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My Child Has a Disability. What Will Her Education Be Like This Year?

Public schools are obligated to teach millions of students with disabilities. But as learning moves online, many services that parents fought for are at risk.

By Nicole Chung
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When our younger child received an autism diagnosis at 3, my husband and I had no premonition of what fighting for her education would require of her, or of us.

She's now 9 — an enthusiastic and sweet-tempered kid who loves her teachers, classmates and school routines. Since kindergarten, she has been educated at our neighborhood

public school, and I think often of what families like ours owe the activists who fought for disabled children to receive the education they deserve. As of the 2018-19 school year, 14 percent of public-school students nationwide received special-education services under the Individuals With Disabilities Education Act. That includes our child, whose learning is guided by an Individualized Education Program, or I.E.P., which tracks her learning and her needs, outlining the services her school is legally obligated to provide in order to give her what she's entitled to: a free and appropriate public education, with the support she requires to learn, in the least restrictive environment possible.

Like so many parents, we see the details hammered out at an annual I.E.P. review — roughly three hours spent in a too-warm, windowless room updating the plan for another year. The team we meet with generally includes a meeting chair, a case manager, a classroom teacher, a speech-and-language pathologist, an occupational therapist and an administrator; sometimes we might be joined by additional teachers or specialists, a separate district representative or a school psychologist. Most work with our child regularly, though occasionally there's someone who doesn't know her well. There's always a box of tissues on the table; the I.E.P. review may sometimes feel like any other interminable administrative meeting, but it can also be an emotional minefield. Children qualify for special education based on documented needs, which means the discussion often revolves around deficits: What's harder for this student? What don't they seem to grasp? And then the crux of the matter: What specialized support do they need in order to learn?

This meeting tells a story about the student, and early on my husband and I were led through that narrative by educators. We could speak about who our child is and how she communicates, but we didn't yet know she would benefit from one-on-one time with a special educator, or a balance-ball chair that let her move while working, or a schedule to

help her manage changing routines. It took years for us to learn the unique push-pull of parental advocacy, the necessity of highlighting her strengths and asking for what she needs. Now we never walk into a meeting without a narrative of our own, a list of every concern and request and tiny victory we want to enter into the record.

No one wants the I.E.P. meeting to be adversarial. But families and educators do not always see eye to eye on a child's placement, needs or accommodations. The services identified in an I.E.P. become legal obligations, so schools cannot offer them lightly. As a parent, you learn to question and nudge and butt heads when necessary, even with educators whose work you deeply appreciate — because you might hear that the school or the district can't afford or provide a certain support right until someone decides that, actually, it can.

Last fall, we began the school year with cautious hope. Our third grader had a wonderful classroom teacher, a deeply committed case manager and, for the first time, a one-on-one aide for part of the day. All three got to know her well, adapting their instruction as needed, communicating with us and with one another. Support from the aide proved a crucial contribution to our child's learning, and we were grateful.

Then, in March, our school was one of the thousands that closed because of the coronavirus pandemic, and the bulk of the I.E.P. — the individualized support we'd spent hours discussing, honing and pushing for — seemed to disappear overnight.

Distance learning began in April. Our older child was soon able to find and complete her schoolwork with little oversight, but our third grader needed a parent available for every class and assignment. A school building full of resources was replaced with our kitchen table, a Chromebook and the materials our case manager could fit in a grocery bag left at our door: some books, a dry-erase board and markers, math

manipulatives. Every day, there were two Zoom sessions to attend, multiple platforms to access, assignments to complete and submit.

We never felt abandoned. Her aide attended every online class. Her teacher patiently coached 20 third graders on using Zoom. (“You have to unmute before you answer”; “Friends, please don’t type things into the chat unless I ask you to.”) Our case manager hosted support sessions, ran a virtual reading group and sent late-night emails with suggestions for the next day’s lessons. The speech-and-language pathologist offered teletherapy, but we were so overwhelmed keeping up with academic work — as well as mandatory art, music and physical education — that we never took her up on it. Remote special education already meant extra work for our child, meetings her peers didn’t have to attend. Yet we greatly appreciated her team’s efforts, and if she’d been asked to do less, we might have had other worries: stagnation, regression, boredom.

My husband and I were privileged to be able to rearrange our work schedules, but we still found it impossible to replicate the support our child received at school. I fretted about her, about all of us, as we struggled to home-school through multiple crises. My grandmother died in April, my mother in May. For weeks, while I grieved and began to settle my mother’s affairs, my husband juggled his job with the major share of parenting and schooling.

At our I.E.P. review, held over Zoom in early June, there was consensus regarding what our child needed. Her hours would remain the same; she would keep all her supports; her teachers would continue to help her access as much of the curriculum as possible. But our team had to draft every point

and goal, every accommodation and service, based on the assumption that she would be back in a brick-and-mortar classroom come fall.

That isn't happening. Our kids began the year online, though it's possible they will eventually transition to an amalgam of in-person and distance learning. Our 9-year-old's I.E.P. will soon be adapted into a specialized distance-education plan, removing goals she cannot work on outside the classroom and curtailing some services and supports best delivered by a qualified educator in a school setting. Which is to say, many of the ones we've spent years identifying and championing.

Teachers of Special-Needs Students Struggle With Feelings
of Helplessness  April 23, 2020

It's unclear how many underfunded schools will be able to reopen this school year, or how long they'll remain open if they do. President Trump and Education Secretary Betsy DeVos are among those who pushed for on-site instruction, despite educators' concerns about reopening amid widespread infection. Christine Esposito, a teacher in Virginia, notes that the consequences of past slashes in education budgets — “overcrowding, old H.V.A.C. systems, teachers and therapists working in closets with no ventilation” — would make it especially difficult for many schools to follow social-distancing recommendations. “A teacher constantly worrying about their safety is walking a mental tightrope in the classroom,” she says, “and that's not good for anyone.”

As many schools begin the year partly or fully online, thousands of their students are still dealing with the fallout from the spring. Among this multitude are children, many of them disabled, who “just fell off the grid,” as one teacher friend put it, when schools closed — whether because of illness, poverty, lack of reliable internet or a host of other

reasons. There are students whose underfunded schools could barely support them before the crisis, who now go without any special-education services at all. There are students with physical disabilities who receive therapies their parents aren't trained to do; students with attention issues who find it difficult to focus in a classroom, let alone on video instruction; students who rely on structure their new virtual classrooms can't provide; dyslexic or reading-delayed students who have to read even more in order to access online learning. As every child is different, so are the educational challenges they now face. And while my husband and I worry about our 9-year-old's unmet needs, we know that our struggle to be her advocates — with our combined educational and material resources, the ability to navigate the I.E.P. process in our first language, the stalwart support we've received from some of her educators — is and has long been magnified, many times over, in families without these advantages.

Kathi Foley, who spent the spring teaching students with learning disabilities, says she and her fellow teachers “were directed to prioritize goals and objectives that were critical to maintain, which resulted in a reduction of services.” Still, she ended up working with students far more than she was required to, meeting kids every day on video platforms. “Most of my services had been delivered in co-taught settings,” in a general-education classroom, “and that was lost,” she says. “It was difficult to assess progress over the screen.” Mary Sophie Filicetti, who teaches visually impaired students in Virginia, found herself coaching parents as much as children, having them hold cameras so she could see students' feet or canes during mobility lessons. “Hopefully the families can integrate the skills more fully,” she says. “It is very challenging when families have barriers — like no Wi-Fi — or there are language differences.”

Some parents I know have been told that their child's I.E.P. simply can't be fully met while distance learning persists — that they will receive not only less instruction than usual but

also far less of the individualized support that makes that instruction meaningful. “I think most families are being reasonable, but students’ rights don’t change during a pandemic,” says Julia Bascom, executive director of the Autistic Self Advocacy Network. Denise Stile Marshall, the chief executive of the Council of Parent Attorneys and Advocates, emphasizes that there have been no waivers to schools’ obligations to disabled students. “You can amend the I.E.P. with mutual consent of parent and district, and you can create an addendum based on what’s feasible given the current conditions,” Marshall says, “but parents and administrators need to remember that ‘doing the best you can’ is not the legal standard.”

“I think most schools’ approach to students with I.E.P.s was to desperately hope they’d be able to have in-person instruction in the fall,” Bascom says. But even if the option of some on-site learning eventually materializes in our district, I wonder about the impact on my autistic child. She needs a consistent routine to feel secure; will switching between home- and school-based instruction make it harder for her to focus? If she struggles to keep a mask on all day, will she face discipline? Will teachers be able to guide and support her — and all other students with their varying needs — from six feet away? Tiffany Jeng, a speech-and-language pathologist who worked with disabled students in on-site Extended School Year classes this summer, says: “It was impossible to maintain six feet between us and our students, and not only because we’re used to giving therapy sitting right next to or across from kids. Many kids need close proximity to understand what we’re asking of them.”

I feel some relief over our school year starting virtually — I don’t want to send my kids into school buildings knowing that their teachers, and our entire community, could pay a steep price. But I have no idea how we’ll manage an even longer school day at home without more support. “Which one of us will quit our job?” I keep asking my husband. We still

have to work. We aren't trained teachers or therapists. Worse than wondering how we'll help our 9-year-old make progress is knowing we're bound to fall short.

We won't be able to assess the full impact of school closings and distance learning until the worst of the pandemic is behind us, but we already know that longstanding educational inequities are increasing. When all our kids are back in physical classrooms, will they find schools less committed to inclusion and to the rights and needs of disabled students? “The pandemic has magnified these huge structural issues,” Bascom says. “Ultimately it's going to be disabled and marginalized students bearing the burden, being delayed, losing time and progress.”

Whether teaching online, in person or both, many educators will need to adapt how services are delivered. Tim Villegas, the founder of Think Inclusive and communications director for the Maryland Coalition for Inclusive Education, says this will require “innovative teaching” — a hallmark, he believes, of special educators, who are used to “modifying, accommodating, thinking outside the box.” He added, “Hopefully we'll see more intentionality and planning for students with I.E.P.s this year. But special-education staff and administrators have to be at the table when decisions are made.”

Whether that's happening everywhere is unclear. As one parent told me in August, "Our district has been sending the message that they're concerned about special-ed issues and thinking hard about solutions — but we start in a week and have not heard anything save the fact that they're working on it." I've heard that our teachers will have more time for planning than they did in the spring. Some practices that were scattershot last year — such as breakout Zoom sessions for small-group and individualized instruction — might prove the new standard. We've picked up a loaner Chromebook, attended virtual class meet-and-greets, struggled to adjust to the new all-day virtual-school schedule. But after all those hours of planning around conference tables in windowless rooms, we're starting the school year with few details about how our fourth grader's needs will be met.

Many have worked for years to help her get this far, and no one has worked harder than she has. I cannot help wondering what she stands to lose, compared with her nondisabled peers, in this uncertain interim — and here I am less concerned about any arbitrarily defined academic "progress" and more worried about how a lack of it could be held against her. Her public school has been her least restrictive learning environment and her home away from home, but in the years since she first walked through its big red doors, her place there has not always felt secure. Sometimes we found that she had the support and understanding of one educator but not another. Our district is obligated to support her learning, public-health emergency or not, but ultimately *she* is the one with the most on the line — the one whose hard-won gains might evaporate, whose placement could be challenged, whose progress will most likely be compared with that of nondisabled peers even after many months without all the supports and services she needs.

The stakes, for her and so many other children, could hardly be higher. Behind every worry we have about our child's access to education, there lurks the fear that some lack of crucial support or inclusion now could threaten her ability to

find her way into the life she wants after she has left formal schooling behind — these years when a group of well-meaning people still gathers to discuss the resources she needs. This is why it's so hard to see essential support disappear in this crisis, or to be told to “wait out” the pandemic. Like many parents, we are aware that time is precious, and what's lost now might not be so easily recovered. We cannot be her advocates forever, and we know that what we fight for is not only her education but perhaps her future happiness and security as well.

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