Original sin(s): lessons from the US model of special education and an opportunity for leaders

Lessons from US model of special education

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Abstract

Purpose – The United States (US) system of special education committed three original sins that perpetuate inequities between children with disabilities and their peers. The purpose of this paper is to examine the history of the US system, contrast this history against international disability law and identify opportunities for leaders to transform policy and practice for inclusive education.

Design/methodology/approach — This paper explores the development of the three sins in US special education law: (1) weaving throughout it a medical model of disability, (2) failing to mandate inclusion and (3) hampering meaningful enforcement. The paper contrasts the US system with the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), an international law adopted by 180 nations that requires inclusion of people with disabilities at all levels of systems.

Findings – This paper finds that the United States has not embraced inclusion in education, but has permitted a continuum of segregation and integration. After a discussion of the three sins and the CRPD, the authors describe opportunities for international and US leaders to learn from the original sins of the United States and develop a system of true inclusion for all students through the transformation of policy and practice.

Originality/value – This paper contributes to the literature on policy development and implementation, with implications for future amendments to US education law and international public administration of education.

 $\textbf{Keywords} \ \text{Inclusion}, Special \ education, IDEA, UN \ convention \ on \ the \ Rights \ of \ Persons \ with \ Disabilities, Civil \ rights, Policy$

Paper type Conceptual paper

Introduction

The Catholic theologian St. Thomas Aquinas, working in the 13th century, described how the sins of the first man have been passed on to humankind, generation after generation. This is what Aquinas (1920) referred to as "original sin" [1]. The original sins of the United States (US) model of special education and the laws that shaped the model continue to perpetuate inequity between students with disabilities and their peers. Chief among them is the original sin of adopting a national policy built on a medical model that identifies deficits, diagnoses disability and prescribes treatments in controlled conditions meant to remediate the deficit as symptoms of the disability (Sailor *et al.*, 1980). Identifying and acknowledging the failures of this model creates an opportunity for special education leaders in other nations implementing Article 24 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) to adopt laws, policies and practices that place equity at the center of an educational system that provides specialized supports and services to any child who needs it. Furthermore, it creates an opportunity for leaders in the United States to make penance for these sins by revising US law, policy and practice [2].

Historical understanding of special education law in the United States

Throughout the world, through most of modern history, people with disabilities were viewed as welfare recipients not entitled to equal rights under the law (UN Committee on the Rights of



Journal of Educational Administration Vol. 58 No. 5, 2020 pp. 507-520 © Emerald Publishing Limited 0957-8234 DOI 10.1108/JEA-10-2019-0175 Persons with Disabilities, 2016). As such, the few government programs for people with disabilities that were created merely provided for the basic needs of people with disabilities. However, over time many nations have recognized the rights of people with disabilities and the claim children with disabilities have to equal opportunity in education alongside their peers.

In the United States, the slow recognition of the rights of children with disabilities, enactment of laws and creation of government programs to support equal access to education were an outgrowth of the civil rights movement of the 1950 and 1960s and can be traced through three landmark court decisions and three laws enacted by Congress.

Court decisions in the United States

In 1954, the Supreme Court of the United States ruled in *Brown v. Board of Education (Brown v. Board)* that "separate but equal" was a violation of the 5th and 14th Amendments to the US Constitution and ordered the integration of African American children into public schools. While race-based segregation was found to be unconstitutional in 1954, many states and public schools continued in the decades that followed to exclude students with disabilities as a matter of law, policy or practice [3].

Disability rights advocates viewed the *Brown v. Board* decision as laying the legal footing for parents to challenge these discriminatory practices (Abeson and Zettel, 1977; Lazerson, 1983). However, it took nearly 20 years after *Brown v. Board* for the courts to strike down state laws that excluded children with disabilities (PARC v. Commonwealth of Pennsylvania, 1972) and to rule that insufficient funds for special education service and support do not permit denial of equal access to public education for children with disabilities (Mills v. Board of Education of the District of Columbia, 1972). In summary, the courts found in 1972 that children with disabilities have a constitutional right to equal access to public education. In response, to the court's decisions and at the urging of parents, Congress set to work to create a federal program to effectuate this right.

Special education law in the United States

In 1975 the Education for All Handicapped Children Act (EAHCA), later renamed the Individuals with Disabilities Education Act (IDEA), in 1997, was signed into law to effectuate the rights of children with disabilities. The US Senate and House of Representatives Committee reports explicitly reference the *Mills v. Board of Education of the District of Columbia, PARC v. Commonwealth of Pennsylvania* and *Brown v. Board* decisions, among others, that rely on the principle of equal opportunity to education for children with disabilities and children of color. In reviewing court decisions that led to the writing of the EAHCA, the Senate Committee quoted a passage from *Brown v. Board*, "In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity [...] is a right which must be made available to all on equal terms" (p. 875).

Through the IDEA, Congress created a system of shared responsibility for financing special education services and supports, which requires states and school districts to seek out and identify all eligible children, conduct nondiscriminatory evaluations to determine eligibility, involve parents in decision-making, provide a free and appropriate public education in the least restrictive environment, create a system for due process protections and report on the participation and performance of children with disabilities in assessments (Turnbull *et al.*, 2007; Turnbull and Turnbull, 1978).

Civil rights law prohibiting disability-based discrimination in the United States

The IDEA set the "national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities" in the least

restrictive educational environment (IDEA § 601(c)(1)). Additionally, Title II of the Americans with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973 (Rehabilitation Act) are civil rights laws that protect students from discrimination on the basis of disability in educational settings, government-funded or -operated programs and other public places [4]. These two laws prohibit states, public schools and any recipient of federal funds from discriminating against a child and their family on the basis of disability and mandate certain accommodations for students with disabilities. Accommodations must be provided pursuant to a written plan, which are colloquially called "504 plans" in many schools, named for the section of the Rehabilitation Act that prohibits disability discrimination.

If a school violates its obligations under the ADA, the child or the family may skip the IDEA due process system to enforce their rights under the ADA (*Fry v. Napoleon Community Schools*, 2017) by filing a lawsuit against the school district or seeking assistance from the US Department of Education [5]. The ADA and the Rehabilitation Act broadly define a person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activities (ADA \S 3; Rehabilitation Act \S 504). While all children under the IDEA are generally covered under the ADA or the Rehabilitation Act, many children with disabilities who are ineligible for services under IDEA are covered under the ADA and the Rehabilitation Act. The fact that children and parents have direct access to the Courts to enforce their rights places added pressure on school systems to ensure the school's programs do not discriminate against children with disabilities.

Fundamental to understanding the relationship between these civil rights laws and the IDEA is that satisfying one law does not insulate the school from being found in violation of another law. For example, a school may be in complete compliance with the IDEA yet simultaneously violating the rights of children under the ADA, therefore subjecting itself to significant liability. Moreover, relatively few cases of discrimination on the basis of disability under the ADA have been brought against public schools, making this a developing area of the law. Of particular relevance are the IDEA regulations and lower court rulings that expanded on a few vague provisions in the law to allow for a "continuum of alternate placements" (34 C.F.C. § 300.115). The continuum of alternate placements includes settings outside the general education classroom that range from brief removals of the student from general education to institutional settings where children are segregated from their peers. This continuum of alternate placements allows school districts a degree of discretion that too easily leads to the unnecessary segregation of children with disabilities from their peers (Hasazi *et al.*, 1994; Lazerson, 1983; Skrtic, 1995; Taylor, 1988).

There is no court decision squarely examining whether a continuum that unnecessarily segregates children with disabilities can result in unlawful disability discrimination prohibited by the ADA. However, in 1999, the Supreme Court considered the case of two women with disabilities confined to noneducational institutional settings in Georgia. The Court ruled in Olmstead v. L.C. (1999) that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA. The Court's decision is commonly referred to as an "integration mandate." In light of this integration mandate, special education leaders should work to integrate children with disabilities in nonrestrictive settings to avoid any inadvertent violation of the civil rights of children with disabilities under the ADA or Rehabilitation Act, notwithstanding the continuum under IDEA that condones the segregation of children, frequently unnecessarily.

An increasingly apparent conflict between the integration mandate of the ADA and the permissive segregation of children under IDEA must be reckoned in the United States. In the broader international context, other nations have the opportunity to learn from this mistake and avoid the negative effect of segregating children with disabilities from their peers.

United Nation's convention of the rights of persons with disabilities

In 2006, the UN adopted the CRPD, a sweeping international law meant to give hope and legal rights to billions of people with disabilities around the globe. Article 24 of the CRPD recognizes the rights to inclusive education for all people with disabilities. Moreover, in 2016, the UN Committee on the Rights of Persons with Disabilities noted that after ten years "profound challenges persist" and that many people with disabilities "continue to be denied a right to education, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision" (p. 2).

The CRPD's text is brief, powerful and direct. Nations that have ratified the CRPD "shall ensure an inclusive education system at all levels" and the text enumerates how this applies:

- "Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- (2) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- (3) Reasonable accommodation of the individual's requirements is provided;
- (4) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (5) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion" (CRPD Article 24(2)).

Further, the CRPD mandates the involvement of people with disabilities and their representatives in the development of laws, policies and systems of inclusive education. The United States has not, but 180 other nations have, ratified the CRPD.

Essential to understanding the meaning of this right to inclusive education is recognizing the differences between exclusion, segregation, integration and inclusion. The UN Committee on the Rights of Persons with Disabilities (UN Committee) explains that exclusion is the direct or indirect prevention of denial of access to education in any form (2016, p. 4). Blatant exclusion from schools is less common in the United States at present because such action would be a clear violation of the IDEA. According to the UN Committee, segregation is when education "is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities" (2016, p. 4). The UN Committee describes integration as educating a child with a disability "in existing mainstream educational institutions" so long as the student "can adjust to the standardized requirements of such institutions" (2016, p. 4). Under the current legal concept of the continuum of alternate placements, both segregation and integration are special educational placements in the United States. These include separate schools or classrooms. In contrast to exclusion, segregation and integration, the UN Committee describes inclusion as

a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences. Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organization [sic], curriculum and teaching and learning strategies, does not constitute inclusion. Furthermore, integration does not automatically guarantee the transition from segregation to inclusion (2016, p. 4).

While the US law prohibits the exclusion of children with disabilities from public education, limits their segregation and encourages their integration, the law has failed to adequately support inclusion as described by the UN Committee and failed to mandate changes to content, teaching methods, approaches, structures and strategies necessary for inclusion of students with disabilities. As Schuh and colleagues described, "true inclusion ensures the system itself provides equitable access for all students rather than making changes to the placement of each student without a lens on equality and systemic barriers" (2018, p. 48).

Throughout the struggle for equal access to education in the United States, parents were the driving force behind the courts and Congress prohibiting segregation and mandating children with disabilities be integrated in public education alongside other children (Abeson and Zettel, 1977). However, parents' effort to require inclusion has not yet been successful in the US Ratification of the CRPD and ongoing work to comply with this landmark international law presents an opportunity in other nations for leaders to partner with parents in adopting laws, developing policies and recreating systems that draw upon the experiences of the 45-year-old special education system in the United States and, most importantly, avoiding the original sins of the US model.

Original sins of the US special education system

In 1975, when Congress enacted the EAHCA, it committed three original sins that have been handed down from generation to generation of the special education system in the United States and through its laws. These sins were (1) weaving throughout the law a medical model of disability, (2) failing to mandate inclusion and (3) hampering meaningful enforcement. Each major update to the law in 1983, 1986, 1990, 1997 and 2004 (Education of the Handicapped Act Amendments of 1983; Education of the Handicapped Act Amendments of 1986; Education of the Handicapped Act Amendments of 1990; Individuals with Disabilities Education Act Amendments of 1997; Individuals with Disabilities Education Improvement Act of 2004, respectively) presented an opportunity for Congress to reconcile with children with disabilities for these three sins. However, instead of shifting away from the medical model, mandating inclusion and allowing for robust enforcement, Congress made modest, incremental improvements to the law that had minimum effect on the system as a whole. Moreover, educators and leaders are provided minimal information and support on IDEA and the three sins are reinforced in their practices. Insufficient support for educators and leaders over decades has led to a lack of high-quality training and professional development in the field, further exacerbating the three sins.

Medical model of disability in education

In the 19th century in the United States, disability was given relatively little attention by the public and policymakers. Simultaneously, the field of psychology was advancing intelligence testing as a tool to measure and categorize people, including to determine fitness for military service (Winzer, 1993). This new tool helped legitimize notions of ability being an internal fixed characteristic of a person (Winzer, 1993). More and more, society became focused on difference and categorization. The medical model of disability (medical model) was born out of a belief that the person with the disability bears a quantifiable difference. "[This] model regards the person as having an inherent impairment that the professional (physician, special educator, or other specialists) must remediate" (Turnbull *et al.*, 2007). The medical model places the disability within the person and seeks to cure, fix or resolve the difference between people with a disability and people without disabilities. The medical model inherently places people without disabilities as "normal" and as what should be the ultimate goal.

Skrtic's insightful critique of special education's assumption – that disability is a pathological condition of the person instead of a pathological condition of the organization

(1995) – helps demonstrate the failures of the basic assumptions underpinning the medical model, Namely, the model fails to consider the environment, context or organization the student learns within. The assumptions underlying this model create what Rauscher and McClintock describe as "a pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities" (1996, p. 198) [6]. Instead the blame is immediately placed on an individual. For example, if a person is having difficulty accessing public transportation due to the only access point being stairs, rather than viewing the problem as the environment, society views the problem as the person (e.g. the person cannot climb stairs). This approach leads to fixing the person rather than the environment, context and organization. Alternatively, fixing the environment (e.g. removing the stairs) and organization (e.g. preventing construction of new transit centers with stairs) allows many people access to the public transportation (e.g. not only people with a disability but also people with luggage, people pushing strollers, older adults and others). Although not all situations are as simplistic, the societal view of disability as a "problem" within a person, which underpins the medical model and special education in the United States, influences thinking toward what people cannot do rather than setting expectations of what people can achieve and then remove barriers to aid achievement.

During the 1970s, as Congress drafted the EAHCA disability services relied on the medical model – children with disabilities would be identified, categorized, provided interventions to "fix" the child to become more similar to children without disabilities. In exchange, states and school districts would be provided funding to carry out this work. Under the EAHCA, the goal of the special educator was to provide a treatment to the student (intervention), documented in the individualized education plan (IEP), to improve the student and make them more acceptable for society through functional conditioning or academic instruction. Never is the teacher directed to consider whether the context, teaching or learning environment may be the problem, not the child. Put simply, the EAHCA focused on internal deficits of the child, not the barriers in the environment and system.

Since 1975, academic instruction has changed, yet the focus remained on fixing the child through a series of interventions to make the child more similar to peers without disabilities rather than changing the context, teaching or learning environment.

Failing to mandate inclusion

When Congress enacted the EAHCA, it found that among more than 8 million children with disabilities in the United States, 1 million were outright excluded from education and more than 4 million did not receive appropriate services necessary for equal educational opportunity (EAHCA § 3(a)). The law set minimum requirements that states and school districts must meet to be eligible for federal funding to support special education and related services for children with disabilities (EAHCA §§ 612; 614). Among other requirements, the law required states to establish "procedures to ensure that to the *maximum extent appropriate*, [children with disabilities. . .] are educated with children [without disabilities]" (EAHCA §§ 612(5), emphasis added; 614(a)(1)(C)(iv)). The law did not define "maximum extent appropriate." This provision of the law implicitly endorsed the idea that *some* children with disabilities will not be educated alongside their peers within the school.

Furthermore, states and school districts were required to develop a plan to comply with the law, including "a description of the kind and number of facilities [...] necessary" to provide full educational opportunity to all children with disabilities (EAHCA §§ 612(2)(A)(iii); 614(a)(1)(E)). This provision in the law implicitly endorsed institutional settings separate from the neighborhood school, therefore perpetuating and legitimizing segregation of children with disabilities instead of ending the practice. The law further required that "special classes, separate schooling, or other removal [...] from the regular educational environment occurs only when the nature or severity of the [disability] is such that education in regular classes

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[...] cannot be achieved satisfactorily" (EAHCA §§ 612(5); 614(a)(1)(C)(iv)). The law does not define "satisfactorily." In creating this national policy, the law included an aspirational purpose that nods toward inclusion of children with disabilities in their neighborhood school (EAHCA § 3(a)) and a fraught set of requirements that support integration (EAHCA §§ 612(5); 614(a)(1)(C)(iv)) but permit segregation of children with disabilities from their peers, including in institutional settings (EAHCA §§ 612(2)(A)(iii); 612(5); 614(a)(1)(C)(iv); 614(a)(1)(E). This original sin continues to plague public education in the United States.

While the UN Committee describes exclusion, segregation, integration and inclusion as four separate models of how systems relate to people with disabilities in education – the EAHCA policy framework contemplates these models as a continuum (Taylor, 1988). In 1975, Congress was concerned with ending exclusion – but in writing the EAHCA, it created a framework that permitted segregation, supported integration and mostly ignored the possibility of inclusion. In drafting the law, there is little evidence that Congress seriously considered whether the context, teaching or learning environment was the root cause of the problem, not the child. This resulted in Congress embedding into the law a set of vague provisions that allowed for a continuum of segregation and integration to be legitimized while failing to mandate inclusion. Across states, the percentage of students with disabilities in the general education classroom 80% or more of the time ranged from 37 to 83%. Similarly, for students with disabilities who spend less than 40% of the time in general education, the percentage ranged from 5 to 21% (US Department of Education, 2017). State-level variation in this continuum (White *et al.*, 2018) compounds problems with this national policy. This failure continues to plague children in the United States currently.

School leaders and teachers may struggle with inclusion in schools due to the lack of mandate in the law. Paired with a medical model on disability, the lack of mandate of inclusion causes significant hurdles in moving toward inclusive schools. Teachers and leaders often lack the training for inclusive education (Kurth and Foley, 2014) and the fundamental belief of many educators is that children with disabilities need specialized education in special, separate places (Fuchs *et al.*, 2010). Leadership for inclusive education requires clear goals, training, resources and monitoring, among other critical implementation steps (Billingsley and Banks, 2019).

Hampering meaningful enforcement

The practical impact of law and policy is linked to a person's ability to allege violations and realize permanent enforcement of the law's requirements for that person and other people in similar situations. Recognizing the power imbalance that exists between school districts and parents and the government's obligation under the due process clause of the 14th Amendment to the US Constitution, in 1975, Congress required that states and school districts meet a set of minimum procedural safeguards in order to receive funding for special education from the federal government (EAHCA § 615). While the goal of creating procedural safeguards was laudable and could be helpful to families, the scheme created by Congress was slow, cumbersome and failed to correct the power imbalance that exists between school districts and individuals, while creating a significant departure from enforcement of other civil rights laws.

The procedural safeguard scheme created by Congress granted parents of children with disabilities the right to examine all relevant records and obtain an independent educational evaluation (EAHCA § 615(b)(1)(A)); be notified of any action related to the identification, evaluation or education placement of their child (§ 615(b)(1)(C)); be informed of procedural safeguards available to the family (§ 615(b)(1)(D)); and file a complaint and receive an impartial administrative hearing before the school districts or state on the complaint (§ 615(b)(2)). While Congress permitted parents to be accompanied and advised by an attorney at any administrative hearing (§ 615(e)), it did not provide funding for families that could not

afford to pay an attorney nor did it create an independent system of free legal providers as it did in other areas of disability rights (e.g. Developmentally Disabled Assistance and Bill of Rights Act).

This enforcement scheme perpetuated the power imbalance that exists between school districts that can financially afford to be represented by an attorney and many families of children with disabilities who are left to make their case without the aid of a professional advocate. The administrative review process that Congress created is run and supervised by the very recipients of federal funds who could lose funding for violations of the law. This inherent conflict denigrates procedural safeguards meant to protect families. Furthermore, only after exhausting this administrative process could a family seek relief from a truly independent branch of government – the courts (§ 615(e)(2)).

This enforcement scheme was a radical departure from enforcement of civil rights law in the United States, which generally relied of federal agencies to investigate allegations, which are independent from the states and school districts that receive federal funding (e.g. Title VII of the Civil Rights Act or Title IX of the Educations Amendments Act of 1972) and permit individuals and groups of people to pursue their claim in the courts without exhausting a lengthy administrative process run by the state or locality (e.g. Civil Rights Act of 1871). The scheme Congress created frustrates the original purpose of the EAHCA "to assure that all [children with disabilities] have available to them [...] a free appropriate public education which emphasizes special education and related services designed to meet their unique needs" (§ 3(a)).

Despite the burdensome and challenging process for enforcement of rights through procedural due process under EAHCA, families continue to fight against the power imbalance and challenge decisions by school districts currently. However, new principals report a limited understanding of special education law, which can lead to significant compliance issues, challenges with leadership and difficulty effectively providing special education services or responding to complaints (Davidson and Algozzine, 2002). This lack of knowledge is likely due to inadequate training in leadership preparation, as available research shows few states require a special education law course for administrators (Valesky and Hirth, 1992).

Best practices for US and international school leaders to transform policy and practice. The original sins of the US model of special education – and the laws of the United S – illuminate how shortcomings in the development of a legal framework and enforcement scheme can persist for decades, therefore frustrating the rate of advancement and progress for children with disabilities. By examining these original sins, nations working to comply with the CRPD may avoid repeating the mistakes of the United States. This is accomplished by rejecting the medical model of disability in favor a social model, demanding inclusion as the only option available for the education of students with disabilities and allowing for individual parents and groups to enforce the right to inclusive education for all people with disabilities.

Notwithstanding shortcomings in the law, school leaders in the United States may choose to exceed the federal and state minimum requirements. If school leaders choose to take this step, states and school districts will shake off the legacy of exclusion, segregation and integration and embrace inclusion for children with disabilities alongside their peers. Examining history and research is helpful when gazing to the future of special education for both policymakers and school leaders and will require different policies, administrative practices and leadership.

Redesigning laws for inclusion and guaranteeing of rights. Creating a legal framework in nations implementing the CRPD that avoids the original sins of the US model – or amending laws in the United States to address these shortcomings – while embracing inclusion as the future of special education requires a radical rethinking of the law and enforcement scheme. While not a comprehensive list, these laws should:

- (2) provide the absolute right to inclusive education;
- (3) close and disallow separate institutions for children while requiring appropriate supports in the community and school, including behavioral health;
- (4) entitle children to adequate public financial support through mandatory spending by the central government to meet the needs of each child with a disability;
- (5) require independent investigations of violations of children's rights by independent agencies of the central government;
- (6) establish a nationwide protection and advocacy system to pursue legal, administrative and other appropriate remedies to ensure the protection of, and advocacy for, the rights of children in special education;
- (7) provide attorneys to parents at no cost when disputes arise with the school;
- (8) permit parents, groups of parents and organizations representing the interests of children to immediately seek relief in court for violations of the law by providing a private right of action under the law;
- (9) ensure local transportation, accessible housing and other societal barriers do not interfere with the right to inclusive education; and
- (10) make schools accessible to all children by designing and redesigning the schoolhouse with the needs of children with disabilities in mind.

This broad legal framework avoids the harmful continuum of alternate placements and thereby one of the original sins of the US model. This framework also allows for multiple avenues to meaningful enforcement of the law's requirements, avoiding another of the original sins. In summary, this alternative legal framework provides people with disabilities an equal right to education and independent, meaningful avenues to enforce their rights.

Leadership of educational systems for inclusion. Leadership for inclusion is challenging and complex (DeMatthews, 2015; Billingsley and Banks, 2019) and requires a rethinking of how schools are organized (Ball and Green, 2014; Boscardin and Jacobson, 1997; Skrtic, 1991, 1995), how to lead (Billingsley and Banks, 2019) and how to improve instruction for inclusive education (Cornett *et al.*, 2019). In short, leading an inclusive educational system requires a sea change in how school administrators in the United States perform their job.

Skrtic's (1995) analysis of school organization and change shows that most schools are organized as professional bureaucracies that resist adapting its structures and practices to meet new challenges. When asked to change, these schools build "symbols and ceremonies of change" that do not relate to actual practice in the school (p. 203). Leaders must resist the urge to create separate, segregated administrative systems while working to dismantle these symbols and ceremonies in favor of solving "problems of practice in equitable and socially just ways inherent in diverse, complex, high-stakes educational environments" (Boscardin and Lashley, 2019, p. 39). For this to occur, all staff must feel responsibility for the success of children with disabilities.

Change requires continuous monitoring, evaluation and leadership. Leaders must create administrative systems that solicit complaints of discrimination and rights violations, thoroughly and independently investigate and take steps to intervene and remedy the problems found. To understand whether the legal framework is being appropriately adopted and changes made, leaders must collect data and other information to continuously evaluate the system and how children are experiencing the system. The policy and administrative

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changes described will aid leaders in other countries in avoiding the original sins of the US model and assist leaders in the United States to adopt inclusion as the only educational option.

Inclusion is a paradigm shift for many educators and leaders; special education, as previously described, is often thought of as occurring in separate settings by different school staff and having to be conducted in those settings due to the unique nature of the services (Fuchs et al., 2010). This mind-set of how to "fix" children so they can participate in the academic environment is rooted in the medical model (Turnbull et al., 2007). To move toward a system of full support, leaders and educators must abandon this old model and embrace academic and social inclusion of children with disabilities — complete and full inclusion of the child. In practical terms, separate classrooms must be converted, staff must be retrained and reassigned and, most importantly, structural changes to the organization of the school, curriculum, teaching and learning strategies must be undertaken to provide access to all children.

In 2017, the Schoolwide Integrated Framework for Transformation, known as SWIFT, put forth an operational definition of equity-based inclusive education that is instructive for school leadership:

Equity-based inclusive education means all students, including those with the most significant support needs, are educated in age-appropriate classes in their neighborhood schools. Students receive the help they need to be full members of their general education classrooms. Every member of the school community is welcomed, valued, and participates in learning. Inclusive education means that districts support schools, and schools and families support one another as ALL students are welcomed and included in their communities (SWIFT Center, 2017, p. 2).

This definition is instructive for how to lead for inclusion. The definition outlines that inclusion is academic and social inclusion, *all* children are included and children are in age-appropriate classes, not separated by skill level. Defining inclusion is simply the first step. McLeskey and colleagues (2014) outline five key elements identified in the research needed for successful inclusive schools:

- (1) systemic change for the entire school;
- (2) coherent, clear focus for change;
- (3) time for planning and training;
- (4) continual focus on capacity building and professional development; and
- (5) strong leadership (p. 11–12).

The definition helps to develop a focus, then leaders must determine how to reassign staff and provide necessary training to meet the needs of children in each classroom, receive training themselves on inclusive practices under the new paradigm and determine the necessary changes to the curriculum needed to ensure all children are successful (Shogren *et al.*, 2015).

Support for educators on inclusion may include different instructional methods, such as coteaching and differentiated instruction (Waldron and McLeskey, 2010), and professional development on models of supporting all children, such as positive-behavior interventions and supports (Billingsley and Banks, 2019; Shogren *et al.*, 2015). As Waldron and McLeskey noted "high-quality professional development is of critical importance in ensuring that teachers and other school professionals have the necessary skills to implement and sustain new practices that are needed to support inclusive programs" (2010, p. 62). Leaders that are prepared to support educators in each step of the process and provide ongoing, job-embedded professional development opportunities and a coherent focus are critical to the success of children with disabilities in an inclusive school (Cornett *et al.*, 2019). Although the changes are not easy, the benefits to all children from inclusive education are significant (Choi *et al.*, 2017).

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Conclusions and opportunities for educational leaders

The original sins of the US model of special education have limited the potential of generations of children with disabilities in the United States. This paper has explored how those original sins came to be and what could be done to reconcile with children and families for these sins. Educational leaders outside the United States in nations that have adopted the CRPD have an opportunity to avoid the original sins of the US model by adopting strong laws that demand inclusion, prohibiting discrimination, examining and changing environments and organizations to support inclusion, closing institutions and developing an enforcement scheme that provides for the expedient enforcement of rights through multiple avenues. Moreover, in the United States, the lessons of history create an opportunity for legislative leaders to improve laws and for other school leaders to reshape special education services and supports to be inclusive.

While there is an extensive research base on the benefits of inclusion for children with disabilities and their peers, novel questions remain on the transition of systems from segregation and exclusion to systems of inclusion on a national scale. Future research should explore systems change and provide a path for policymakers, school leaders and stakeholders to create an inclusive system that supports all children. As new research is conducted, action is also needed. Given the extensive research base, leaders have a pathway for change. What is needed now is action and leadership to reform school systems to be inclusive and support *all* children.

Notes

- 1. The middle-ages "religio-moral" construction of disability persists currently in some parts of the world. It views a person's disability as punishment for their sin, flaws or moral shortcomings. Authors reject and oppose this view. Aquinas relied on a version of the religio-moral construction to link original sin to prevalence of disability among humankind more broadly, which we also reject. For a brief discussion of why viewing disability as a moral condition is inconsistent with a modern view on disability, see the introduction of Goodley (2011, p. 5–10). Nevertheless, Aquinas's original sin concept is useful for examining the impact of EAHCA's framework on children's equity and inclusion 45 years beyond enactment.
- Authors use the term "leader" to embrace a wide group of stakeholders who make laws, set policy, direct actions and hold influence over the educational system. This is consistent with a distributed model of leadership used in most educational settings and scholarship on policy implementation (Spillane et al., 2002).
- After the Supreme Court's decision in 1954, state laws and policies that mandated or permitted segregation on the basis of race were invalidated. However, school segregation on the basis of race continues because of various forms of institutional racism in the United States (Rothstein, 2013).
- 4. In addition to discrimination on the basis of disability, under civil rights laws in the United States, children are protected from discrimination on the basis of race, national origin, religion, language spoken (Civil Rights Act of 1964) and sex (Title IX of the Education Amendments of 1972). Significant scholarship has explored the intersection of multiple of these characteristics with disability, see, for example, Artiles et al. (2010). This paper focuses on discrimination on the basis of disability.
- In Fry v. Napoleon Community Schools (2017), the Supreme Court unanimously ruled that a child with
 a disability need not exhaust all IDEA administrative procedures before suing over access to
 education under the ADA. The exhaustion requirement narrowly applies to a child's right to free
 appropriate public education.
- 6. The medical model of disability also underpins as the concept of ableism. Rauscher and McClintock's (1996) insightful writing describes the effect of the medical model. There are clear parallels with Skrtic's (1995) critique of special education, which views disability as a pathological condition instead of an organizational pathology. As Hehir noted, these realities lead to the realization that

- "many of the problems that disabled students experience have discrimination at their core" (2009, p. 9).
- In the United States, under the ADA and the Rehabilitation Act, discrimination on the basis of disability is strictly prohibited.

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