

Caroline's Story

Caroline is a 15-month-old child (adjusted age*) who lives with her parents, Carl and Lindsay, and paternal grandparents on a farm in rural Wisconsin. Lindsay has an Associate's Degree in early childhood and works at a day care with 2-year-old children. Lindsay and Carl tried to enroll Caroline in the day care where Lindsay works, but it didn't work out. Caroline was very hard for the staff to settle, and Lindsay was starting to feel like her colleagues resented Caroline being there. Caroline is at home with her maternal grandmother while Lindsay works a reduced schedule. Caroline seems much more settled at home.

Caroline was born at 28 weeks gestation and was in the NICU for three and a half months in a city 90 miles from their home, before being discharged. Lindsay reduced her time at work for the three and a half months, but was not able to stay with Caroline as much as she wanted to. Caroline came home from the hospital feeding orally and breathing completely on her own. She is currently receiving Birth to 3 services. Her primary provider is an early educator. Her individualized family service plan (IFSP) outcomes center on feeding and developing Caroline's play skills.

Caroline's parents are concerned that she does not always make eye contact with them, but she does seem happy some of the time when they, especially her dad and brother, engage with her. Her parents describe her as being "in her own world." She does not seek them out very often, even when she is upset. She does not always respond to her name, unless you touch her or get down on her level and make eye contact with her. She will stop briefly when her parents firmly say "no." She seems content, but it is hard to get her attention to look at things. Books hold her interest, and she will stare at pictures in a book for long periods of time. She sometimes responds to her mother's affection, but she gets overwhelmed easily and melts down. Lindsay has wondered if Caroline is mad at her for all the time she had to spend in the NICU. Caroline does not reach for her mother; in fact, Lindsay feels that Caroline pushes her away. When Caroline uses her voice, Lindsay responds to her, but she reports that she has a hard time knowing if Caroline is trying to communicate with her. Caroline's parents rely on the daily routine to "guess" what she might want or need. She is saying one word, "ba" (which the family thinks means "dad," because she usually says it when Carl is around). She does not seem to be trying to imitate words, and she is not using many gestures, except lifting her arms to be picked up. Caroline likes to shake and throw toys, and she often puts toys in her mouth. She is just starting to use both hands in her play. For example, she can hold a ball with both hands and push it. She is starting to imitate some play, like banging on a drum. She is very interested in musical, light-up toys. She delights in music, but seems to be very frightened of other sounds, like dogs barking. Her brother, Louie, can make her laugh by blowing on her. Caroline loves to be swung by Carl. She gets very excited when he asks her, "Do you want to 'fly'?" Caroline's motor skills are starting to take off after a slow start. Caroline rocks repetitively sometimes while standing at the coffee table.

Mealtimes are the major challenge for the family. Caroline is not very interested in feeding, only eating a few Stage 1 baby foods (smooth purees), and frequently spits out her food. She gags on any food with textures. She often gets very upset during meal times, which is upsetting to the entire family. She is difficult to settle once she has become upset. Lindsay usually holds her and tries to rock her and sing to her, but



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Caroline often arches and screams louder. She has had evaluations at the gastrointestinal and allergy clinics, but nothing has emerged as a cause of Caroline's distress around feeding. Lindsay often gets frustrated and puts Caroline in a playpen during meal times so the family can eat without a lot of disturbance. Feeding takes over an hour or more, even when Lindsay feeds Caroline with just the two of them present.

Caroline is not a great sleeper. She naps for about 30 minutes in the afternoon. Getting her down at night requires a bath and rocking for about 30 minutes. She often wakes up at night, and it takes some rocking to get her to sleep again.

Caroline's parents notice when they volunteer in the church nursery that Caroline's skills seem more like the younger babies in some ways and not at all like the other 14- to 18-month-olds. The children around her age are trying to talk; many of them have lots of words. They are walking with good balance, and finger-feed snacks. Most of all, they seem curious about each other and investigate their environment.

*When a child is born prematurely pediatricians adjust the age of the child based on weeks of gestation. Caroline was born at 28 weeks, instead of 40 weeks. Therefore, she was 12 weeks early and her chronological age in this story is 15 months. However, she is a 12-month old in terms of our developmental expectations, and she would fall within the age cohort of 12-18 months on the CLTS Functional Screen. Adjusted age is used until the child is 2 years old; by age 2 years, children who were premature and are capable of catching up developmentally will look like typically developing 2-year-olds. However, for the purposes of the Functional Screen, we use a child's chronological age, not adjusted age, because the screen is designed to assess how a child is functioning compared to what would be expected based on the child's actual (chronological) age.

