

A MATTER OF PERSPECTIVE: A SHARED FAMILY JOURNEY

By Jeffrey Symes
One Sky

As summer keeps its steamy pace, the Lang family calendar unfolds a lot like that of many Seacoast families: a visit to the Isles of Shoals, Water Country, camping, birthday parties, and cook-outs with family and friends. It's a fun but hectic season, with dance classes for Rylee and horseback-riding for her big sister, Sydnee, to squeeze into a busy schedule.

For 8-year old Sydnee, the pace can become overwhelming sometimes, but the family gathers around her. She was diagnosed with dyspraxia when she was 3 years old and since she was profiled here last August, it has been a year of gains and new challenges. Both for Sydnee and for her family.

"We're go, go, go and it can get her off her routine," says her mother, Alanna. "But in some ways, things have gotten easier, better. There's always dynamics in a family and then there's this other layer that we work out. It affects everybody's well-being at times."

Dyspraxia, also known as developmental coordination disorder (DCD), is a lifelong neurological disorder that affects the way the brain and body communicate. In the 1970s, the medical world recognized something called "clumsy child syndrome." While it manifests differently for each individual, the constellation of signs and symptoms can be similar to other disorders like autism and ADHD, making an accurate diagnosis difficult but crucial.

For Sydnee, DCD creates a list of challenges to her fine and gross motor coordination and planning, social skills, focus and attention, speech, memory, sensory, and proprioception. All of which means that even a simple task like using a utensil or any tool, to eat or to write for instance, takes extraordinary planning and effort. Today, it's estimated to affect 5-



KURTIS AND ALANNA LANG WITH THEIR DAUGHTERS SYDNEE, LEFT AND RYLEE ARE GETTING READY FOR A NEW SCHOOL YEAR. SYDNEE WAS DIAGNOSED WITH DYSPRAXIA WHEN SHE WAS 3 YEARS OLD AND THE WHOLE FAMILY WORKS TOGETHER TO MAKE GAINS AND FACE NEW CHALLENGES WITH HER.

to 6-percent of children with some estimates putting it even higher worldwide. In its campaign to raise awareness, DyspraxiaUSA put the odds at 1-in-10 that you know someone with dyspraxia.

Like any parent, Lang would like to emphasize the positive, to talk about achievements and gains. But the support system requires data on deficits, on areas where a child misses developmental markers. The emphasis is on what a child can't do. It's a mixed message that parents often have to translate and work through. What can get lost or misperceived in the ways it manifests is that DCD doesn't affect intelligence, but it can bring challenges in learning.

So Sydnee works hard, academically and socially, and her mother sees the strides she's made in the past year. "She has a great personality," says Lang. "And she's very smart. She knows more than what she can express accurately. She's aware of her differences and she tries hard to keep up."

So while Sydnee may struggle riding a bike, she thrives riding a horse. She's been riding for about five

years already and has taken part in the therapeutic horse-riding program at the University of New Hampshire for a few years. This past spring, she competed in her third Special Olympics Equestrian competition.

The early diagnosis may have given the Langs a little head start in researching and finding tailored treatments and supports for Sydnee, such as speech and occupational therapy and therapeutic horseback-riding, and Lang has tried to share that information when she can. But her own efforts at advocacy to ensure future promise for others is tempered by an all-too-real present.

"I'd like to help people walk their own journey, but I'm still trying to figure out ours," she laughs. "I mean, how much more progress, how many more gains will she make? Will she drive, will she live independently? We still can't see the future."

Last year, Lang appeared on EDGE Radio, trying to help spread word about a condition that is more common than it is known. In the year since, the

whole family has absorbed the unpredictability of Sydnee's condition into their routine. Lang still has regular shifts at the Golden Egg where she's worked for a dozen years, and her husband, Kurtis, still starts his workdays in the middle of the night as a commercial fisherman. And their daughters, both Sydnee and Rylee, continue to grow, alternately strengthening and testing their bond as sisters.

Lang observes that Rylee, though younger in years, sometimes takes the role of a protective big sister, lending support and encouragement as Sydnee tackles a new challenge; and sometimes she's simply a young girl, embarrassed by what her big sister is doing or can't do because of her condition. She points out that, in many ways, Sydnee's condition belongs to all of them.

"Sydnee's journey impacts all of our lives in a multitude of ways," says Lang. "It's a shared journey. I mean, we're a family unit living in the same household and we experience much of life together every day. There are hurdles and gifts that Sydnee's condition presents for all of us, as a family unit and individually, too. I know how it can have a negative impact on Rylee but it can and does uplift her and mold her - all of us - into being the best versions of ourselves."



Incorporated in 1983, One Sky Community Services has been dedicated to providing a comprehensive array of services, supports and programs to individuals and families with intellectual and developmental disabilities, as well as acquired brain disorders. A private 5013C nonprofit organization, it is the designated area agency serving the following communities: Brentwood, Deerfield, East Kingston, Epping, Exeter, Fremont, Greenland, Hampton, Hampton, Falls, Kensington, Kingston, New Castle, Newfields, Newington, Newmarket, North Hampton, Northwood, Nottingham, Portsmouth, Raymond, Rye, Seabrook, South Hampton and Stratham. One Sky works with nearly 1,200 individuals and families on a yearly basis.