

JAMA article teaches doctors about learning disabilities

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Lisa Rossignol's daughter Lily had a stroke before she was even born. Afterward, the child suffered some 300 epileptic seizures per day. Ultimately, doctors determined that the best way to eliminate her seizure problem was to perform a hemispherectomy, or remove the right half of her brain. Today, Lily is an active six-year-old with some learning disabilities. Her mother is active in educating the medical establishment about how to communicate with children who have learning disabilities so that their health care needs are understood and met.

Rossignol, who only this fall was admitted into a doctoral program in the University of New Mexico Department of Sociology, is the primary author of "Empowering Patients Who Have Specific Learning Disabilities," an article that appears online in the *Journal of the American Medical Association (JAMA)* and will be in the print edition of the journal next month. Rossignol's co-author is Michael Paasche-Orlow, M.D., Boston University School of Medicine.

Rossignol met Paasche-Orlow at the International Conference on Communication in Healthcare in Scotland last year. "We both have an understanding of IEPs (Individualized Education Programs). Teachers already know how to communicate with and educate children with learning disabilities as a result of a federal mandate – the Individuals with Disabilities Education Act (IDEA) – that required school systems to accommodate the needs for an equitable learning environment," she said.

Dr. Paasche-Orlow said, "To improve health outcomes, clinicians will

need to take the mission of patient education and empowerment much more seriously – the population of people with specific learning disabilities is actually much larger than many people realize. The IDEA has been broadly implemented - and over 12 percent of public school students have identified specific learning disabilities – this is much higher than most people would imagine."

He added, "The health care system is unnecessarily complex. We – the clinicians – need to learn how to help people with specific learning disabilities."

"It might not occur to physicians to ask patients or their parents if they have an IEP," Rossignol said. "Students who first had IEPs in the 1990s are now adults. It could give doctors good information about their best way to learn," she said, adding that many may be embarrassed about it, but even asking patients is a good start. "People develop tricks to work around their disability that they can teach to physicians to share with others," she added.

Among the learning disabilities that Rossignol and Paasche-Orlow explored is auditory processing disorder, dyslexia, dysgraphia and dyscalculia. "A patient with dysgraphia who was sent home with printed complicated dosing information that involved breaking pills and such, wouldn't be able to follow it and would need to be given easier delivery options," she said. Other options for accommodating learning disabilities could include having the patient voice record the doctor's treatment plan or email it to them.

"In other cases they might use visual aids, like Draw MD to explain things to both visual learners and those with auditory processing disorders," she said. Other doctors might give a patient a pen and pad to write things down. "We teach our children how to advocate for themselves in the world. They also need to know how to advocate for

themselves in the medical system," Rossignol said.

The Affordable Care Act provides funding to PCORI, or Patient-Centered Outcomes Research Institute. Rossignol, affiliated with PCORI, said that their goal is for patients and the public to have the information they need to make decisions that reflect their desired health outcomes. "My husband and I are both educated, middle class people and we had a hard time getting care for our child. We want to close the gap in health disparities for others," she said.

Provided by University of New Mexico

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