

November 2021

What are Intended as Systems of Support become Systems of Struggle

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Recommended Citation

Timpe, Kevin (2021) "What are Intended as Systems of Support become Systems of Struggle," *Ought: The Journal of Autistic Culture*: Vol. 3: Iss. 1, Article 8.

Available at: <https://scholarworks.gvsu.edu/ought/vol3/iss1/8>

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Cover Page Footnote

I'm grateful for helpful comments from Rob Rozema, Bekah Hereth, and Tony Stiff on earlier drafts.

What are Intended as Systems of Support Become Systems of Struggle

Kevin Timpe

Disabled students regularly get the shaft when it comes to public education. While things are admittedly better than they used to be—there are, after all, now systems and laws that seek to protect them—those very systems that are supposed to support disabled students all too often themselves are part of the problems that disabled students and their families face. The systems of support often are systems that cause people to struggle because the system requires that families make sure students get what they should. The systems do not enforce themselves, and so families have to, putting a further burden on them. Let me explain.

The United Nation's 1975 Declaration on the Rights of Disabled Persons lists education among the human rights owed to disabled individuals. Their reasoning, in part, is that education is needed to help disabled people “develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration. The Declaration (1975) continues that disabled people are to be given the same dignity as non-disabled people, and have

. . . the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible . . . These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, color, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.

For most of our country's history, there was no right to a public education for disabled students (much less the other rights the Declaration mentions—in what follows, I'm only going to focus on public education).

Massachusetts was the first state to pass a compulsory education law in 1852, based on a similar law when it was a British colony. In 1918, Mississippi became the last state to enact a compulsory public education. (Alaska wasn't yet a state.) Despite this rather quick move toward compulsory public education across the United States, most states didn't offer much less require education for disabled students. For most of the 20th century, options for disabled students to receive a public education varied widely by state, and even often within a state. The Education for All Handicapped Children Act (EAHCA) became the first US federal law extending the right to public education to disabled students when it was passed in 1975, the same year as the UN's Declaration.

The EAHCA's passage was, in part, a response to a congressional investigation that found that less than half of the country's 8 million disabled children were receiving an appropriate education, and that nearly 25% weren't receiving any public education at all. While an important step in securing civil rights, the EAHCA didn't establish the civic works needed to implement and enforce the law. The EAHCA was updated in 1990, including changing its name to the Individuals with Disabilities Education Act (IDEA). IDEA guarantees disabled children the right to a "free appropriate public education" (FAPE). Furthermore, it requires that education to be provided in the "least restrictive environment" (LRE)—that is, for them to be educated with non-disabled students in the general education setting to the maximum extent appropriate.

So IDEA seeks to be a system of support that guarantees an education for disabled students, at least up through high school. And while it does guarantee a right to a public education regardless of disability status, in actual implementation IDEA causes many of the struggles that even to this day families wrestle with, largely because IDEA lacks measures to ensure enforcement. It is good that our disabled students are guaranteed an education, but it'd be nice if we didn't have to push back so hard against school structures to get them that education. It can be especially difficult for students with hidden disabilities to get accommodations and supports. And it'd be good if our colleges and universities were also more accessible than they are. At these levels, many students have to continue the advocacy that their families began, though now in institutions that are often even more deeply ableist than secondary schools (see, for instance, Dolmage, 2017).

While I'm an academic, for most of the past decade I've also been an advocate for disabled students in public educational settings. My spouse and I began this process when we lived in Idaho. We realized that our son's public school district had been violating state and federal law with regard to his education for over a year. (I detail our experience at greater length in Chapter 1 of my book, *Disability and Inclusive Communities*.) According to my favorite section of IDEA to quote at schools, public school districts must ensure that—

(i) To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled, and

(ii) special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

It took us a year of hard, drawn-out advocacy to get our son's district to allow him to go to the elementary school that we could see from our house rather than being bused across town where the district funneled many of the disabled elementary students into a single school, where they spent most of their time in a self-contained classroom. We also were able to get the district's policy changed. For subsequent years, he was able to go to school in our neighborhood. He was in the general education classroom more, not just with his non-disabled peers for recess, lunch, and 'specials' like art or music. The school admitted that he didn't need to be working on the same assignments as his non-disabled students to be in the general education classroom. The same was also true for other disabled students. The district had to hire additional aids. As a result of our advocacy, not only our son but many other children were actually given the kind of education that a 39-year-old federal law said they were entitled to.

We took that as a major win, even if the fight shouldn't have been needed. (Since there are no real enforcement teeth in IDEA, districts have little reason to follow it unless pressed by families. See the discussion in Laviano & Swanson, 2017, pp. 75-79.) The district's director of special education was reassigned until he was able to retire, and his replacement, as well as some of

his new staff, worked closely with us to make sure that the education offered our son, and the other children we advocated for, was better than what the district had offered.

Exclusion in the Time of COVID

Five years ago, we moved from Idaho to Michigan. I've continued to do advocacy work, and the COVID-pandemic made it possible, through the widespread use of Zoom and other similar software, for me to advocate from a distance. I've been contacted by three different families back in our home district who were notified that their children would be reassigned to a school other than their neighborhood school so that they could be a part of a new autism-focused program. Perhaps unsurprisingly, information on this program cannot be found on the district's website, but the district is trying to congregate lots of autistic students in one school in a largely self-contained program that would keep them separate from their non-disabled peers much of the time.

I've been working with these families to push back against the change in placement. According to the law, parents have the legal right to participate as equal members of the team to decide their child's IEP. An IEP is an Individualized Education Plan, and is a legal document specifying what kinds of special educational services a disabled student will receive from the district. It also specifies where they will be placed, both in terms of classrooms and school buildings, to receive those services. A district cannot change the building where a student is educated without updating the child's IEP. (The best resource I know of for families in understanding IEPs is Laviano & Swanson, 2017.) As mentioned above, parents are supposed to be equal members of the team that decides the details of the IEP. In the past few weeks, over 3 hours of IEP meetings have secured one student the opportunity to start the school year in their neighborhood school rather than being forced into the new autism program across town. I continue to work with other families to try and help them secure the same goal.

But why is this needed? Why do we have to force district staff to admit that they don't have data that justifies removing students from their neighborhood schools? Why aren't the school staff charged with carrying out IEPs trained in disability studies? Why do districts try to do this to families

without their full consent in an IEP meeting and then pass it off as somehow motivated by the student's best interest rather than district finances and staffing levels?

The answer that I've learned is that the special education system that was set up to provide disabled students with proper access to public education has actually become a system that makes it hard for families to realize its vision. The system, that is, has itself become a *source* of struggle.

One of my academic projects these days is a paper on how the pandemic has disproportionately impacted disabled students—the very students that are often already disadvantaged, even in the absence of a pandemic, by the very system that is supposed to secure them a proper public education. One public discussion piece I read on the topic is Tamaira Reid's 2021 article, "The Great Erasure of (Special) Education." In it, Reid talks about how school closings in the NYC public school system have impacted her son Ollie and over 220,000 other students with disabilities. While there are parts of the article that I disagree with (as an academic, it's quite rare that I read something that I completely agree with), parts of her telling Ollie's story resonate quite close to our own experience. And this paragraph strikes a particular chord:

I've learned to navigate the Special Education system by way of the Department of Education; this is an ongoing, often grueling and frustrating process. I have had to learn what is afforded to my child by law, under the Individuals with Disabilities Educational Act, and to identify when his civil right to an "equal and appropriate education" (IDEA) has been violated. Together we have weathered the storm of the Early Intervention experience and subsequent clinical evaluation and diagnostic tests (beginning at age 2), secured a spot in a center-based preschool after having to apply and go through a harrowing vetting and admissions process, have attended dozens of IEP meetings with teachers, specialists, social workers, and DOE representatives, have benefited from endless hours of therapy and interventions by fantastically devoted, skilled, and dedicated educators, and ultimately

transitioned to a public school special education program with an ICT (Integrated Co-Teaching) classroom designation on his IEP (2021).

Our experience with our disabled son is a little different, both in terms of our earlier advocacy in his public school when we lived in Idaho, but also the past few years here in Michigan. Our is autistic and has other disabilities. He attends a private school, and has since we moved to Michigan. Private schools are not bound by IDEA, the federal law outlining the protections and services for disabled students in public education. For years in Idaho, IDEA and the Idaho Special Education Manual were our primary weapons in getting our son the services that he and then others were entitled to that Nampa Public Schools had denied them.

So when we enrolled him in a private school, we were hesitant and conflicted. But it's been a great experience. Not perfect. But the school has always not only listened to but also taken into account our input. I've been told, not by people at his private school but in general, that I'm "sometimes hard to get along with," or that I'm "not nice" and "confrontational." I don't seek out confrontation for its own sake, but I'm not afraid of it and will engage in it if it's needed. Sometimes, social systems need pushed. I'm willing to be a fulcrum. School staff often see me as "not nice" or "confrontational." In fact, I was once called "an instrument of Satan" in regard to my advocacy work. But this is to join a long line of pioneering advocates, from Ed Roberts to Judy Heumann to Arthur Fleischmann, that caused similar discomfort.

There is, of course, a long history of very problematic advocacy by non-disabled parents for their disabled children. It can become overbearing, demeaning, and oppressive if done wrong. One way that I've sought to avoid falling into this trap is by listening to disabled voices and modeling my own work on advocacy by disabled people. We hope to train our son to eventually be able to engage in his own self-advocacy. But at present, he needs others to advocate for him so that he can get the education he should get.

In his private school, our son receives certain therapy services from the public school district that the private school is in, as required by state law. He isn't entitled to an IEP, but has a non-public service plan (NPSp) that we have to update every year. The NPSp details his goals and the services that the public district is required by IDEA to provide. The spring of 2020 was, of

course, a pandemic-caused shitshow. The public district our son receives services from, like all too many across the country, ended up considering their online instruction to be optional resources and supplemental learning activities, sometimes also referred to as enrichment learning resources, rather than official instructional time.

While this was understandable in the early days of the pandemic, things got more problematic as the initial weeks spread to the rest of the academic year. We found our son unable to receive the services he's entitled to. But he, like hundreds of thousands of other disabled students, wouldn't get those services at all when official instruction was suspended for the rest of the year. As the Executive Director of Special Education and Early Intervention Services said in an email:

No official instruction? No FAPE [that is, a free appropriate public education as guaranteed by IDEA]. When we shift from [Optional Online Enrichment] Resources to [official] Instruction, we shift to FAPE. If we move to a virtual learning platform, we will be mandated to open every IEP (2843), 504 Plan (188) and NPSP [non-public service plan] (294)—and at least amend . . . to identify what they will be receiving as our offer of FAPE. (Because FAPE needs to change when environment changes....) We will be crushed with [legal] compliance when we should be thinking about instruction. (L. Lamore, email, March 20 2020; obtained via FOIA)

As the email indicates, the district's short-term solution to being "crushed with compliance" was to declare the entire semester lost in terms of official instruction. Rather than ensure that disabled students have access to their education as required by IDEA, the district decided not to count spring 2020 as actual instruction. We'd hoped for an improvement during the fall of 2020 when official instruction began again. Some of our son's school-based therapy services were provided virtually, a real struggle given his autism; but at least he was receiving some of the services his NPSP required. I realize I shouldn't be prepared to offer public schools cookies for providing what's required by law, but I know all too well that too often the law doesn't succeed in ensuring what it's supposed to. So even getting back to services seemed like progress.

We'd been warned by the staff at his private school that the public school was cutting back the services they were willing to offer lots of students in the private schools. And that's exactly what we found at his NPSP meeting. At our yearly update meeting in December, the school suggested keeping his weekly speech therapy services in place, cutting his OT services by over half, and completely eliminating all direct PT services. When the school is functionally able to specify 'the nature of severity' of the student's disability, overruling the parents' input, such reductions are all too common.

We thought that cutting these services didn't serve our son well. The private school's staff thought the same. As did our son's private therapist. We vocally opposed the proposed NPSP. But, given how the Michigan Administrative Rules for Special Education are written, the district didn't need us to sign our agreement with the plan to make it official. In states where a signature is needed for a plan or IEP to go into effect, refusing to sign a proposed IEP is one tool families can use, for without a current IEP the school is in violation of state and federal law. This was a move we'd used in Idaho. But that's not how it works in Michigan. And so the public school staff was able to put into place a NPSP that we and his private school staff, who are supposed to be equal members of the team, actively disagreed with.

It was an instance of what Priya Lalvani and Chris Hale call "the pacification of the parental voice" (2015, 32) and "systemic parental disempowerment" (2015, 34). Our only recourse was to file a state complaint, which we did. As part of our preparation for that complaint, we filed a FOIA (Freedom of Information Act) request with the district, getting every email from district staff that mentioned or referred to our son from the previous year, as part of his educational record that we have a legal right to. We learned that there had been a meeting of district staff prior to our meeting. (Rather suspiciously, we were told that nobody took any written or typed notes about that meeting.) We also found out that district staff's response to us pursuing dispute options laid out under state law was "Ughhh" (M. Townsend, email, December 16 2020; obtained via FOIA). Given how badly the meeting in December went, we also filed a formal complaint with the Michigan Department of Education. And the Department of Education found the district to have failed to provide him with the education that he's entitled to by law.

But I also know that even if we make progress with our son's current NPSP, that's not likely to make a big difference to the system. The law is all too frequently ignored. Over half the districts that I've been in as an advocate have violated IDEA in some way or others. And that's just considering the students I've advocated for. In principle, failure to follow IDEA puts a district's federal and state education funding at risk. But to the best of my knowledge, no district has ever lost its federal education funding because of IDEA violations, though there have been numerous cases. The pacification of parental advocacy is made possible by the absence of serious budgetary accountability. Some of these violations are massive in scope. And given the lack of enforcement, the burden falls on families to try to ensure that the violations and failures are addressed.

The Struggle for Inclusion Continues

Evidence suggests that many children who qualify for special education services under IDEA are not properly identified, especially in poorer communities where such students are less likely to have access to health care and testing. The reliance on private enforcement of identification and enforcement undermines some of IDEA's intended aims, since families in poverty are also less equipped to pursue those private means (see Sauer & Albanesi, 2008). As Eloise Pasachoff notes, "the available evidence suggests that wealthier parents continue to come out ahead in the enforcement game . . . Families with more financial (and perhaps also educational) resources are better situated to pursue their rights under the IDEA" (2011, p. 1426f). As a result, many children who should receive special education services fail to. Many children 'fall through the cracks', so to speak.

Sometimes, this is a result of a family not knowing how to navigate the procedures required. This ignorance is often compounded by the way the IEP process is set up, requiring parents to "negotiate with school committees who are not always well educated about the child's specific disability and who often try to save money, even at the cost of not supporting a special placement for a child who clearly needs one" (Nussbaum, 2010, p. 85). But the fact that many local and state educational services have policies in place that fail to provide what IDEA is supposed to guarantee suggests that perhaps a better metaphor is that students are actively 'pushed into the cracks'.

Consider, for example, Texas. In 2004 the Texas Education Agency suggested that its districts should aim for providing no more than 8.5% of its students with special education services. While this was intended as a benchmark and not a cap, since such caps have no place under IDEA, the US Department of Education's Office of Special Education Programs found that Texas districts had used the 8.5% number as a cap, a percentage nearly 35% below the rate of services provided in the other 49 states (Chung 2020). This led to widespread denial of services that IDEA requires. In 2018, the US Department of Education sent a letter to the Texas Education Agency indicating

TEA's use of the 8.5 percent indicator contributed to a statewide pattern of practices that demonstrate that TEA did not ensure that all [districts] in the State properly identified, located and evaluated all children with disabilities who were in need of special education and related services. (Matos, 2018)

The Texas Education Agency would later admit that its policy led to up to 189,000 students who qualified for such services not receiving them. Then Texas Governor Greg Abbott instructed the Texas Education Agency to prepare a plan to address those students who were denied services. "Parents and students demand significant actions be taken now to improve special education in Texas" (Matos, 2018). And while 101,400 students were eventually identified as eligible for compensatory services, as of May 2020 fewer than 8,000 of those students had actually received them (Webb, 2020). Even when the state recognized a systemic failure, the burden too often fell on individual families affected rather than collective action to ensure that compensatory services were actually provided (see Ong-Dean 2009, 2).

According to the most recent report by the US Department of Education, only 21 of the 50 states' educational services actually meet the requirements and purposes of IDEA part B, which serves students with disabilities between the ages of ages 3 and 21 ("2020 Determination Letters on State Implementation of IDEA"). Over 5,000 written state complaints are filed under IDEA each year, and more than three times as many due process complaints ("IDEA Data Brief: Written State Complaints." 2017; see also Vu, Launey, & Ryan 2020). While not every filed case indicates a failure for disabled individuals to receive the services afforded to them by IDEA, it's pretty obvious that the law has not achieved the kind of protections it aims

at, despite being 31 years old (or 46 years old if we count from the passage of EAHCA). And how the law is implemented, both in state law and in de facto functioning, places the burden on families. This burden is laden with heavy investment of time, emotional labor, work, and often money.

One of my favorite philosophy articles on disability is Eva Kittay's "The Personal is Philosophical is Political" (2010). Kittay, the mother of a cognitively disabled adult child, subtitles the paper as "Notes from the Battlefield." In each of these ways—personally, philosophically, and politically—I'm now convinced that our country's present approach to special education, which is supposed to support students with disabilities, is actually a system of struggle. Personally, I've seen how the burden of ensuring that districts are following the law falls on families. Given the work, time, and money involved, parents are "often reluctant to resort to the law and retreated in the face of what they actually thought to be unjust and unfair" (Dierenfield & Gerber 2020, 16). Philosophically, I've argued in print that existing public regulations "not only permit but often give rise to administrative injustices" (Timpe, 2018, p. 258) that disadvantage disabled students.

This disadvantage is closely connected with other demographic features that also increase the likelihood of disadvantage, such as class and race. Gregg Beratan argues, for example, that IDEA functions to "maintain the effects of the unacceptable and illegal segregation by race" (2008, p. 337; see also Lalvani & Hale 2015) even if that is not the law's intent. Politically, the system is too much like other aspects of our communities, of our polis—it reinforces the power dynamics afforded by the status quo, even if we give lip-service to the problematic nature of the present system. COVID exacerbated these inequalities that were already entrenched in public education: chronic underfunding, gutting public education and the charter school movement, school quality tied to socioeconomic status and property values. As Carol Hay puts it, one outcome of the pandemic is "exacerbating social problems that have always been there, making them such that even the socially privileged can no longer avoid them, and of course making them even worse for those who have been suffering their brunt all along" (2020, p. 8).

Advocacy, to me, is a moral imperative—one that needs to be done for the sake of those whose communities are marginalized or ignored. Since I see

it as an issue of justice, I care about not only our son but other disabled students, especially those whose families, who for reasons related to education, class, and other resources are less equipped to advocate for themselves. If it is so hard to get our son proper services when we're a white, middle class, two-parent, and highly educated family, how much harder for those who don't share our privileges? The system is supposed to support all such families. But the simple fact is that it fails far too many of them.

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