

Lily's Story

Lily is a 4-year-old girl. She lives in rural Wisconsin with her mother and father, Jennifer and Justin. Jennifer is a full-time mother of three children: Alex (age 8), Cecelia (age 6), and Lily. Justin works as a technician for a chainsaw manufacturer. Jennifer home schools all three children, whom she describes as smart. She enjoys her life and getting together with other families in the area who home school.

Lily was born full term and was a very easy baby according to her mother. She slept well, ate well, and seemed content. She started talking when the other kids did around age 1. She seemed to soak up words, but what she was saying was hard to understand. Around 18 months of age, Lily's words seemed to gradually slip away. Lily's talking was not at all like her siblings who seemed to just chatter effortlessly by age 2. Justin's mother said that Justin had been a late talker but came out with full sentences around age 2½, putting her own worries about him to rest. Lily continued to make lots of sounds, but they just didn't seem like real words. Then she would suddenly say a word like "Mommy." Her words just didn't seem to stick; she'd say them once, and then Justin and Jennifer wouldn't hear them again. Sometimes her voice was very high pitched, and Jennifer wondered if she was getting frustrated with being unable to say words. Jennifer was also worried that Lily didn't seem to hear her name or follow directions.

When Lily was almost 2½, Jennifer talked to her pediatrician about her concerns and was referred for a hearing test, which Lily passed. The audiologist suggested contacting Birth to 3 to see if Lily might be eligible for speech therapy. Her pediatrician asked if the older kids talked for Lily, which Jennifer said they did. He suggested that she talk with Alex and Cecelia about giving Lily time and space to do her own talking. Justin's mother intervened again, telling Jennifer to be patient and take the doctor's advice. Justin thought his mother was probably correct, but could see Jennifer wasn't "sold on the idea." Jennifer agreed to give it a few more months. Lily made some progress and started using a few phrases: "Like it," "So funny." She seemed to be learning the alphabet and numbers. She seemed obsessed with counting, although her names for the numbers were completely unclear and never sounded the same twice. She lined up everything—blocks, fish crackers, stones—and counted them. Lily's play was not like the other children, either. She was not at all into pretending. She had no interest in dolls and stuffed animals. Lily enjoyed two activities: lining up toys or other objects to count them and drawing. She drew the same thing, a tall building with lots of windows, every time she got hold of markers and paper. Jennifer tried reading with Lily. Lily looked at pictures but did not seem interested in the story when Jennifer read. Lily pointed to pictures and appeared to be labeling them, but her words were not clear. Lily had favorite pages in books and often took a book from Jennifer while she was reading and turned to her favorite page. When Jennifer asked Lily to point to pictures, Lily sometimes complied.

Lily was very awkward on the playground, definitely a child Jennifer had to keep an eye on. Instead of running, Lily did a funny galloping step and she often tripped. She tended to drift off by herself at the playground, usually stirring the pebbles under the play structure with a stick or collecting things and lining them up. She liked to line small stones up at the end of the slide and got extremely upset when other children used the slide and swept away her stones. When Lily's family got together with other families, Lily would sometimes scream and writhe rather than enter a room. Jennifer thought this was related to her not being able to talk as well as others.

Typical and Atypical Child Development
Module 2: Early Childhood, Ages 4-8
Case Study

When Lily turned 3, Jennifer decided that while there had been progress, Lily was not enough like the other children. She called Birth to 3; after all Lily was just 3. She was told she was too old for their program and referred to her physician and the public schools. Because Jennifer home schooled, she didn't think the public schools would help her, so she returned to the pediatrician for a referral for speech therapy. She called a clinic with therapy services and was put on a three-month waiting list for an evaluation. Lily was seen by a speech therapist for an evaluation and diagnosed with a receptive language delay and an expressive language delay secondary to childhood apraxia of speech (CAS), a neurologically-based motor speech disorder that affects the child's ability to accurately sequence and time the movement of muscles to produce clear speech. The therapist was concerned about Lily's apparent delays in understanding of language and her lack of gestures to communicate. Her scores on the *Preschool Language Scale-5th Edition* were below the 16th percentile in both Auditory Comprehension and Expressive Communication. If Lily's communication problem was just CAS, her language comprehension would be more like other almost 3½-year-olds, and it would be very likely that Lily would gesture in order to get her ideas across. Lily only seemed to point to pictures she was interested in and didn't seem that interested in trying to communicate with her mother.

The therapist wondered if Lily had lost her motivation to try to communicate because it was just so hard for her to produce clear speech. The therapist decided to focus on improving Lily's speech while getting to know her a little better. Jennifer decided to work with the speech therapist and committed to doing speech work at home with Lily every day as prescribed. She found it extremely difficult to get Lily to do the activities and to practice making sounds based on the therapist's recommendations. As a result, Jennifer's frustration and fear that Lily was not a "normal" child began to increase over the next six weeks. She took heart in Lily's beginning to show an interest in letters and writing letters and even saw her write some words, but Lily did not seem to care that her mother was pleased with her achievement. She didn't do "high-5s" or clap for herself. She actually screamed sometimes when her mother clapped. Justin wasn't sure what to think, but he could definitely feel Jennifer's anxiety about Lily's progress.

Jennifer decided to talk with the therapist about her concerns and found the therapist equally concerned but did not expect to hear the word "autism." The therapist brought up the delays in understanding language, Lily's repetitive play patterns, her lack of pretend play, and her decreased motivation to communicate with family members. The therapist asked Jennifer to complete a Social Communication Questionnaire (SCQ). Lily's score was above the cutoff score for suspected presence of autism.

Summary

Lily's parents are wondering what they did wrong in raising Lily. She was such a perfect baby and seemed to be so smart. Jennifer is feeling terribly guilty that she did not push the pediatrician more when Lily was younger and angry that other people did not support her when she talked about concerns.

Lily is developing atypically, like children who have autism spectrum disorder (ASD), and would benefit from an evaluation for this disorder. In addition, she has childhood apraxia of speech, a very challenging to overcome speech disorder. Additionally, she is showing some awkwardness and clumsiness that suggests that she may have a more global dyspraxia that affects her gross motor movements and safety on the playground.

Follow-Up Suggestions and Recommendations

1. *Refer for an evaluation of autism spectrum disorder with a psychologist. This evaluation should include a cognitive assessment, adaptive behavior assessment, and autism specific assessment.*
2. *Explore the access to intensive in-home behavioral therapy for ASD if she does meet criteria for that diagnosis.*
3. *Discuss with the family a possible referral to the public schools for early childhood special education services.*
4. *Continue with speech therapy and explore the use of assistive technology to help develop a more accessible path for expressive language development.*
 - a. *Shift therapy focus to emphasize social interaction and social communication with the use of assistive technology/augmentative communication.*
 - b. *Reintroduce specific therapy for CAS as Lily's social communication skills develop.*
5. *Refer Lily for outpatient occupational therapy and physical therapy evaluations to gain more information about her praxis. This could also be completed as part of the service provided by the public schools.*