

Excerpted from **Lives in Progress: Case Stories in Early Intervention**,
by P.J. McWilliam, Ph.D., with invited contributors.

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chapter 17

An Uncertain Future

P.J. McWilliam

Shannon Eason was going to be a challenge. There was no doubt about it. The child had been born at 23 weeks' gestation, weighing only 1 pound 7 ounces, and had spent 5 months in the neonatal intensive care nursery before going home. Now, at 13 months of age, she still needed supplemental oxygen and an apnea monitor. What worried Beth most about working with this baby was the fact that she also had a significant visual impairment. Although Beth had worked as an early interventionist for more than 3 years, she had never felt completely comfortable working with children who had sensory impairments. After all, she hadn't specialized in that area when she was in college.

Comfortable or not, Shannon Eason would be Beth's responsibility; she didn't have much choice in the matter. The referral had come by way of Virginia Cousins, a vision specialist who was responsible for serving all children with vision impairments who lived in the district. The Eason family was apparently new to the area and had requested a

vision assessment for their daughter. Virginia Cousins conducted the child's assessment and subsequently referred her to the early intervention program. According to her referral letter, Virginia Cousins believed that the child's delays might not be related to her prematurity alone and that Shannon and her family might benefit from additional assessments and services. Given her current caseload, however, Virginia could offer the family only a once-a-month consultation, and even that was questionable.

"She's not the only one with a caseload," Beth muttered. Every time they requested vision services for an infant, the vision specialists' caseloads were always too full to provide them. Beth wondered just how full their caseloads really were. Maybe they just didn't see working with children younger than school age as their responsibility. But then, who was Beth to question what they could or couldn't do? The vision specialists didn't even operate under the direction of the same state agency as her program did.

She sighed and looked at the pile of papers in front of her. Enclosed with Virginia Cousins's letter were various medical reports on Shannon Eason and a summary of her vision assessment. Beth flipped through the reports, making notes as she went along:

SHANNON EASON

*Born 23 weeks' gestation—1 pound 7 ounces
3rd child, complicated pregnancy, bleeding, cesarean section.
Air transport to Level III nursery (300 miles from home)
Heart surgery (12 days old)—PDA
Bronchopulmonary dysplasia
Low blood pressure—dopamine, hydrocortisone
Hyperbilirubin—phototherapy
Ultrasound revealed no intraventricular hemorrhage
Browiac catheter inserted (6 weeks old)
Necrotizing enterocolitis—temporarily discontinued oral feedings
Gavage feeding
Retinopathy of prematurity (ROP)
Panretinal photocoagulation (8 weeks old)
Cryotherapy (10 weeks old)
Off respirator (4 months old)
Transfer to general hospital near home (for 2 weeks)
Discharge to home—5 months old (6 pounds 2 ounces)
Stage 3+ retinopathy
Apnea monitor and continuous oxygen*

After she finished writing, Beth put down her pen and read through the list she had made. This baby had obviously been through a lot! Beth wondered what Shannon Eason would look like. From the reports, she could tell that Shannon still experienced medical problems and feeding difficulties. She probably also had some motor delays. But what about her cognitive development? Even without intraventricular hemorrhaging, could her cognitive abilities have remained untouched by the ordeals that follow such premature births? Beth had never worked with a child born so prematurely. Then again, how many babies weighing just a little more than 1 pound survived at all?

Beth scanned Virginia Cousins's report of the baby's vision assessment for more clues about her development.

Student: Shannon Eason
Grade: Infant
Parents: Bruce and Kaye Eason
Address: 4501 Parkview Circle

Chronological Age: 12 months
Adjusted Age: 8 months
Type of Assessment: Initial
 Reassessment

Background Information

Shannon Eason was referred by her pediatrician, Dr. Neil Kramer, for a vision assessment. Background information was provided by Dr. Kramer, Mrs. Eason, and reports from Dr. Jonathan Sharpe, pediatric ophthalmologist, and Dr. Terry Pendleton, retina and vitreous specialist. Shannon was also seen by the Pulmonary Clinic at St. Agnes Hospital; however, reports from the clinic were not available at the time of this assessment.

Shannon is the product of a 23-week gestation. She was hospitalized for 5 months after her birth and underwent heart surgery (PDA ligation) during that time. She was diagnosed with bronchopulmonary dysplasia and continues to receive continuous oxygen. She is presently taking vitamins, potassium, two diuretics, and Zantac. Three weeks ago, continued feeding difficulties led to the insertion of a gastrostomy tube, and she is presently fed throughout the night. Shannon is on an apnea monitor at night; however, the mother reports no apnea episodes recently.

Shannon was diagnosed with Stage 3+ ROP and was treated with laser surgery and cryotherapy. A right esotropia, nystagmus, and myopia of both eyes was also diagnosed. Patching of the left eye 1–2 hours per day was recommended by Dr. Sharpe. A hearing test conducted at age 9 months by the NICU follow-up program indicates "abbreviated behavioral audiometry failed to show any deficiencies. She brightens and localizes to sounds and voices."

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Assessment Results

Shannon's vision was assessed at home, using natural lighting for the majority of testing. Both eyes were clear, with no matting or redness. There was evidence of nystagmus when Shannon attempted to fixate and focus on an object at a near distance. She oriented her gaze to peripheral activity on her far left side, with this response more clearly noted when a penlight or movement was used as a stimulus.

Shannon did not respond to moving stimuli in her far right periphery. Placing stimuli within 12–14 inches from Shannon's face, she visually followed objects/light across midline using her left eye, with the right eye moving as the head moved. She awkwardly tracked left to right, breaking her gaze at about 20 degrees past midline on the right. Shannon also attempted to follow a light from her visual horizon upward. Shannon was also observed to shift her gaze from one object to another by moving her head and left eye to fixate first on one object (10 inches in front of her face) and then to another object about 6 inches to the side of the first object.

With patching of the left eye, Shannon attempted to fixate on an object at a distance of 10 inches and presented centrally to her right eye. Her right eye rested close to her nose then, as the stimulus entered her field of vision, she moved her right eye from this inward position to a more central position and was able to maintain this position for a few seconds. With patching, she was also observed to follow a reflective object from right to left and vertically.

When Shannon was held by her mother, she fixated on her mother's face for at least 4 minutes. When laying on the floor, Shannon followed her mother moving away from her and up past her head. Overall, Shannon seems attracted by movement (usually a person entering the room) and will visually follow as the object/person moves closer. When left alone, Shannon was consistently observed to orient her head toward the picture window.

It should be noted that all of the above observations were conducted with Shannon positioned on her back and with maximum head support. Supported sitting and lying on her stomach do not offer enough support for Shannon to concentrate on anything but her postural security. It should also be noted that Shannon was not observed to reach for any objects presented within her field of vision. Mrs. Eason reports, however, that Shannon has recently begun to regard her own hand.

Virginia M. Cousins

Virginia M. Cousins
Vision Specialist

Virginia Cousins's report didn't help to make Beth feel more comfortable about working with this child. It only made her feel more anxious. Beth stacked the reports together in a neat pile and put them in a crisp, new manila folder. Then she wrote a note to put on Lloyd Farmington's desk that afternoon. Lloyd was the team's occupational therapist who worked 3 days a week for the early intervention program. Beth wanted him to accompany her on her initial visit with the Easons. From what Virginia Cousins had written, it sounded as though Shannon Eason could benefit from his services. At the very least, Beth would benefit from his advice about positioning and motor development.



On the way to the Easons' home the following Wednesday, Lloyd read the reports about Shannon for the first time while Beth drove the car. There was plenty of time for reading and discussion as the Easons lived out in the country—a good 45-minute drive from the program. Shannon's father, Bruce, was a manager for a company that manufactured and distributed large farm equipment. The company operated several plants across the country, and Bruce's reassignment to the plant in Paxton—the heart of the state's largest wheat-producing region—had been the reason for the family's recent move.

Beth and Lloyd pulled up to the Easons' two-story frame house, which sat about an eighth of a mile off the main road. They could see a few scattered houses beyond the Easons' where the road stretched north toward even more remote rural areas. Kaye Eason met them at the door when they arrived. She was an attractive woman in her early thirties with shoulder-length, auburn hair. A small boy accompanied her to the door, his hazel eyes staring intently at the two strangers as he clung to his mother's long denim skirt. Brett Eason was 3 years old.

Beth and Lloyd followed Kaye to the kitchen, where she had been busy preparing soup stock for that night's supper. The large windows, southern exposure, and flowered wallpaper created a cheerful atmosphere in the kitchen. Kaye immediately introduced them to Shannon, who was lying quietly on a palette in the corner of the room, facing a window. "Perhaps you could spend a few minutes getting acquainted with Shannon," suggested Kaye. "I just need to finish putting a few things into this pot, and then I'll be right with you." Beth's eyes followed Kaye as she walked over to the stove and lifted the lid on the simmering kettle. Beth couldn't help noticing the boxes of medical supplies stacked on the far corner of the counter beside the microwave oven.

Lloyd began talking to Brett about the papers and felt-tip markers lying on the kitchen table. He must have been drawing when they arrived. Within a matter of minutes, Lloyd had persuaded the shy toddler to join him at the table, and they were soon busy chattering about the rainbows, trees, and trucks that Brett had drawn. Meanwhile, Beth had knelt down on the edge of the palette to talk to Shannon.

The little girl had the unmistakable head shape of a preterm infant, and her sparse blonde hair was neatly pulled together on top with a small, lavender hair clip. The stream of light coming through the window revealed a glint of red in her hair that must have come from her mother. Shannon's nasal cannula was held in place by clear plastic tubing that looped over her tiny ears. The remainder of the tubing ran along the baseboard and disappeared around the corner and down the hallway that led to the living room.

"I really like your hairdo," Beth said to Shannon, leaning close to the little girl's face. "I'll bet your mom fixed it up for you, huh?"

Shannon turned her head away from the window and toward Beth. Her right eye lagged behind her left, never coming quite to center. Her left eye danced, searching for and quickly locating Beth's face.

"My name's Beth. Your mom invited me to come and play with you today. How about that? You think we could have some fun together?"

Shannon gave Beth a brisk smile and kicked her legs against the palette.

"Oh, good!" said Beth. "I was hoping we could have some fun."

Shannon gave Beth another quick smile and kicked her legs. Beth noted the quivering nystagmus of both eyes as she continued to talk to Shannon, and Shannon attempted to maintain her focus on Beth's face. Beth was also somewhat surprised that, although Shannon smiled and kicked in response to her prattle, she never made a sound in return. Furthermore, Shannon's arms moved only slightly in contrast to her rapidly thrusting legs. For the most part, her arms remained in a flexed and retracted position.

Beth spied a wicker basket of toys at the foot of the palette and poked around in it. There was an assortment of rattles, balls, and squeaky toys, some of them partially encased in crumpled aluminum foil. She picked out a rattle with a red-and-white candy-striped handle attached to a clear globe full of brightly colored balls. She held the rattle in front of Shannon's left eye and shook it gently. Shannon appeared to focus on the toy but made no attempt to reach for it. Beth took Shannon's hand and gently guided it to the rattle, whereupon Shannon's tiny fingers wrapped tightly around the handle. Holding Shannon's forearm, Beth helped Shannon to shake the rattle. Shannon maintained her grasp and smiled at the sound of the rattle, but she

dropped her arm as soon as Beth stopped helping. Beth noticed that Shannon didn't release the rattle after her arm dropped.

"I'm afraid she's not very good at that yet."

Beth looked up at the sound of Kaye's voice, unaware that Kaye had been watching her play with Shannon.

"She likes her mobile, though," continued Kaye. "Wait just a second, and I'll set it up so you can see." Kaye quickly rinsed her hands then wiped them on a dish towel. On her way around the table, she took a few carrot sticks from the pile she had been slicing for the soup and handed them to Brett, who was still chattering away to Lloyd. "Why don't you go upstairs and find Holly," she told him. "If you give her one of your carrots, maybe she'll read you a book." Brett took the carrots from his mother's hand and scampered out the door, leaving Lloyd at the table by himself.

Kaye reached behind the walnut-stained sideboard and pulled out a baby gym made of PVC piping. A variety of toys, some wrapped in aluminum foil, dangled from the plastic link chains that were attached to the crossbar. Kaye set up the baby gym so Shannon would be able to see the dangling toys. "Virginia Cousins, the vision specialist who came out, suggested that we use the aluminum foil so Shannon could see the toys better," Kaye explained to Beth. "It helps reflect the light."

Shannon turned toward the sound of her mother's voice, smiled, and made a raspy but happy inward gasp. "Hi, sweetheart," cooed Kaye. "Have you been having a good time with Beth? Do you want to play with your mobile for a while now?" Kaye brushed a few stray wisps of blond hair off her daughter's forehead then gently unfurled Shannon's fingers from the handle of the rattle and set it aside. Kaye then shifted her weight onto her other hip to position herself behind the baby gym. "Look, sweetie! Look here!" she called, gently shaking the aluminum-covered toys on the crossbar. Shannon searched with her left eye and located her mother. "Come on. . . . Kick, kick, kick!" encouraged Kaye. "Where are those happy feet?" Shannon smiled and kicked her legs. Both heels struck the palette at the same time, and the toys on the crossbar swayed in response. "That's the way! You did it!" exclaimed Kaye. Shannon responded with another raspy, inward squeal. A little surprised that Shannon's tiny feet could produce such a large reaction, Beth glanced at the base of the baby gym. Someone had installed a circle of small springs under the base of each upright bar to make the gym more sensitive to movement. What a clever idea, thought Beth.

"That's great!" said Beth. "Does she enjoy playing with the gym a lot?"

"Yes," said Kaye. "She really does. She also likes the mobile over her crib, now that we've put things on it that she can see."

“Does she seem to know she’s the one who’s actually making the toys move?” asked Beth. “Or do you think she just enjoys the spectacle?”

“I think she knows she’s doing it,” said Kaye. “Sometimes she even seems to be analyzing how she does it. You know, she’ll change how hard or how fast she kicks her feet and then stop and stare at the toys—like she’s figuring out what made them move differently.”

“Wow, that’s wonderful!” said Beth. There was a brief, awkward silence, then Beth continued, “I noticed that she sort of squealed in delight while you were playing with her. She didn’t make any sounds when I was playing with her earlier. Do you think that’s just because I’m someone new?”

“I wish I could say that was all it was,” replied Kaye. “It’s one of the things I’m a little worried about.” Kaye turned her face away from Beth and looked out the window. “I remember all the sweet baby sounds my other two made when they were infants. . . . It’s only been within the last month or so that Shannon has started to coo when we talk to her, and even then she doesn’t do it very often.”

“It sounds as though that’s something that’s pretty important to you,” suggested Beth.

“Oh, I don’t know,” said Kaye, turning around to face Beth. “Nothing’s been the same with Shannon as it was with the other two. I don’t suppose I should expect this to be either. I remember in the hospital when they finally took her off the respirator, and I heard her cry for the first time . . .” A bittersweet smile stretched across her face. “It was such a pitiful cry, but it was music to my ears.”

“I’ll bet it was,” said Beth. “How long was she on the respirator?”

“Four months.”

“Wow! That’s a long time to wait to hear your baby’s first cry.”

“Could being on the respirator for so long be the reason she doesn’t coo and babble as much as other babies?” Kaye’s anxious eyes waited for an answer.

“Well . . . I’m not really sure.” Beth looked down at Shannon and absently lifted the baby’s hand with her forefinger. She hated questions like that. How was she supposed to know why Shannon wasn’t making sounds like other babies? Shannon grasped Beth’s finger and held on tightly.

“I guess it doesn’t really matter why,” said Kaye. “The important thing is that she’s starting now.”

Beth played with Shannon for a while longer, trying to assess her cognitive skills. It was hard to sort out the extent to which her delays were caused by her vision impairment and medical problems, and what, if any, additional problems might be responsible. On top of everything else, she had to keep in mind that Shannon had been born 4 months

prematurely and had been hospitalized for nearly half of her life. That alone would be enough to cause significant delays.

Shortly after Brett had run upstairs with his carrot sticks, Lloyd joined Kaye and Beth on the floor but had remained silent throughout their conversation. He, too, now played with Shannon and asked Kaye questions about her motor skills and feeding. Kaye told them that Shannon had gotten a gastrostomy a month ago. Before that, she and Bruce had been using a combination of bottle and gavage feedings, but Shannon had begun to fight the gavage feedings. Agreeing to the gastrostomy had been a difficult decision for Kaye and Bruce to make. They had hoped that Shannon would get better at bottle feeding so they could eliminate tube feeding all together, but that hadn't happened. Kaye said they were glad now that they had decided to go ahead with the gastrostomy. Shannon was gaining weight, and they could finally get some sleep at night.

Kaye talked a bit more about Shannon's medications, her apnea monitor, and the difficulties associated with her continued need for oxygen. Overall, Kaye didn't seem all that concerned about Shannon's present health status. She said that they used the apnea monitor only at night now and that Shannon hadn't had any episodes of apnea at all over the past 2 or 3 weeks. Kaye was hopeful that this was a sign that Shannon had passed a major hurdle toward recovery. Kaye also mentioned that she felt more comfortable transporting Shannon because they no longer needed to take the apnea monitor along with them in the car. Still, she said, transporting Shannon and her oxygen wasn't exactly a picnic. Kaye also wasn't very comfortable with the stares and questions of strangers when she was out with Shannon in public.

OCCUPATIONAL THERAPY ASSESSMENT

Child's name: Shannon Eason **Type of assessment:** Initial
Age at testing: 13 months **Test administrator:** Lloyd Farmington
Parent(s) or guardian(s): Bruce and Kaye Eason
Age adjusted for prematurity: 9 months

Background

Shannon was born at 23 weeks' gestation and weighed 1 pound, 7 ounces at birth. She spent 5 months in the neonatal intensive care unit (NICU) before being discharged to home. Complications following birth included hyaline membrane disease, chronic lung disease,

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retinopathy of prematurity, and prolonged feeding intolerance. Shannon has recently undergone surgery for the placement of a gastrostomy. More detailed medical information is available in Shannon's records. The referral to the early intervention program was made by Virginia Cousins, a vision specialist for the school district who is providing services related to Shannon's visual impairment.

Testing Situation

All observations and testing were conducted in the family's home and in an environment that is familiar to the child (a palette on the kitchen floor with natural sunlight from a nearby window). Kaye Eason, Shannon's mother, was present during the assessment and served as informant for background information and present levels of performance.

Observations and Assessment

Shannon has excess tone in her upper and lower extremities, with reduced tone in her trunk. When supported in a sitting position, her neck and back are rounded and head bobbing occurs after 20–30 seconds. Shannon displays full passive range of motion throughout; however, she has a tendency to "fix" in her shoulders initially during ranging, and there is occasional resistance to rotational movements. Some degree of tightness was noted in ankle dorsiflexion, bilaterally.

Shannon is somewhat resistant to being placed in a prone position, but she was observed to clear her head and move it to each side when placed on her stomach on a firm surface. She does not as yet use her arms to elevate her upper body when placed in prone position; however, when her arms are positioned well under her shoulders, she can clear the supporting surface and sustain this position briefly. Ms. Eason reports that Shannon spends the majority of her time lying flat on her back and that she appears most content in this position. Some hyperextension of the neck and shoulder retraction were noted in supine; but, for the most part, Shannon appears relaxed when lying on her back.

Very active symmetrical movement in her legs was observed while Shannon interacted with her mother and also while she was engaged in "playing" with a mobile suspended within her range of vision. Shannon, however, is not yet able to round her hips off the floor. Shannon can roll from her back to her left side and from either side to her back. Rolling is accomplished through hyperextension of the back with little or no abdominal support or flexion. Very few volitional arm movements were observed during the assessment session. Arm movements that were observed consisted of Shannon's bringing her hands together at midline and bringing a hand to her mouth. All arm movements are

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primarily from the elbow, with shoulder stiffness limiting her range of motion. Ms. Eason reported that Shannon does not reach out to touch toys; however, she has been bringing her hands together and to her mouth more often over the past few weeks. Shannon's hands are primarily opened, and although she will grasp an object that is placed in either hand, volitional release is not yet present. It is difficult at this point to determine the degree to which Shannon's delays in reaching and grasping are attributable to her visual impairment. It should be noted, however, that delays in reaching and grasping are not unusual for children with significant visual impairments.

Shannon was observed while being bottle-fed by her mother. Shannon does not have sufficient strength and speed to receive total nutrition by mouth and has a tendency to gag. She is bottle-fed throughout the day and drip-fed through her gastrostomy at night. Gavage feeding was eliminated after placement of the gastrostomy. Shannon was also observed while her mother attempted to feed her semi-solid foods (strained bananas). Ms. Eason has only recently begun offering semi-solid foods, and she reports that Shannon frequently gags and spits out food that is placed in her mouth. Observations verified Ms. Eason's description of Shannon's response to spoon feeding. At most, Shannon consumes 1–2 teaspoons of strained fruits or cereal at a feeding.

Test Results

Bayley Scales of Infant Development (Motor Scale)

Psychomotor Developmental Index (PDI): less than 50 (Greater than 2.3 standard deviations)

(Note: PDI below 70 and standard deviations greater than 1.5 standard deviations below the mean are considered to be significant)

Lloyd S. Farmington, OTR/L

Lloyd S. Farmington, OTR/L

Discussion Questions

1. Was it a good idea for Beth to have taken Lloyd with her on her first visit with the Easons? How might the visit have been different if Lloyd had not accompanied Beth?
2. How important was it for Beth to have read Virginia Cousins's report and the medical information about Shannon before making the home visit? What additional information, if any, would have been important for her to have before the visit?
3. Did Beth and Lloyd conduct themselves appropriately on this home visit? What did you like about their interactions with the Easons? What, if anything, would you have done differently?
4. Beth seemed to have difficulty determining the level of Shannon's cognitive abilities. What can you conclude about Shannon's developmental status based on her medical history, Virginia Cousins's assessment, Beth's own observations of Shannon, and Lloyd's occupational therapy assessment? Venture a prediction as to what Shannon will be like in 6 months, 1 year, 3 years, and at school age.
5. Would additional testing or other forms of assessment be helpful in determining Shannon's current level of cognitive functioning? If so, which instruments or strategies might be employed, and should these be mentioned to Kaye now?
6. How much of what Beth and Lloyd observed or thought about Shannon's development should they share with Kaye at the end of this first home visit? Make a list of the information that they should share with the family and rank the items from most to least important. Choose one of the top three items on your list and write down the exact words you would use to give this information to Kaye.
7. In your opinion, what are the most important skills for Shannon to develop during the next few months?
8. What types of services might be useful to Shannon and her family? Make a list. If all of these services were available, which would you tell the Easons about right now?
9. In your community, which of the services you listed in your answer to Question #8 are available to families like the Easons? Are

there fees for each of these services? If so, how are fees assessed (e.g., sliding scales, flat rate, insurance/Medicaid reimbursements)?

10. What are the Easons' concerns about and priorities for Shannon and the rest of the family? What do we know about the Eason family's resources?
11. What concerns would you have about Shannon and her family? What additional information, if any, would you need if you were responsible for providing home-based intervention to Shannon Eason and her family? How would you obtain this additional information?
12. Beth appears to be somewhat uncomfortable working with Shannon because she has a visual impairment. To what extent should all early intervention practitioners be knowledgeable and skilled in working with children who have sensory impairments?
13. How can Beth coordinate the services her program provides to the Easons with the services provided by Virginia Cousins?