

OPINION: US schools must stop excluding children with disabilities

Despite laudable progress, too many schools still offer the bare minimum to disabled students

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We are at a watershed moment in the history of disability rights in the United States. Laws and cultural norms have shifted to create new opportunities, better access and a relatively more inclusive society. And yet people with disabilities, their caregivers, families and allies have never been more aware of the many barriers they face. We encounter these barriers not just in our own lives but also through social media, with individual struggles shared more easily, revealing patterns of discrimination and exclusion. For parents, that struggle is nowhere more apparent than in schools.

“The school district is not accountable for whether your child receives the best education for them or even a good education,” a lawyer for a rural Midwestern school wrote in a recent letter to the mother of a child with Down syndrome. “The district is legally required to provide the minimum ... and that is what we are doing.” (Names have been withheld to protect the child from retaliation, since the dispute is ongoing.)

Here is the worst part: The attorney is not necessarily wrong. All schools have to do is the minimum and they can skate right on by.

I am acutely aware of these challenges. My son, Nico, has Down syndrome and has just finished second grade at a lovely public elementary school in a suburb of Chicago. His teachers and the school’s support team are well trained and appear to be people of goodwill. Yet I spent much of the year growing increasingly upset about the ways in which he is excluded from academic and enrichment activities.

He spends in-school social time with his classmates (recess, lunch, art, gym, music), but very little academic time. We regularly got notes about events in which he was not included. Sometimes we found out about opportunities only after they had passed, because although our son communicates effectively in many ways, expressive speech remains a challenge. While neurotypical kids generally tell their parents about upcoming school events, we sometimes miss messages buried in bags, if we get a message at all. Every Pajama Day or Spirit Day is an opportunity for Nico’s differences to stand out.

Class assignments were sent home with no guidance as to how or whether Nico might take part. During an annual musical performance in March, we received an email that said every child was to wear a shirt matching his or her mask, but Nico’s teacher told us she hadn’t seen a mask for him. Last month the

teacher put on Readers Theater (in which kids acted out books) and told us in an email that “Nico would get to participate as an audience member.”

I am in regular conversation with parents across the U.S. who are struggling through much more difficult situations, whether from abuse, [mockery](#) or just general resistance to meeting a child’s needs. Sometimes school districts are resistant to change, claiming they are not required to provide the best option for students, instead opting to offer the bare minimum to students with disabilities. It’s too easy for special education to turn into baby-sitting.

In the past, children with disabilities faced two possibilities: Be diagnosed and segregated or be undiagnosed and have their needs ignored. These outcomes reflected the social and medical norms of their times. Today we’re much better at diagnosing disabilities. For example, the growth in autism diagnoses is largely due to [diagnostic shifts](#) in the [Western world](#). Moreover, our school systems now offer a variety of models to discover the least restrictive environment (LRE) to provide a free and appropriate public education (FAPE), thanks to the 1975 Education for All Handicapped Children Act (EHA) and a series of reauthorizations, renamings and some expansions.

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However, the shift in practice happened more slowly. For one, in 1990 Congress passed one of the greatest civil rights bills in U.S. history: The Americans with Disabilities Act (ADA). Its “reasonable accommodation” guarantee has reshaped the American society in many ways. Its power [continues to be contested in courts](#) and [popular culture](#), but the overall effect is undeniable.

“The ADA over the past 25 years has been a success in creating a more accessible environment,” Lennard Davis, the author of [“Enabling Acts,”](#) wrote in a recent email. “Access to communications for blind and deaf people have improved dramatically. Buses and trains are almost completely accessible now. Access to universities and schools [is] much better.” The ADA also changed attitudes. There is an increasing awareness to the diversity and complexity of disability as more people with disabilities gain access to public spaces.

Schools have become more inclusive over the past few decades — meaning that people with disabilities spend more time in classrooms with students who do not have diagnosed disabilities. The percentage of students with individualized education programs, who spend more than 80 percent of their time in typical class, has risen from 55 to 62 percent since 2006, according to the Department of Education. Ruth Colker, the author of [“Disabled Education,”](#) attributes this shift to many factors. Cost is one of them, because it’s often cheaper to have students in one classroom rather than to staff separate spaces. And it takes time for policies such as LRE and FAPE to take effect. And as social norms shifted, the EHA and its reauthorizations have kept the legal pressure on.

But schools too often balk at real inclusion. Despite evidence that [inclusion enhances the quality of](#)

[education](#) for all kids, many schools offer only integration. “Integration works from the premise that, for the most part, it is the student with disability that needs to fit in,” Cátia Malaquias, an Australian inclusive education advocate and [writer](#), said in a recent email. “Inclusion requires systemic change to accommodate all learners — that is, a system based on the methodology of universal design for learning, differentiated instruction and adapted curriculum.”

In order to build a truly inclusive society, we have to break the idea that inclusion is something that can be measured out in percentages or limited numbers of hours per day. Inclusion requires total commitment and a radical shifting of mindset from policy makers, teachers, parents and all adults. And then we can make sure we teach it to our children.

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