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## From Global Delay to Literary Award

Advocacy and AAC open a path to communication for a child with a rare syndrome.

By Diane Slonim

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What makes for a rewarding career in speech-language pathology? An open heart and a curious mind. I am thankful for both and eager to share my story of Peter and his remarkable family.

I evaluated 7-year-old Peter at the Westchester Institute for Human Development in Valhalla, New York, in 2016. As a preschooler, Peter received a diagnosis of autism with global developmental delay, but his parents strongly suspected that he had advanced intellectual aptitude—albeit an inability to use speech to communicate.

In fact, he reportedly understood three foreign languages (French, Spanish, and Arabic) and was able to complete 12th-grade math. Moreover, he showed a keen interest in his mother's medical school textbooks. Peter presented with an array of disorders (severe speech and limb apraxia, pica behavior, severe hyperactivity, perseverative paper shredding)—coupled with extraordinary talents. He proved to be one of the most challenging students to evaluate in my 15-year career.

Peter was barely capable of sitting in a chair and directing his attention to me without frequent redirection and calming reassurances from his parents. He lifted his shirt and put his jacket over his head repeatedly. Nonetheless Peter smiled in response to my explanation, “We know you want to talk. We want to help you talk.”

Peter's behavior significantly improved on his second visit. With the use of a symbol-supported communication app, Peter could immediately convey his basic needs (I want paper, I want to go home, I want to talk). With the feelings folder displayed, Peter communicated that he was sad.

At Peter's second visit, I learned he had an enormous vocabulary, identifying words such as *inhaling*, *isolation*, *interior*, *reprimanding*, and *citrus*. His superior vocabulary and reading comprehension skills were reported in a recent neuropsychological evaluation.

What to do next to educate Peter?

I referred Peter for a comprehensive assistive technology evaluation. I attended his next IEP team meeting as a pro bono advocate. I successfully advocated for increased speech-language treatment to address his speech apraxia.

Given my success with Peter, and my passion for excellence in special education, I steered my private practice toward school advocacy. I developed expertise in language and literacy evaluations that go beyond what a school district can reasonably provide—qualitative assessments of narrative language and social pragmatics, and extensive documentation of literacy skills, for example. Working closely with the legal firm representing Peter at the time, I've expanded my evaluation skills and learned to look critically at the assessments we use in our field.

Peter's mother worked tirelessly to uncover Peter's diagnosis—a rare genetic disorder known as KAT6A that most typically includes severe apraxia of speech and developmental delay. Peter's parents began a [foundation to support research into the disorder](#).

Peter's behavioral issues diminished significantly because of proper diagnosis and treatment. He now attends a private school that fits his behavioral and academic needs. He won the New

York State Award of Merit in literature in 2018; in 2019, he won the New York State Award of Excellence in literature for his essay “Heroes Among Us.”

An open heart and a curious mind brought me into Peter’s life.

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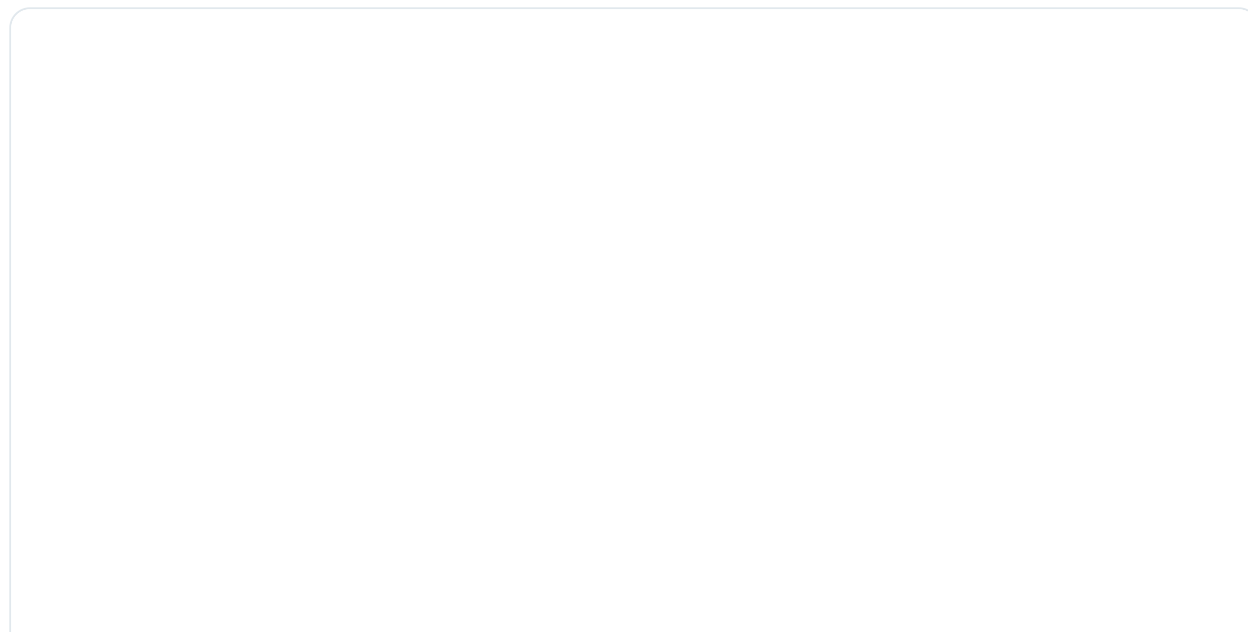
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