

Project HEAL helps families navigate the disabilities maze

By Jonathan Pitts, The Baltimore Sun

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Maureen van Stone is the founder and director of Project HEAL, an organization based at the Kennedy-Krieger Institute that provides legal and organizational help for the families of children with developmental disabilities.

(Kim Hairston, Baltimore Sun)

She has been intellectually disabled and mostly deaf since early childhood. Cerebral palsy leaves her movements stiff. She has yet to be potty-trained.

But for years, her family says, the public schools in which 15-year-old Colbi Wike was enrolled advanced her from one grade to the next, even placing her, at times, on the mainstream honor roll.

"I kept telling her [teachers and administrators] she wasn't progressing, that something was missing, but they kept saying, 'She's doing fine, she's getting everything she needs,'" said Colbi's mother, Tisa Wike, of Capitol Heights. "I can't tell you how many of those meetings I left crying."

Then she turned to Project HEAL.

Based at the Maryland Center for Developmental Disabilities within the Kennedy Krieger Institute, Project HEAL — the acronym stands for Health, Education, Advocacy and Law — is a legal and clinical nonprofit that offers low- to moderate-income parents help in navigating the often-mystifying systems by which counties and school districts classify, educate and otherwise serve their developmentally disabled children.

The brainchild of Baltimore attorney Maureen Van Stone, Project HEAL makes attorneys, law students and other advocates available to parents for a modest fee, whether those families are seeking a better school-placement fit, fighting the termination of benefits or grappling with government forms.

The group's attorneys, together with student volunteers from Baltimore's two law schools, also travel around the state to teach clinicians the intricacies of federal disability law and how it can be leveraged to improve health outcomes.

"There are 6 million students with disabilities [in the U.S.], and when parents enter this arena, many simply don't know their rights," said Denise Marshall, executive director of the Council of Parent Attorneys and Advocates, a national nonprofit that represents students with disabilities. "Programs like Maureen's offer a critical service. It's important that there's equal access to the protections offered by the law."

Unlike many in her field, Van Stone, 40, a Baltimore native, knew no developmentally disabled people while growing up. After earning an undergraduate psychology degree from the University of Southern California, though, she found work back in her home town as a direct-care staffer in the neurobehavioral inpatient unit at Kennedy Krieger.

Van Stone fell in love with the field, she said, but noticed a major gap in the system: Though the behavioral staff numbered in the thousands, there were no attorneys advocating for the patients.

She then attended the Whittier Law School in California, which offered a course program with a special-education component. Armed with her J.D. degree, she began seeking ways of blending her fields of expertise.

In 2003, she found the funding to establish Project HEAL, a joint initiative of the Johns Hopkins University, Kennedy Krieger and the Maryland Volunteer Lawyers Service.

The program, now a Kennedy Krieger enterprise, was and remains a so-called medical-legal partnership, a relatively new model for health care nonprofits.

In such organizations, clinicians put lawyers on the health care team to help patients address the kinds of nonmedical factors that bear on overall health, from physical living conditions to their familiarity with medical terminology.

There are about 260 medical-legal partnerships in the U.S. today, each dealing with a public health concern of its own. Van Stone's is the only one in Maryland and may be the only one in the nation focused on developmentally disabled children in low-income settings, said Ellen Lawton, executive director of the National Center for Medical and Legal Partnerships in Washington.

Project HEAL has brought services to 20 of Maryland's 24 counties and netted multiple public service awards, all with one and a half paid lawyers on staff and an annual budget of about \$250,000.

Kennedy Krieger provides most of the funding, backed by a few small foundation grants, corporate partners such as RE/MAX, and sliding-scale fees from clients.

Dozens of law students have contributed more than 10,000 hours' work.

It's not nearly enough, Van Stone said. There are 102,000 developmentally disabled children in the Maryland public schools, she said, and 30 private lawyers and four nonprofits to work with them. "Need far outweighs capacity," she said.

Project HEAL staffers take calls from anyone in need and offer referrals to relevant agencies. But its modest resources mean it can only take on complicated cases. Most clients are children with several overlapping disabilities — autism, ADD, anxiety disorder, language impairments and more, including occupational therapy needs.

Federal disabilities law guarantees every child an education at government expense, but it can be hard for Maryland parents, teachers and administrators to agree on what kind of setting is most appropriate, from the least restrictive option available (enrollment in a mainstream school) to more intense solutions, including placement in a county-run school devoted to similarly disabled children.

Disagreements about placement are legion. Some families want more intense services; others want their children in "the neighborhood school," Marshall said.

A spokesman for the Prince George's County Public Schools, Max Pugh, said he could confirm that a Colbi Wike did attend mainstream county schools through this year but could not comment further on the case for confidentiality reasons.

Tisa Wike said she simply watched Colbi getting older but not better.

"I know she can learn, because she learned a lot of what we've taught her at home, but I kept telling them that, beyond that, I wasn't seeing any improvement," she said, adding that her complaints and suggestions fell on deaf ears.

She happened on Project HEAL during an Internet search. A lawyer for the group saw that Tisa and her husband had five children, leaving her too busy to research her rights, that Colbi's intellectual capacity lagged far behind that of her mainstream classmates, and that her services had been cut significantly over the years, said Van Stone.

Weeks' worth of meetings at her school and months of letter writing, she added, persuaded the county that Colbi needed the highest level of attention available — placement in a dedicated private facility, with the county footing the bill.

She said the problems Colbi faced are far from rare in Maryland schools and that she was satisfied the county was able to respond.

Total cost to Wike: \$250. But for her, the triumph has been bittersweet.

"I think about all those years my daughter lost, and I want to cry," she said. "But Project HEAL did what I couldn't in 15 years. She's getting a new start."

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