental movements—or further balkanized into his-

21. *Burwell v. Hobby Lobby Stores, Inc.*, 134 S. Ct. 2751 (2014).

22. *Id.* (describing faith, belief, or claims as sincere or insincere almost 100 times).

23. VINCENT HARDING, *HOPE AND HISTORY: WHY WE MUST SHARE THE STORY OF THE MOVEMENT* (2d ed. 1990).

24. Peter Kirsanow, *Strangulation by Regulation*, NAT’L REVIEW (April 21, 2011, 10:13 AM), <http://www.nationalreview.com/corner/265362/strangulation-regulation-peter-kirsanow>.

tories about laws and public policies pertaining to a myriad of different illnesses and injuries—are difficult to write or edit. The intersections and hierarchies within the different organizations are hard to overcome. Indeed, the fact is that most persons with disabilities—or those who care for persons with disabilities, such as the parents’ movement or what should be a children’s movement for elder care—do not recognize their own self-interest.

For a rights movement trying to be effective, balkanization is, by definition, marginalization. While not all agree, many academics, activists, and academic activists begin the history of disability here. Pelka is no exception.

Like many disability-rights scholars, Pelka in his introduction and commentary in *What We Have Done* maintains that balkanization is a self-defeating solidarity strategy.²⁵ It is not just those with imperfect vision at war with the deaf (or the Deaf), but also persons with temporary conditions such as pregnancy, or a genetic predisposition to an illness, or simply an infirmity gained over time, who are “less deserving” of freedom from disability than those with more severe or longer-term conditions, according to Evan Kemp and Justin Dart, who worked with Republicans in the Ronald Reagan and George H. W. Bush administrations.²⁶ The Republican backers of the ADA supported the workplace reforms most extensively, arguing against a broad definition of disability.

Justin Dart, a disability-rights activist who, after a business career, moved to Texas and then Washington, D.C., believed disability rights revolved around a conception of “empowerment” that could be embraced by both Reagan’s and Bush’s administrations.²⁷ This became clear when Dart, who first directed the National Council on the Handicapped and then became the Commissioner of the Rehabilitation Service Administration (RSA), condemned the latter for its “obsolete, paternalistic” perception of disability.²⁸ After resigning in 1987, Dart, who had once been on the inside, became a full-time ADA activist. An insider/outsider, as Pelka concisely describes him, Dart had been born into a wealthy family, whose own father raised funds for Reagan, among others.²⁹

Evan Kemp, born in New York City to “old money,” was another insider/outsider.³⁰ In 1987 C. Boyden Gray, a confidant of then Vice President George H. W. Bush, recommended that Kemp become an EEOC commissioner. Kemp’s position “inside” the GOP helped him play a critical role, and when Gray became Bush’s White House counsel, Gray helped ensure the ADA’s passage. Ironically in 1990 Kemp succeeded Clarence Thomas as EEOC chairman.³¹ Even more than Dart, Kemp, who had a disease related to polio and, after having an accident as an adult used a wheelchair, did not fight for an expansive definition of disability in the workplace.

According to Pelka, Kemp’s wife, Janice Bertram Kemp, explained that disability rights for her husband stemmed from being rejected from all law firms he applied to, despite being in the top ten percent of his University of Virginia law-school class.³² Kemp

26. PELKA, *supra* note 4, at 448.

27. *Id.* at 167.

28. *Id.*

29. *Id.*

30. *Id.* at 444.

31. *Id.*

32. *Id.* at 446.

believed in disability-rights activism, though he also believed in empowerment, particularly self-empowerment.³³ Whether empowerment or self-empowerment, this pertained to persons with visible disabilities rather than invisible ones, and certainly not those “regarded as” being a person with a disability, such as people with a facial scar, who in some places were prohibited by “ugly laws” from appearing in public.³⁴

While both Dart and Kemp passed away before the ADAAA, neither might have supported Obama’s expansive regulations; since the regulations are all-inclusive and all-expansive, and they embrace the notion that persons with disabilities requiring no accommodation could still be “regarded as” having a disability and therefore in need of statutory protection from discrimination. Whether this condition is a six-month depression, pregnancy, or being a person who is a quadriplegic does not alter the rights for protection against discrimination in the workplace.³⁵ Thus, it was all the more surprising that George W. Bush signed the Act.

This depth of explanation is what makes Pelka’s book so valuable and compelling for students and scholars, as well as for general reading. Pelka sets this five hundred-page oral history in context by presenting concise introductions and deftly editing the voices of many persons with and without disabilities who constituted the disability-rights movement, whether they emerged from independent living, were psychiatric survivors, or initiated the parents’ movement.

Pelka’s book contains numerous revelations. This reviewer did not know, for example, about the full extent of the Section 504 training sessions, nor that three-thousand people came to the original signing of the ADA.

Pelka begins by explaining how thrilled he was that an important decision, *Pennsylvania Association for Retarded Children (PARC) v. Pennsylvania*,³⁶ was fought along Fourteenth Amendment due process and equal protection grounds.³⁷ The “transition,” Pelka writes, “from ‘pity and fear’ to ‘equal citizenship’ has been little short of revolutionary.”³⁸

Pelka’s book is especially excellent given how well it covers all the issues up to 1990. There are few texts out there that do not specialize in mental, physical, developmental disability, or the parents’ role; so, books that navigate this wide range of topics are particularly welcome for avoiding the marginalization problem. Many books also select institutionalization, education, or employment, instead of all three. But Pelka meticulously studies institutionalization and deinstitutionalization from the perspective of children and adults.

He discusses exclusion and inclusion in education—first in higher education, with the “Rolling Quads” at University of Illinois at Urbana-Champaign, where students with disabilities were expected to define their disability in terms of the rehabilitation model;

33. *Id.*

34. SUSAN M. SCHWEIK, *THE UGLY LAWS: DISABILITY IN PUBLIC (THE HISTORY OF DISABILITY)* (2010).

35. Michelle A. Travis, *What a Difference a Day Makes, or Does It? Work/Family Balance and the Four-Day Work Week*, 42 CONN. L. REV. 1223 (2010); CIVIL DISABILITIES: THEORY, CITIZENSHIP, AND THE BODY (Nancy J. Hirschmann & Beth Linker, eds., 2014); Michael Ashley Stein, Anita Silvers, Bradley A. Areheart, & Leslie Pickering Francis, *Accommodating Every Body*, 81 U. CHI. L. REV. 689 (2014).

36. *Pennsylvania Ass’n for Retarded Children v. Pennsylvania*, 334 F. Supp. 1257 (E.D. Pa. 1971).

37. PELKA, *supra* note 4, at 1.

38. *Id.* at 4.

and then at University of California, Berkeley, where students forged the political consciousness underlying the independent-living movement.³⁹ By 1995, there were four-hundred Centers for Independent Living.⁴⁰ The movement also spread to kindergarten through twelfth grade, where it was dependent upon parents and the parents' movement, and then it blossomed into a full-fledged disability-rights movement similar to all American rights movements.⁴¹

The parents' movement had started early, with the founding of the United Cerebral Palsy Associations in 1940, among others. The movement's importance can hardly be overstated, since *PARC v. Pennsylvania* assured children of a public education when it was settled in 1972, and led to the Education for All Handicapped Children Act of 1975⁴² (now the Individuals with Disabilities Education Act, or "IDEA")⁴³ so that school boards could no longer find children "uneducable and untrainable."⁴⁴ Flipping to the "zero reject principle" and from the idea that the individualized education program ("IEP") must come from the "least restrictive environment,"⁴⁵ *Pennhurst v. Halderman* was the crucial deinstitutionalization decision.⁴⁶ Civil Rights were applied in employment, mandating that employers hire persons with disabilities and make accommodations if necessary. Finally, Public accommodations of private places, like restaurants, became accessible to all persons with disabilities.

Pelka delineates most chapters by dividing them into epochs—from the moral or religious model to the medical model, and finally concluding with the social model. Within the moral model, those with disabilities were "special," which denoted an unusual situation with God. This person, in other words, was tainted, or "touched."⁴⁷ For instance, Pelka includes the eugenics movement of the late nineteenth and the early twentieth century.⁴⁸ In *Buck v. Bell*, Justice Oliver Wendell Holmes best expressed the idea that persons with disabilities were now considered a threat to society and had to be eliminated with his famous quote that "[th]e principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough."⁴⁹

While the kinder, gentler years of Rehabilitation begin after World War II, the "whole man" theory of disability, instigated by Dr. Howard K. Rusk, among others, still underwrites the medical-model epoch.⁵⁰ Disability rights emerged alongside the epoch dominated by medicine, dating as far back as the 1850s with the Deaf—though persons with disabilities gained more consciousness in the 1930s and 1940s, when the League of

39. *Id.* at 22-23.

40. *Id.* at 24.

41. *Id.*

42. Pub. L. No. 94-142, 89 Stat. 773 (1975).

43. Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, 104 Stat. 1103 (1990).

44. PELKA, *supra* note 4, at 139 (internal quotation marks omitted).

45. *Pennhurst State Sch. & Hosp. v. Halderman*, 465 U.S. 89, 93 (1983).

46. PELKA, *supra* note 4, at 137.

47. *Id.* at 5.

48. *Id.* at 9-11.

49. *Buck v. Bell*, 274 U.S. 200, 207 (1927).

50. PELKA, *supra* note 4, at 14-16.

the Physically Handicapped protested discrimination in New York City by the Works Progress Administration (“WPA”) and the National Federation of the Blind was organized.⁵¹

As was true with the women’s movement, it was the success of the African-American, predominately male civil-rights movement that “sparked” disability rights.⁵² The success of the disability-rights movements in striking for Section 504 regulations in 1977 constituted one of the longest strikes ever.⁵³ “Nobody was physically injured on either side—not the guards, not the FBI, and not us,” said Corbett O’Toole.⁵⁴ “It was all a battle of words and a battle of wills, and it was very successful. . . . we actually [held] the record for the longest occupation of federal property”⁵⁵ James Donald said it all with the phrase: “[Y]ou can change public morality with law.”⁵⁶ Donald, like Ed Roberts (who is considered the “father” of disability rights, though in today’s parlance he would be considered the “parent” of such rights), had the insider/outsider position after Governor Michael Dukakis took the “radical step” of having him head the Massachusetts Rehabilitation Commission in the 1970s.⁵⁷

As with all disability history, parts of Pelka’s book trigger the worst-case scenario imaginable, setting forth how frequently rape by caretakers occurred. The death rate was nine times higher in Willowbrook State School and Hospital on Staten Island, for instance, than in any New York City neighborhood. Children as young as six, recounted Ted Chabasinski, a founding member of the Psychiatric Survivor Movement, screamed as they suffered insulin-coma therapy and electric shock treatment.⁵⁸ Unable to speak for themselves, and abandoned or dropped off by their parents, these children with disabilities were in shockingly vulnerable positions, and they and their plight eventually helped initiate the parents’ movement as well.⁵⁹

Aside from these disturbing details, all the more haunting for being preserved in the oral tradition of the survivors and witnesses themselves. Pelka also teases out of many pivotal leaders, such as Mary Lou Breslin, who co-founded the Disability Rights Education and Defense Fund (“DREDF”), memories of when they became conscious of their rights as persons with disabilities worthy of human dignity. She was particularly concerned about those persons with “visible” disabilities.⁶⁰ “They [a]re keeping you out because you have a disability,” explains Breslin.⁶¹

For Roberts, once he left home, having everyone stare at him was not as painful as he anticipated. It made him realize “maybe it was [not] all [his] problem, because when [he] looked back they would look away.”⁶² Finally he realized that “[a]ctually, [he] could

51. *Id.* at 19.

52. *Id.* at 23.

53. *Id.* at 275.

54. *Id.*

55. *Id.* at 275.

56. *Id.* at 307.

57. *Id.* at 303.

58. *Id.* at 291.

59. *Id.*

60. *Id.* at 554.

61. *Id.* at 67, 553.

62. *Id.* at 115.

enjoy being stared at, if [he] thought of [himself] as a star, not just a helpless cripple.”⁶³

Becoming aware of their rights as people made those with disabilities into activists in a way that today cannot be turned back, no matter what the blowback. Lee Kitchens, a little person, said it well in describing his only career option in *What We Have Done*: People like him could only work in the circus and were second-class citizens. “That was the perception and perception was reality.”⁶⁴ Little people had employment, even if it was degrading and humiliating, but others felt they were at the mercy of the able-bodied. Pelka quotes Corbett O’Toole, who had polio as a child: “How they interpreted their discomfort was to make me miserable, to say bad things to me, to hurt my feelings, to shame me, to basically single me out as an oddity that was unacceptable and needed to be modified, fixed or whatever.”⁶⁵

Interviewing Breslin, Roberts, Dart, and many others, Pelka has them explain how persons with disabilities realized that their rights were being held back by a “mind frame” or a perception that they could overcome, whether this was couched in terms of the independent-living movement, self-advocacy, or forming the California Association of the Physically Handicapped (“CAPH”). The word *of*, not *for*, made all the difference to some disability-rights advocates, even if not all agreed with CAPH’s “aggressive strategy.”⁶⁶

And indeed, activists like Norma Vescovo staged bold moves. As she explained, these acts, while sometimes scary, were essential to get the public to notice. They had to stage theater or undertake symbolic gestures that could not be ignored, like “going out on freeways.”⁶⁷ This is still not widely accepted. Meanwhile, other activists, like Judith Heumann, who helped found Disabled in Action, fought by lawsuit.⁶⁸

Finally, one activist, Lucy Gwin, who escaped from the New Medico Brain Injury Rehabilitation Center in Cortland, New York, in 1989, came up with a clever idea that is now, finally, possible—*qui tam* litigation.⁶⁹ This type of litigation is contained in laws to encourage civilians who know of individuals or companies making false claims for profit to report them. These civilians can receive a whistleblower reward, since they can share in revenue recovered by the federal government. The law goes back to the Norman Conquest.⁷⁰ As Gwin explains, who could know better that this whistleblower law could become part of self-advocacy, or, more precisely, create a foundation for a self-enforcement movement?⁷¹

Gwin did not follow through, unfortunately, after a shortsighted lawyer explained that whistleblowers had to be employees of the offending institution, not victims of fraud under the auspices of Medicaid and Medicare.⁷² (This situation is changing, as a few states

63. *Id.* at 114-15.

64. *Id.* at 32.

65. *Id.* at 37.

66. *Id.* at 160.

67. *Id.* at 165-66.

68. *Id.* at 125.

69. *Id.* at 319-23.

70. Randy Beck, *The False Claims Act and the English Eradication of Qui Tam Legislation*, 78 N.C. L. REV. 539, 567 (2000).

71. For class action, see Michael Ashley Stein & Michael E. Waterstone, *Disability, Disparate Impact, and Class Actions*, 56 DUKE L.J. 861 (2006).

72. PELKA, *supra* note 4, at 322.

have adopted expansive self-advocacy or self-enforcement laws in addition to the 1996 False Claims Act, so that whistleblowers can be victims as well.)⁷³

While Pelka organizes this book carefully, leaving readers riveted, what makes it so special is the diversity of voices. And he published it just in time as the heroes of 1960s and 1970s have started passing away. Pelka's *What We Have Done* fulfills the promise of its title, showing just how far we have come.

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Meanwhile, Ruth Colker's *Disabled Education: A Critical Analysis of the Individuals with Disabilities Education Act* will help the parents seeking IEPs as well as disability-studies academics addressing reform. She shows how much further we should go in educating persons with disabilities.

Before 1975, public schools alone denied a full twenty percent of children an education.⁷⁴ They were deemed "uneducable," a lost cause.⁷⁵ By 2004, this perspective had been reversed. Not only does every child have the right to an education, this education is granted under the "zero-reject principle."⁷⁶

Colker, unlike Pelka, spells out IDEA's limitations as well as whom it benefits. The IDEA was initially signed into law in 1975 as the Education for All Handicapped Children Act ("EAHCA").⁷⁷ President Gerald R. Ford did not try to veto this legislation, as Richard M. Nixon had done two years earlier with the Rehabilitation Act.⁷⁸ Last reauthorized in 2004, the EAHCA also underwent a name change, becoming the IDEA. Its purpose is to provide for the educational needs of children (or adults) from age three to age eighteen or twenty-one, depending upon whether they seek education beyond high school.

Unlike disability rights in the ADA, the IDEA is a social policy based upon federalism—or the federal government and states and territories sharing responsibilities and obligations. It contains a spending clause. That is, it applies only to the states, and to local educational agencies that accept federal funding and therefore federal responsibilities and obligations. Like Obamacare, the states can decide not to accept the monies, and thereby duck their obligation for enforcement. IDEA, however, has more support than Obamacare, with all the states and the District of Columbia accepting these federal dollars.

An IEP must be designed to meet the unique educational needs of every child in what is called the "least restrictive environment" appropriate to the specific child's needs. A child can learn only in the least restrictive environment. Yet, this is not enough, as Colker convincingly explains. She sets out to review the "seemingly neutral rules on the educational experiences of poor and minority children."⁷⁹

73. See generally RALPH NADER, UNSTOPPABLE: THE EMERGING LEFT-RIGHT ALLIANCE TO DISMANTLE THE CORPORATE STATE (2014); KATHRYN BOLKOVAC & CARI LYNN, THE WHISTLEBLOWER: SEX TRAFFICKING, MILITARY CONTRACTORS, AND ONE WOMAN'S FIGHT FOR JUSTICE (2011); FREDERICK D. LIPMAN, WHISTLEBLOWERS: INCENTIVES, DISINCENTIVES, AND PROTECTION STRATEGIES (2011).

74. RUTH COLKER, DISABLED EDUCATION: A CRITICAL ANALYSIS OF THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT 5-6 (2013).

75. *Id.* at 18.

76. *Id.* at 14.

77. Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (1975).

78. COLKER, *supra* note 74, at 27.

79. *Id.* at 3.

The problem, Colker rightly argues, is that in 1975, when Congress devised the EAHCA, it offered a spectrum of fourteen specified categories defining the range of physical, cognitive, emotional, and mental disabilities that affect a person's development.⁸⁰ This did not work because the fourteen categories are not only segregated along racial, ethnic, economic, and spatial grounds (e.g., the suburban/urban divide),⁸¹ but these categories limit the very definition of what constitutes a disability and are therefore less expansive than the 2008 ADA. Another critical distinction is that the ADA is an anti-discrimination law but contains no spending clause, as the IDEA does.

To illustrate this fourteen category spectrum and the divisions or inequalities on the basis of demographics, Colker, an Ohio State law professor, describes her own experience with her son Sam, born in 1997, in an affluent suburban community. Diagnosed with a central auditory processing disorder ("CAPD"), Sam has an experience comparable to that of a legally deaf child.⁸² Like many similarly situated parents, Colker filed a due-process complaint under IDEA, under which she could seek resolution through mediation.⁸³ If mediation was unsuccessful, Colker, like other parents, had the chance to go before a hearing officer, who would render a ruling.⁸⁴ Colker did so, retaining two expert witnesses and a lawyer. After a three-day hearing, Colker won resolution for her son.⁸⁵

Colker juxtaposes her experience as a parent with Marilyn's demographic situation. Marilyn (a pseudonym) is a single African-American mom who, like Colker, goes to battle for her son, Kevin, but with the opposite results. Unlike Sam, experts slot Kevin into the "emotionally disturbed" category, diagnosing him with Attention Deficit Hyperactivity Disorder ("ADHD").⁸⁶ On one hand, Colker's son receives a private audiologist who diagnoses him with central auditory processing disorder, enabling him to get a Personal Listening Device ("PLD"), though his school district contested its utility.⁸⁷ On the other hand, Kevin receives very little academic support and winds up getting suspended from school.⁸⁸ Colker, an upper-middle-class, suburban, white career-woman law professor, had the money (i.e., knowledge and power) to hire not one but two experts in addition to a lawyer. Kevin's mother could not participate in his case or file a brief on his behalf.⁸⁹ "While Sam soon flourished in school," Colker concludes, "Kevin was suspended."⁹⁰ The two children represent individuals from the opposite ends of the spectrum. "Why," Colker queries, "do we have a statute that requires families to make advocacy into a full-time job in order to prevail?"⁹¹ There are white and black categories: mental retardation and emotional disturbance are black, and autism is white (meaning that diagnoses if these conditions are disproportionately divided along racial lines). What is more, "special education"

80. *Id.* at 27-42.

81. *Id.*

82. *Id.* at 3.

83. *Id.*

84. *Id.*

85. *Id.* at 3-4.

86. *Id.* at 4.

87. *Id.* at 5.

88. *Id.*

89. *Id.*

90. *Id.*

91. *Id.*

is used to segregate African-Americans, intertwining disability discrimination with racial segregation.⁹²

In addition to outlining the limits of advocacy and self-advocacy, Colker outlines the history of plaintiffs in well-known cases, such as Amy Rowley and Michael Panico. In her discussion of *Board of Education v. Rowley*,⁹³ Colker explains how the U.S. Supreme Court overturned a lower federal court ruling that a school district had to provide Amy with a sign-language interpreter.⁹⁴ Not only did the school district recover costs from the Rowley family in this well-known case, but the district put a lien on their house.⁹⁵ Amy's family moved so she could receive interpreter services, whereas Michael Panico's parents fought, through *pro bono* legal counsel, to place Michael in a private school in order for him to receive an adequate education.⁹⁶ So, even in the best of circumstances, Colker argues, IDEA fell short.⁹⁷

While Congress amended IDEA in 2004, extending more legal leverage and power to parents, this law still does not do enough, in Colker's assessment, to let the underprivileged "take advantage of this new rule."⁹⁸ Evidence of this is how Colker herself, along with many other parents, such as those of Brian Schaffer, endured five to eight to even ten years of litigation, while the Supreme Court ruled that the burden of proof should remain on the parents, who must challenge the so-called "adequacy" of an IEP. Colker does not stop there. She also provides invaluable resources by examining the decisions of hearing officers in states such as Ohio, Florida, New Jersey, and California, along with the District of Columbia. These decisions, like the federal court decisions, lead Colker to the same conclusion—"an enormous enforcement disparity exists between the use of the IDEA's enforcement mechanism for wealthy and poor families."⁹⁹ There is nothing counterintuitive about this: more due-process claims prevail in wealthy, largely white, areas for all types of law.

Some of the reforms Colker prescribes are now coming into place, such as health care for all children as well as transportation to and from special education to child-care centers and independent educational consultants.¹⁰⁰ All this is necessary to help parents navigate the cumbersome special-education system. Like most education advocates, Colker calls for more equitable funding formulas independent of where a child lives, just as American education has become more national than ever with No Child Left Behind, and yet no better funded.¹⁰¹ Clearly something needs to be done, but in this climate in which tenure is jeopardized as one measure, among others, of student performance, this is unlikely to happen.

These two books create their own spectrum of how far we have come and how far we wish to go if we want to live in a nation that values education. Pelka's book puts it in

92. *Id.* at 6.

93. *Bd. of Educ. of the Hendrick Hudson Cent. Sch. Dist., Westchester Cnty. v. Rowley*, 458 U.S. 176 (1982).

94. COLKER, *supra* note 74, at 45-64.

95. *Id.*

96. *Id.* at 65-80.

97. *Id.* at 45-80.

98. *Id.* at 101.

99. *Id.* at 12.

100. *Id.* at 239-46.

101. *Id.*

perspective and Colker's book spells out the "bad" news for the parents' movement. Doing any better in educating our children in this climate of educational and income inequality, along with a predilection for charter schools, is unlikely.¹⁰²

The social program with a spending clause, however, is different. Parents are all fighting the cost of education in pre-kindergarten to eighteen (or twenty-two if they go to college), but in a climate as hostile to kindergarten through twelfth grade and higher education as the current one, it does not bode well. This is a zero-sum battle in which they even get rid of tenure to save costs.¹⁰³

More importantly, Colker's book gives evidence of how limiting the medical model is, and unwittingly gives proof of how important these thirty years were—1978 to 2008. Persons with disabilities no longer think it wise to be boxed into disability categories. These categories—no matter if there are 14 or 1,400—create many problems that a functional definition of disability avoids.¹⁰⁴ The ADAAA is based upon a functional definition of disability that is so broad, expansive, and inclusive that there is hope for a self-enforcement movement somewhat akin to the disability-rights self-advocacy movement. Gwin had it right, now that *qui tam* litigation provisions are included in so many civil-rights and social-policy laws that contain spending clauses.

Pelka's *What We Have Done* and Colker's *Disabled Education* bookend disability rights and social spending on disabilities. This reader encourages you to read the good or efficacious news before reading the academic critic, though both volumes constitute significant contributions in disability studies.

102. See generally SUZANNE METTLER, DEGREES OF INEQUALITY: HOW THE POLITICS OF HIGHER EDUCATION SABOTAGED THE AMERICAN DREAM (2014); DEREK BOK, HIGHER EDUCATION IN AMERICA (2013); THOMAS BYRNE EDSALL, THE AGE OF AUSTERITY: HOW SCARCITY WILL REMAKE AMERICAN POLITICS (2012); JEFF MADRICK, THE CASE FOR BIG GOVERNMENT (The Public Square) (2010).

103. See Howard Blume & Stephen Ceasar, *California Teacher Seniority and Tenure System Is Struck Down*, L.A. TIMES (June 10, 2014), <http://www.latimes.com/local/education/la-me-teacher-lawsuit-20140611-story.html>.

104. See Bradley A. Areheart, *When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L.J. 181 (2008); Deirdre M. Smith, *Who Says You're Disabled? The Role of Medical Evidence in the ADA Definition of Disability*, 82 TUL. L. REV. 1 (2007).