



Navigating the special education system can be daunting. Liza Brecher wants to help.

Bret McCabe

PHOTOGRAPHY Christian Witkin

Parental Guidance

Toby's mother knew her son was different from the beginning. She could pick out his high cry from among other newborns', and he was always restless in her arms. His fidgetiness continued through preschool, where his teachers started to complain that he disrupted the classroom, like the time he climbed a bookshelf to get an out-of-reach toy truck—and ended up sending everything and himself to the floor. He was moved to a different class.

This pattern marked his early education: Hyperactivity led to behavioral issues, the handling of which interrupted his schooling. He had difficulty learning the letters in his name. He could do puzzles but was completely uninterested in reading. By the time Toby got to fifth grade, his reading comprehension problems were so pronounced his teacher paid closer attention.

Over the course of a few months, Toby's teacher tried several learning and behavioral interventions to document his performance before referring him to the school psychologist, who tested Toby on a series of reading and spelling tests: the Wechsler Intelligence Scale for Children-Revised, the Wide Range Achievement Test, the Broad Reading and Broad Written Language subtests of the Woodcock-Johnson Psycho-Educational Battery. He performed above average on one, poorly on the other two. More testing ensued. The Hudson Education Skills Inventory-Reading showed Toby's poor performance in phonic analysis, structural analysis, and comprehension; the Classroom Reading Inventory showed that his reading comprehension was at the second- or third-grade level while his listening comprehension was at the seventh-grade level. At this point the teacher contacted the school's learning disability teacher and asked to have Toby removed from her classroom. She was through with him.

"So, what would you talk to Toby's mother about if this case was yours?" Liza Brecher asks one of the undergraduate volunteers taking part in her Homewood Educational Advocacy Resource (HEAR) program. Brecher, herself a Johns Hopkins undergraduate, organized HEAR to

train students to serve as pro bono advocates to Baltimore parents during Individualized Education Plan (IEP) meetings, the annual sit-down between the parent of a child in the special education system and representatives from the public school system.

Tonight is the second of five planned training sessions. The students have broken into two small groups to discuss the case, sitting in desks in a Maryland Hall classroom on the Homewood campus. A laptop is plugged into the overhead digital projector to show a training website. Empty carryout salad boxes sit on the table at the head of the class.

One of the young women brings up the teacher's efforts that did have a positive impact on Toby, such as the observation that practicing saying words before reading a story decreased his mistakes while reading. Brecher and the others bat around ideas to build on these observations: setting goals to decrease the number of Toby's errors per 500 words, providing him with fewer options—such as practicing 15 words instead of 20—and incorporating such practice into his lesson plans. They discuss ways to encourage a parent to talk about setting specific, measurable goals with the IEP team during the meeting. After about 20 minutes, they finish with Toby's sample case and move on to their next section of training.

In Maryland, a student's Individualized Education Plan is a 20-plus-page document, not including addenda, that identifies his or her emotional, psychological, or cognitive challenges; current performance levels; academic goals; and strategies for achieving those goals, among other issues. It's the road map the school system uses to address a child's special needs as mandated by the Individuals with Disabilities Education Act of 1990.

For parents of kids with special needs, the annual IEP meeting can be daunting, and sometimes adversarial. The parent sits across a large table from the team of school system experts: the IEP chair, an IEP case manager, a school psychologist, a speech/language pathologist, a social worker, a general educator, a special educator, a guidance counselor, and, if required, the school system's attorney. If she can afford it, she can bring along a representative, such as an attorney or professional advocate. If the meeting proceeds

without interruption or discussion, the parent endures a nearly hourlong monologue about test results and standard scores that might not mean anything to a noneducator. The IEP team goes through last year's plan and makes recommendations for the coming year. Sometimes, an IEP meeting can feel like a lecture informing a parent of all the things her child can't do.

"It's a really intimidating process," says Maureen van Stone, director of Project HEAL at the Kennedy Krieger Institute. Project HEAL is a medical-legal partnership between the Johns Hopkins Children's Center and the Maryland Volunteer Lawyers Service. "Most of my families are single-parent households, moms who are low-income, who may be raising multiple kids, and so they're going to be doing it alone. This is not their area of expertise by any means. And they're surrounded by a team of professionals who have all of the data available to them. They have all of the child's reports. They have educational expertise. And they have numbers. [Parents] should feel like they're an equal partner at the table, but parents never, ever feel that way."

Liza Brecher started HEAR to let parents know they don't have to go through this alone. She is training HEAR advocates to be able to support a parent hoping that a child isn't segregated into special ed-only classes, to recognize when an IEP meeting is venturing into territory that requires legal representation, and how to refer parents to appropriate service providers. "A big part of being an advocate is listening to the family and understanding how they're feeling and why they're feeling that way," she says. "Because for so many families, they just don't have any support. They have nowhere they can go and say, 'I'm worried about my kid,' or 'I don't know what to do next,' or 'No one is listening to me.'"

Brecher, a class of 2013 history of science major at Johns Hopkins, had no idea what she was getting herself into when she enrolled in January's Leading Social Change intersession course. She had just returned from a semester in Arica, Chile, where she was researching what resources exist for families of kids with Down syndrome. Growing up with a trisomy older brother—Down syndrome is also known as tri-

somy 21 because it occurs when a child is born with an extra 21st chromosome—Brecher has known since high school that she wanted to work with children with special needs. "My ultimate goal is to create Down syndrome clinics like the one we have in Boston," she says.

That clinic is the Down Syndrome Program at Children's Hospital Boston, a comprehensive, multidisciplinary clinic where trisomy kids (and their families) see everyone from pediatricians and psychologists to dentists and nutritionists, from birth through young adulthood. It's where Louis Sciuto, Brecher's brother, went and where Brecher volunteered and worked growing up.

"The clinic is probably the first pediatrician [a] baby is going to see," she says. "It's a very important thing for families, to have that support from the get-go. So, hopefully, I want to start clinics like that all over. I mean, there's still plenty of cities in the United States that don't have them. And there's actually legislation right now, if it ever gets through Congress, that will allocate funding specifically for Down syndrome clinics."

That goal is what attracted Brecher to Leading Social Change, a class that asks students to come up with socially conscious business plans. But the class turned out to be aimed toward local projects instead: Students research needs specific to Baltimore and develop sustainable solutions to address them. They present their ideas at the Social Entrepreneurial Business Plan Competition, and winners receive grants for seed funding.

Baltimore already had a clinic—at Kennedy Krieger, where she did research—so Brecher reconsidered her idea. "What other challenges do families face? A big one has always been education," she says. "I mean, nine out of 10 families who come into the Down syndrome clinic in Boston are asking us how we can help them get enough therapy in school or the right services."

Brecher recalled a Spanish-speaking mother who came into the Boston clinic; her son had a number of behavioral issues. "The doctors were thinking he might have a dual diagnosis with autism," Brecher says. "So one of the things they were stressing was that he needed to get a functional behavioral analysis." Evaluation requests have to be made in writing, but the mother didn't write in English. Brecher drafted the letter for her. "That opened my eyes to the fact that so

many of these families don't have anyone helping them," she says. "So many parents say, 'Oh, the school knows best,' because, obviously, these are the teachers, these are the trained specialists. You trust your teachers to do what's best for your child. And that doesn't always happen, especially in the special ed system, because it's expensive and hard and time-consuming, and schools are strapped."

Brecher looked into Baltimore's special education situation and discovered that of the 84,000-plus students enrolled for the 2011–12 year, about 16 percent were in the special education system—roughly 14,000 kids. She also found out that there were only 20 volunteer advocates in the entire state of Maryland, and only two advocacy agencies in Baltimore. (Private legal advocacy is an option, but an expensive one—averaging \$75 an hour.)

Her project was one of three awarded a \$5,000 grant at the end of January. Brecher immediately asked friend and classmate Rachel Muscat to help coordinate the project, and the two recruited an inaugural class of student advocates. They contacted local advocacy agencies and nonprofits for training advice. They called special-needs organizations to reach out to families. They tried to let schools know they existed. They wanted to train five to seven student advocates and then meet with families by the end of the spring semester, so that come fall, when the IEP meetings start, they would have a plan.

They quickly learned just how many challenges they faced. Kids in Baltimore's special education system primarily deal with behavioral and emotional issues—which are sometimes subtle enough to go undiagnosed and can be more complex to address—rather than developmental ones. The school system and advocacy groups have, on occasion, had a more adversarial than collaborative relationship. And in 2010, the Baltimore City Public School System settled a special education civil suit that directly informs the school system's attitude at the IEP meetings. The suit was filed in 1984—seven years before Brecher was born.

At their first meeting with the Maryland Special Needs Advocacy Project, its director Martha Goodman "gave me this binder that was like this big," Muscat says, her hands suggesting something

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unabridged-dictionary thick. “That was just the parent manual. That’s the *minimum* that a person needs to know in order to engage with this issue.”

“It’s very, very stark,” Brecher says of special education in Baltimore. “I mean, I knew that it was probably not going to be great and it’s always a challenge. But I didn’t realize quite how bad it is. So once I saw that, I was, like, I can’t *not* do this.”

In 1984, the Maryland Disability Law Center (MDLC) filed a class action suit in the District Court of Maryland on behalf of Baltimore City students with disabilities who were not receiving services to which they were entitled by their IEPs. The suit—*Vaughn G. et al. v. Mayor and City Council of Baltimore, et al.*—bounced through the Maryland courts for 26 years.

Leslie Seid Margolis joined the MDLC in September 1985 and worked on the *Vaughn G.* case through its 2010 settlement. It started as a matter of compliance and evolved into a reform effort. “When the case was filed, it was filed on behalf of kids for whom the timelines were violated for assessment and for implementation of IEPs,” Margolis says. “At that point the city had a backlog of many, many kids who were not getting assessment on time and many kids whose IEPs were not being implemented in a timely fashion, and the city was remarkably unconcerned.”

She recalls an early client, an elementary school-age girl with cerebral palsy who had not received a physical therapy evaluation even though the schools had the appropriate request for it. The evaluation was requested and it didn’t happen. The next year the same evaluation request was made. Again, nothing. “Five years this kid waited for a physical therapy evaluation that didn’t happen,” Margolis says. “We go to the due process—I mean, why should I have to request a due process hearing for this? Go to the hearing. I say to the attorney, ‘Your own documents reflect she didn’t have it. Can we just agree that she didn’t have it and resolve this?’ No. He would not concede that. So we had to go through a local-level hearing, [then] we go through state-level hearing. And, of course, they find she *didn’t* have the assessment she was entitled to.”

The problem in the school system was systemic; issues started to be addressed with more

seriousness when Andrés Alonso was appointed superintendent in 2007. “Overall, are things better than they were in 1984?” Margolis says. “I think, yeah—because in 1984, in 1990, in 1995, being able to talk about the quality of education was a luxury. That’s now in the past. It looks like they get IEPs implemented pretty quickly. So the harder issues are the quality issues.”

Those years of failed IEP compliance and institutional apathy, however, can still linger. “In this city, we started off extremely adversarial,” says Project HEAL founding director Hope Tipton. She recalls going to an IEP meeting where, when she requested a progress report, she was forwarded a previous progress report where the date had been changed to make it look like a new one was performed. “And I was—pardon my language—pissed off, because that’s deceitful and lazy. If you had just sent me the previous progress report I would just have thought you were lazy. But when you specifically white out the date to make it look current, that’s deceitful.”

“Where we have come with this kid in the last 18 months is miles and miles away with this team,” she continues. “But where they started was absolutely horrible. And the school’s attorney has told me, ‘We see such a minute number of kids in the special ed system, doesn’t it make you wonder about all the kids we’re missing?’ Those are the kids I worry about—the kids who have no intervention, have no advocacy, who are just slipping through the cracks that way.”

It’s some of those families Brecher and HEAR are trying to reach. They would like to pair each of the advocates with a family by the end of the 2011–12 academic year. They also plan to target the incoming class to recruit new student-advocates, and to grow the program each year.

The goal isn’t just to help a handful of families but to become part of a growing network of special education support and advocacy. For instance, the MDLC co-created the CityWide Special Education Advocacy Project to build a grassroots base and to educate and empower parents, who are always going to be their children’s best advocates. Tipton says she worked with a mother and her older son, and when the younger son entered the special ed system, the mother was able to navigate a great deal of it on her own. Now



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Tipton gives out this mother's number when parents contact her with similar problems.

Learning by doing is common in advocacy, and it's also a reminder of what's at stake in fighting for better integration of special ed into general ed. Education isn't merely pragmatic, where we teach our children the intellectual and social skills they need to become ostensibly functional members of society. It's also aspirational. It's where we imagine how society could be: desegregated, inclusionary, tolerant.

Those are ideals that drive Brecher because she's witnessed them in action. She knows her brother Louis was fortunate to have grown up with supportive parents and family. He participated in Special Olympics, but he also played typical sports with his peers. Louis and Liza had their bar and bat mitzvahs alongside each other. They grew up in a town—North Andover, Massachusetts—that incorporated special education into its school system early on. Today, Louis has a job.

Brecher also knows that not all people with Down syndrome are so lucky. In 2009, she spent a semester in high school at a pair of Camphill communities—planned living situations for people with special needs—in Ireland. "I was so used to how my brother and I were raised, it was very much in the community," she says. "When I got to Ireland and the villages, they were so isolated." She was struck by how few typical children were mixed with the trisomy kids at the children's community. "If there were any, they were the children of the director or the head farmer," she says. "But [the trisomy children] didn't have classes together with the typical children."

She witnessed a range of situations in Ireland. At Trinity College Dublin she encountered a program for adults who have special needs, where students get a peer buddy and the professors change their teaching styles to be more accessible. "I saw schools in Ireland where they had totally normal integrated classes, and I saw an institution where it was like going back to the 1950s," she says. "There were kids in wheelchairs sitting and watching a television screen for hours on end every day."

The previous summer Brecher attended a language program in southern China and worked on

a research project about how people with disabilities were treated in China. She met a young man there with Down syndrome, and the only word he could say was *grandma*. His parents had sent him to an expensive private school, where the only things he learned to read and write were *one*, *two*, and *three*—very basic Chinese characters. Brecher says the young man's father took pride in his son, talking about how he helped at the store they own, how he brought him his lunch every day. "His mother wouldn't even talk to me," Brecher says. "She was so ashamed of him."

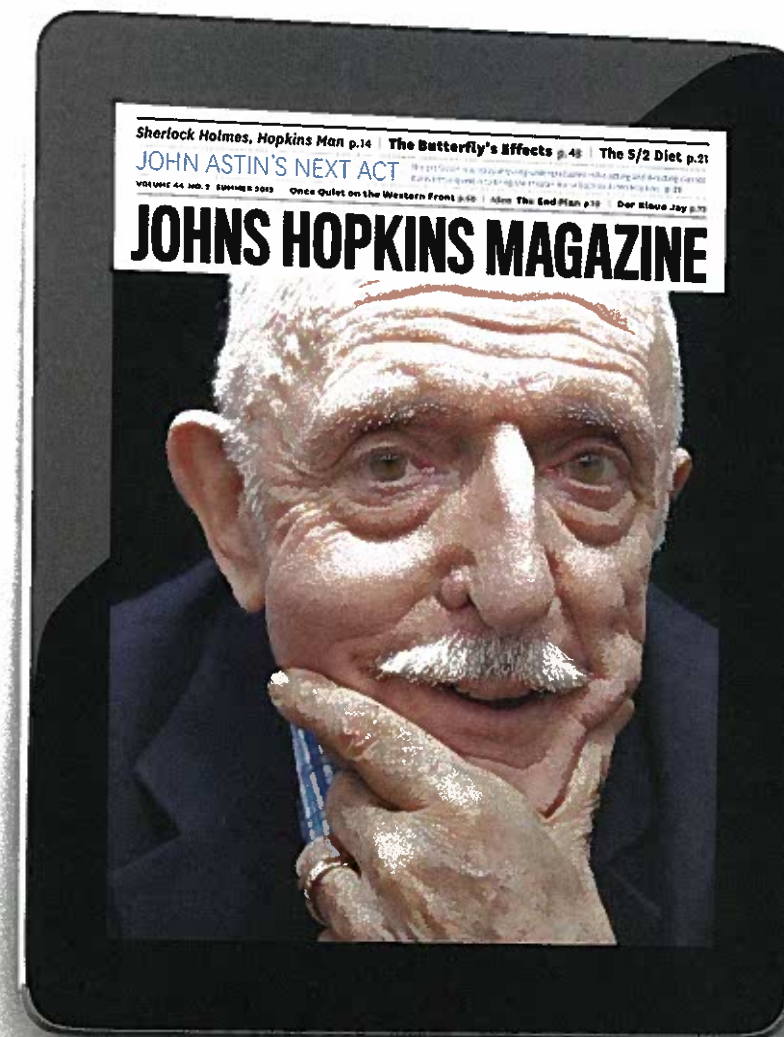
In the village of Lijiang she met a woman who had a 5-year-old son with Down syndrome who paid the fee to have a second child. "She said, 'I had my daughter so there would be someone to take care of my son when my husband and I die,'" Brecher says. "And that kills me."

With HEAR, though, Brecher is entering new territory. "I've grown up in a very specific disability community. We're learning that Baltimore tends to have more strict behavioral disabilities and emotional disabilities, and that's not something I'm really familiar with," she says. "And those tend to have very different effects on families."

A few weeks into training Brecher and Muscat were still a bit apprehensive. They had recruited four other student advocates, and they had reached out to a number of local advocacy groups who were helping them try to connect with families, but it was slow going. The schools had been completely nonresponsive; none of the special educators had returned any calls or emails. And the semester's end was inching closer.

There is a tinge of discouragement in her voice, but Brecher knew the project was going to be difficult. She realizes that raising a child with special needs is never a cakewalk, but she also knows that the first step in being a successful advocate is being there and ready when that first parent reaches out for help. "They need to see that we're actually following through," Brecher says. "A lot of time what happens is people have good ideas for this community and they think it's going to be really great but then it doesn't really get off the ground. So I think we kind of need to prove ourselves first. We need to show that we're actually going to do this and we're actually going to help."

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