



Joe Surkiewicz: Project HEAL celebrates 10 years of protecting the rights of children with disabilities

By: Joe Surkiewicz  September 3, 2015

As a clinician working on Kennedy Krieger Institute's neurobehavioral unit more than a decade ago, Maureen van Stone saw the critical importance of advocating for children with intellectual and developmental disabilities and severe problem behaviors.

So van Stone, now director of Project HEAL (Health, Education, Advocacy, and Law), a community-based program of the Maryland Center for Developmental Disabilities at Kennedy Krieger, made a career change and went to law school with the goal of returning to help children with disabilities.

Now, it's her job to ensure that recommendations made by interdisciplinary teams of healthcare professionals about a child's needs in home, school, or the community are actually put into place.

"Children with disabilities have civil legal rights," van Stone said. "I strive to intervene early to ensure children have a smooth transition from a clinical program to their home, school, and community settings."

Project HEAL and van Stone on Thursday will celebrate 10 years as Maryland's only medical-legal partnership of lawyers and healthcare professionals working together to address the medical and legal needs of patients.

The celebration in Kennedy Krieger's Outpatient Center Lobby and Therapy Garden will bring together community partners, elected officials, parents of patients and law students (nearly 100 have served as interns, externs, and volunteers since 2008).

Parents' testimonial

A highlight of the event will be a testimonial by the parents of a former patient, a 12-year-old girl who had half her brain removed at age three. After a recent follow-up surgery, she had complications and came back to Kennedy Krieger for rehabilitation.

"She had many clinical needs and engaged in self-injurious behavior," van Stone said. "She was being educated in a comprehensive public school in a special education classroom and was referred to me by her behavioral psychologist. She needed a more appropriate educational program and a more restrictive placement."

Van Stone worked with her family through the fall, requested reevaluations by her interdisciplinary team at Kennedy Krieger, and worked with the school system to revise her Individualized Education Program. The end result was a more appropriate educational program and a new placement in a private setting.

"We did it all without the need for mediation or a due process hearing, which was very fortunate," van Stone noted. "It was a great example of the clinical team working with us to share information with the school system for the best outcome for the child."

Of special significance to van Stone: the girl was on the same inpatient unit where she worked for six years before pursuing her career as a lawyer.

Falling through cracks

Project HEAL has two staff attorneys, including van Stone, and handles between 65 and 80 cases a year. In addition, the project provides brief legal advice to 250-to-300 patients and families a year, and provides 250-to-300 case consultations to health care professionals.

"Any child with a qualifying disability under federal and state law is entitled to special education and related services, accommodations, modifications, and supports," van Stone explained. "A school system can fail on multiple levels, missing the things that the children need to benefit from their educational program."

More often than not, children may have complex disabilities and the parents may be low-income and find it difficult to navigate difficult, clinical diagnoses and their child's educational needs.

"They're supposed to get, say, speech therapy and they didn't, and then the parents discover that their child is years behind," she said. "It's a huge problem. After all, the parents can't go to the school every day and monitor their child's progress."

The average age for a Project HEAL client is just before they're about to enter middle school.

"They didn't get what they needed in elementary school, so how do you get them ready for middle school?" van Stone asked. "Kids fall through the cracks and may end up years behind their nondisabled peers."

That's where Project HEAL steps in, usually doing intakes by phone.

Civil legal help

If the child is coming in for a neuropsychological evaluation — the most common type — the parents bring the child's Individual Education Program. After the full-day assessment, the neuropsychologist identifies areas of need.

"The child is getting X, but needs Y and Z, and may benefit from Project HEAL legal services," van Stone said.

After being alerted that the child isn't getting appropriate help in school, Project HEAL determines if it's a real legal issue that may need the intervention of an attorney or only requires legal advice.

"Some families are just starting out on this journey and don't need a lawyer immediately, like in a new autism spectrum diagnosis," van Stone said. "We send them a packet of information and resources and encourage them to call us back if they have questions. It's brief service. Every family that calls gets full representation or brief service."

If the family needs other kinds of civil legal help, they are referred to one of Project HEAL's three pro bono partners — Ober Kaler, Ballard Spahr, and DLA Piper — or to a nonprofit legal services organization.

The Sept. 10 event at Kennedy Krieger is from 6 p.m. to 8 p.m. and features Dr. Nancy Grasmick, the former Maryland State Superintendent of Schools and vice-chair of Kennedy Krieger's board of directors.

Admission is \$40 and includes drinks, hors d'oeuvres, and desserts. For tickets and more information, visit: www.kennedykrieger.org/celebratingprojectheal.

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