

## Lily's Story (Age 12)

We join Lily's family again when Lily is 12 years old. Lily was the youngest of Jennifer and Justin's three children. Since we first met Lily, her parents have had two more children, both boys, Parker and Aaron. Both boys are typically developing like their older siblings.

Lily received a diagnosis of childhood apraxia of speech (CAS) when she was 4 years old. Her speech therapist noted atypical development of Lily's social skills and receptive language skills, both of which caused her to screen Lily for autism. Lily received an evaluation at age 5 for autism spectrum disorder (ASD) and was given that diagnosis. The evaluation consisted of a cognitive and adaptive assessments, and administration of the Autism Diagnostic Observation Schedule-2. Lily's cognitive skills were found to be in the borderline range on the *Weschler Preschool and Primary Scales of Intelligence-IV (WPPSI-IV)*. Lily had a Verbal IQ of 64 and a Performance IQ of 80. Results of adaptive testing, *Vineland 3*, suggested that Lily had significant impairments in social, communication, fine motor, and gross motor skills. Lily was referred to an occupational therapist for a more in-depth assessment of her motor skills and was diagnosed with global dyspraxia.

Lily's family decided to use their insurance to access intensive, in-home behavioral therapy for Lily through one of the autism treatment programs in their area. They chose a program that provided a combination of relationship-based therapy and applied behavioral analysis. Lily had 30 hours per week of intensive therapy for the first two years (ages 5-7). Jennifer continued to home school, working in tandem with the therapists. Lily also had outpatient occupational therapy (OT) and physical therapy (PT) services once a week and continued with speech therapy once a week. When Lily was 7 years old, the family decided to explore the public schools as an option and enrolled Lily when she was in first grade. They continued to receive in-home therapy services 10 hours per week, which continued until she was 9 years old.

Over the next three years, Lily continued to make progress. Her oral language developed slowly and idiosyncratically. She has an unusual vocal melody, speaks in short sentences, and uses third-person pronouns or proper names when talking to people. She often repeats what she hears others say, but she appears to be mimicking rather than communicating with intent. She understands and responds to questions when they are in routines or around her favorite topics but might seem very confused when she hears similar questions in less familiar contexts. She learned to read, and by age 12 was reading at a second grade level. She has keen interests in the solar system and loves to be on the computer looking at planets. She knows minute facts about the solar system. She has been unsuccessful in learning to ride a bike, although she is very interested in learning. Her social skills have improved. There are specific games she enjoys playing with others, but she is not always conscious of the rules. Lily's family has become involved in a week-long summer camp for families and children on the autism spectrum. Jennifer volunteers through the year to help organize auctions to raise money for scholarships for families to attend the camp. Lily adores going to the camp and being with other children like herself. Her sister and brothers enjoy the activities with other children who have siblings with autism, and her parents enjoy a week of reduced stress.

Typical and Atypical Child Development  
Module 3: Middle Childhood, Ages 9-13  
Case Study

At age 12, Lily is beginning to show some changes in her behavior and willingness to participate in activities. She is in seventh grade, and her teachers have raised concerns that Lily is not reading and that her motor skills seem to be deteriorating. Jennifer and Justin noticed changes in Lily's behavior at home. She seemed to not know where she is sometimes, not finishing dressing, needing more help to complete her bedtime routine, and sometimes sitting and staring. They brought their concerns to their pediatrician, who referred Lily to a pediatric neurologist. Lily was diagnosed with epilepsy and treated with sodium valproate. Her dyspraxia made it very difficult for her to swallow pills, so the family needed the medication in a liquid form. The medication did not seem to have much effect on Lily, as she seemed to plateau in many of her skills academically and to continue to lose motor skills. The family returned to neurology to review the medication. Other medications were tried without benefit. Lily's family and teachers began to notice tremors, prompting a return to the neurologist for more testing. What initially appeared to be epilepsy with focal seizures was now diagnosed as progressive seizures. The neurologist had a long conversation with Lily's parents about probable loss of skills across all domains (cognitive, motor, communication, self-help) and what this means for Lily's future.

### *Summary*

*Jennifer and Justin never imagined that Lily would not continue to make progress. They had been looking forward to seeing their daughter someday holding a job and living with them until she seemed ready to live in a supported setting. Their world has been rocked with the high probability that Lily will lose many of her skills; that she has actually reached her full potential and will lose her current capacities to be self-sufficient. They are worried that Lily will not know them or her siblings and that the joy in their family is gone.*

*Lily's diagnosis of a progressive seizure disorder suggests a significant loss of skills across domains in her future. Lily's family will need support in adapting to a new image of Lily, and how Lily's future may unfold.*

### *Follow-Up Suggestions and Recommendations*

- 1. Lily's parents may wish to connect with other families who have children with degenerative disorders for emotional support.*
- 2. Lily's family will need ongoing support in assessing Lily's skills and need for adaptive equipment and support services in her home.*
- 3. It is recommended that school staff reconvene the individualized education program (IEP) team to adjust goals for Lily to maintain her skills and to provide support and strategies as her skills deteriorate.*