

Early Intervention (Part C) Child Example Case Study: “Kim” at 17 Months of Age

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<http://ectacenter.org/~pdfs/knowledgepath/ifspoutcomes-iepgoals/KimCaseStudy-17mos.pdf>

It also appears as a part of the ECTA Center's *Developing High-Quality, Functional IFSP Outcomes and IEP Goals Training Package* at:

<http://ectacenter.org/knowledgepath/ifspoutcomes-iepgoals/ifspoutcomes-iepgoals.asp>

A. Medical and Developmental Background

Kim Doe, who is currently 17 months of age, was referred to the early intervention program by David Johnson, MD, her pediatrician, one month ago due to failure to thrive associated with cardiac anomalies, encephalitis, spasticity (most likely cerebral palsy) and seizures. Kim is followed by neurology and cardiology in addition to her pediatrician, Dr. Johnson.

Mrs. Doe reported that she was very stressed by Kim's hospitalizations, especially since she was unable to stay with her near the hospital (out of town) due to her need to care for Kim's sister, Jana. Jana is 4 and does not attend school. Mrs. Doe shared that her parents live nearby and that they have helped care for Jana when she was with Kim. Her parents are not in good health and it is difficult for them to help for long periods of time with Jana and/or Kim. Her greatest concern for Kim is her health. She also wants Kim to continue to gain weight so she can get off the NG tube. Mrs. Doe reports that she has not had a complete night sleep since Kim came home from the hospital due to the night tube feeding.

Kim was last seen 2 months ago by Ms. Davis, her hospital occupational therapist, when Kim had her follow-up neurologist appointment at the hospital out of town. The following developmental information was shared by Ms. Davis based on her evaluation of Kim at that time:

Kim was able to drink about one ounce of liquid from a spouted cup when it was held for her. She accepted a variety of foods (different tastes, different textures) by spoon and she was able to move the food around in her mouth with her tongue. She had good lip closure. Kim was taking between 5-10 spoonfuls of food per meal (mostly baby food) when seated in an adapted high chair. Mrs. Doe told Ms. Davis that Kim was not eating the same foods that her family eats during mealtime. Kim was starting to make munching motions. She was swallowing liquids of varying consistencies, as well as soft foods, without choking. When new textures or foods were introduced Kim choked/gagged initially. It was not clear if her gagging and choking was due to oral hypersensitivity as a result of her NG tube or due to neurological concerns. She was holding a spoon and waving it when it was placed in her hand; however, she was not controlling the spoon to scoop food or bring food to her mouth or to finger feed. Kim had continued to gain weight, though Mrs. Doe reports that Dr. Johnson wants Kim to gain more weight before she can come off the night feeding tube.

Kim was not able to assist with dressing due to significant challenges in moving her arms and legs. She attempted to move her arms and legs when dressing but due to spasticity was unable to control her movements. Mrs. Doe reported that Kim enjoyed bath time.

Kim was playing by reaching for and batting toys, touching pictures and making sounds, and watching and making sounds in response to what happened around her. Mrs. Doe described the sound as a “guttural sound in the back of her throat.” She was attempting to engage in imitative sound play by making throaty sounds following sounds made by others. She was not babbling or making consonant sounds, which Ms. Davis believed was most likely due to her NG tube since she appeared to have good movement of her lips and tongue. Mrs. Doe reported that Kim sometimes used gestures and sounds to let her mom and dad know when she wanted to be picked up, when she was full or didn’t like a particular food. Kim sometimes made choices about which book she wanted to have read to her. Mrs. Doe informed Ms. Davis that Kim cries and fusses when she is not understood (and this was happening several times every day):

“Kim was able to support her head well when in an adapted seat, when she was held either in sitting or standing supported at her trunk, and when on her tummy or side. She was able to balance momentarily when propped in the sitting position (hands on the floor or on her knees), but was not able to regain her balance or get herself into the sitting position. She lifted her head and used her abdominals to help get to sitting when assisted to sit toward one side. Kim was able to roll by herself from her stomach to her back but with some difficulty. Kim was also able to roll from her back to her stomach. She moved short distances forward, sideways and backwards lying on her stomach mostly by twisting her body to inch along, though she was trying to pull with her arms and to push with her legs. She was motivated to move to get her toys although she was not able to move far.

Kim appeared to enjoy being with adults and other children. When with other children, especially her sister, Kim watched them, laughed, and attempted to imitate sounds they made. Kim enjoyed sound play with her sister and her mother. She had a preference for toys that made sounds (by moving to, looking at and/or smiling when the toy was presented to her). She especially liked ones that played tunes. She showed recognition of a number of toys and objects by looking at them when they were named.

Kim reached with both hands and was able to move objects by swiping at them. She patted pictures and banged toys. She was able to grasp toys and other objects that were placed in her hand, but was not able to consistently open her hand to pick up an object by herself. She did not bring toys or hands to her mouth due to spasticity.”

B. Family Routines and Priorities

What are the daily routines/activities of your child and family (where and with whom your child spends time)?

- Jana usually is up before Kim in the morning so Mrs. Doe has time to feed Jana and get her dressed before Kim gets up.
- During the week when Mr. Doe is working, Mrs. Doe spends most of the time at home during the day with Kim and Jana. She is beginning to do some errands with the girls during the day now that Kim is healthy – she had been doing shopping at night when Mr. Doe could be at home with Kim.
- Kim eats small meals every 3-4 hours. She is tube fed twice a day, around 1:00 AM and around 1:00 PM – she will be weaned from the lunch feeding within the next week or so. Mrs. Doe prepares different foods for Kim than the rest of the family.
- Kim likes to play on the living floor with Jana. She does so several times a day. Jana likes to interact with Kim during the playtime, showing her books and toys, and attempting to engage her in play.
- Mrs. Doe's parents live close by and visit several times during the day each week. They almost always spend time with Kim and Jana after church on Sundays.
- Jana plays with neighborhood children almost every day and Kim likes to watch them play and seems to want to play with them.
- Jana usually naps around 2:00 PM everyday and Kim naps around 3:00. Mrs. Doe has about an hour each day to do chores at home when both girls are napping.
- Jana goes to bed at night around 8:00 and Kim goes to bed around 9:30. Mr. And Mrs. Doe usually go to bed around 10:00.
- Mr. Doe and Kim's grandparents are "uncomfortable" feeding Kim and spending long periods of time caring for her. Mr. Doe is not home a lot due to his long hours of work.

Are there other routines or activities you would like to establish? These can be routines or activities that your family would like to do now or in the future.

- Mrs. Doe would like to be able to have the family eat the same foods at mealtime and not have to feed Kim different foods. Mrs. Doe has been working on introducing new textures and different foods over the past several months. Kim still gags when new textures/tastes are introduced but gagging reduces as she adjusts to the foods.
- Mrs. Doe would like the girls to be on the same sleep schedule so she has some time to herself and to do household chores.
- Mrs. Doe would like Kim to be around children her own age, especially since she really enjoys watching Jana play with neighbor children. Mrs. Doe would like to explore some childcare, respite care opportunities for Kim.
- Mrs. Doe would like to have more support from Mr. Doe and Kim's grandparents in caring for Kim and Jana. She is hoping that Kim's grandparents will be more willing to help with Kim when she is able to eat table foods and not gag. Mrs. Doe understands their reluctance and also recognizes that they are not in the best of health. She knows that caring for Kim is stressful for them – they are afraid they will do something to 'hurt' Kim.

Who are the people and what are the toys, activities, routines, and places your child *enjoys* the most?

- Kim likes riding in the car. The Doe's have a car seat for Kim that with guidance from the OT at the hospital they have adapted.
- Kim likes to be read books by her grandparents. She also enjoys playing games with them (peek-a-boo, pat-a-cake).
- She likes toys that make sound.
- She likes to watch Jana and the neighbor children play. She especially likes Jana to interact with her, showing her toys and books.
- Kim enjoys being with most adults, especially her grandparents.

Which routines or activities are *challenging* for you or your child?

- Mealtime
- Nap and bedtime

What are your family concerns related to your child's development (*Including anything your family identifies that would help to improve your ability to meet the needs of your child*)?

- Kim gags and chokes when new foods/liquids are introduced and Kim's mom has to spend a good amount of time working to help Kim overcome her dislikes of new foods and textures – Kim's mom is concerned about how long it will take to transition Kim to table food that the rest of the family eats.
- Kim and her sister are not on the same sleep schedule (going to bed, awaking in the morning or napping during the day) so Kim's mom doesn't always finish all of her chores and is frequently tired as Kim does not yet sleep through the night.
- Several times a day, Kim cries and fusses because Kim's parents and sister do not always understand what she wants or needs.
- Kim attempts to initiate play with her sister but is unable to move very far around the living room on her own and is unable to tell her sister what she wants to play with.
- Grandmother doesn't like to feed Kim because she gags/chokes on new foods.
- Kim is fed every 3-4 hours during the day and is on a feeding tube at night.
- Kim wakes several times during the night taking 10-15 minutes to get back to sleep.

What are your family priorities related to your child's development?

Kim's mom has prioritized the following concerns to be addressed immediately by the team:

- Would like Kim to sleep through the night and get both Kim and her sister on the same sleep routine so Kim's mom feels rested and better able to do daily chores.
- Would like Kim to be able to gain enough weight to be off the night tube feeding and for Kim to be able to eat table foods with the rest of the family at meal times.
- Would like Kim to be able to let people know what she wants.

What are your family resources, including family, friends, community groups, financial supports, etc., that are helpful to you?

- Kim usually spends her day at home with her mom and sister.
- Kim's maternal grandparents spend time with Kim and her family almost every Sunday after the family returns from church. Her grandparents are helpful with Kim and Jana.
- Transporting Kim to the store, church, etc. is easy.
- Kim spends about 30 minutes 2x/day playing on the living room floor with her sister.

C. Child Developmental Information

Child Strengths: At 17 months of age, what's working well for Kim is she is able to drink from a spouted cup (about 1 oz. of liquid) if the cup is held for her. She accepts a variety of foods (different tastes, textures) by spoon when fed, holds a spoon when placed in her hand and waves and bangs it. She is swallowing liquids of varying consistencies, as well as soft foods, without choking. Kim watches people and is very interested in what is happening around her; recognizes and enjoys familiar people and children, likes toys that make sounds, shows recognition of toys and objects by looking at them when named. Kim plays by reaching for and batting toys, patting pictures, holds toys when placed in her hand. Kim is able to hold her head up when in her adapted seat, held supported in a sitting or standing position or when on her tummy or her side; sits momentarily when propped in a sitting position. She lifts her head and uses her abdominals to help get to sitting. She is able to roll from her back to her stomach and moves short distances forward, sideways and backwards lying on her stomach (twisting her body to inch along. She is motivated to move to get her toys, although she is not able to move very far. Kim is able to make throaty sounds and gestures to let her family know when she wants to be picked up, when she is full or doesn't like a particular food; sometimes makes sounds and gestures to indicate what books she wants read to her; enjoys sound play with familiar adults and children and attempts to imitate sounds. Kim enjoys being with familiar adults and children; she watches other children, frequently laughing and smiling at others, cries and fusses when she is not understood (several times a day).

Child Concerns: Some of Kim's challenges or needs include choking or gagging when new foods are introduced, does not scoop food or bring spoon to mouth, does not finger feed, needs assistance when drinking from a cup, is not able to assist with dressing or bathing.

Assessment Summary: Assessment included observations, interview with mother and use of the *Early Learning Accomplishment Profile* (E-LAP) as the primary source for estimated developmental age in months.¹

Expressive and Receptive Language: (5-6 months) Kim is making throaty sounds and gestures to let her parents know when she wants (i.e., when she wants to be picked up, is full or doesn't like a food, or wants a particular book). Kim enjoys sound play with adults and children

¹ Use of the E-LAP in this case study is not intended to be a specific endorsement of a specific tool, nor a statement of the quality of the tool for use in the outcomes measurement or IFSP planning process.

and attempts to imitate sounds and toys that make sounds. Her ability to make sounds may have been affected by the presence of the NG tube.

Gross Motor: (6 months) Kim is able to hold her head up when in her adapted seat, is held in a sitting or standing position and when on her tummy or sided. She is able to sit momentarily when propped in a sitting position with hands on floor. She is able to roll by herself from her stomach to her back with difficulty. She is able to move short distances forward (twisting her body to inch along) and is motivated to get her toys. Kim is challenged by her limited movement to be able participate in independent feeding and/or dressing.

Fine Motor: (4 months) Kim plays by reaching for and batting toys, patting pictures and banging toys, holds toys when placed in her hand. She is able to hold objects (toys, spoon) if placed in her hand. Kim is challenged by her limited movement to be able to explore her environment and play.

Cognitive: (7 – 8 months with scattering to 14 months) Kim watches people and is very interested in what is happening around her; looks for toys when dropped or rolled from view; likes toys with sound, and shows some recognition of objects when named, and recognizes mom, dad, sister, grandparents. It is difficult to determine Kim's level of understanding due to her motor challenges and limited ways of communicating thoughts, wants and needs.

Social-Emotional: (6 – 9 months) Kim enjoys being with familiar adults and children. She watches children and adults, laughs and smiles at others. She cries and fusses when she is not understood. The NG tube affects her sleeping at night, which leaves Kim fussy during the day.

Adaptive: (Under 6 months) Kim is able to drink a 1 ounce of liquid at a time out of a cup held for her. She is accepting a variety of foods (different textures and tastes) by spoon; however, while she is holding a spoon, she is unable to bring it to her mouth. She is not able to assist in dressing or bathing due to her motor challenges.

Hearing: (Normal) Passed Newborn Hearing Screen and subsequent screens by her physician. Next well-baby check is at 18 months.

Vision: (Normal) physician checks vision at each well-baby check and no concerns. Next well-baby check is at 18 months.

Health: Kim has been hospitalized off and on out of town for the majority of her first 16 months of life due to seizures, numerous viral infections and significant nutritional issues. Kim has had an NG tube since 6 months of age. Repeated efforts have been made to wean Kim from the NG tube, however, her illnesses prevented that from occurring. Kim has been home from the hospital for the past 3 months and has been healthy since that time. Her primary care physician and his nutritionist have made significant gains in weaning Kim from the tube feedings since that time due to improved health and weight gain. Kim is currently is tube fed twice daily – at noon and during the night. The goal is to ensure sufficient weight gain and removal of Kim's NG tube by late summer. She is being weaned off her seizure medication. Recent EEG shows no seizure activity.