

with a history of choking episodes and cyanosis¹ (Tr. 138). The discharge summary from Newton-Wellesley Hospital noted that the eight pound one ounce child was the product of a full-term, uncomplicated pregnancy and delivery. They noted that there was a strong family history for GI reflux and post-prandial hypermotility syndrome². She was discharged to her home on theophylline, zantac, and reglan and also with a home apnea/bradycardia³ monitor to be followed up by Dr. Alec Flores in one week's time.

She was readmitted to the same hospital on December 23, 1988 for persistent choking spells and circumoral cyanosis (Tr. 144). The record reflects a third hospitalization at two and a half months old for a follow-up of a history of GE-reflux and choking spells (Tr. 145). Testing done at that time showed no evidence of esophagitis. It was Dr. Flores' impression that she had GE-reflux and an immature respiratory control. Id.

A subsequent admission to Newton-Wellesley Hospital on February 23, 1989 to February 27, 1989 required a colonoscopy⁴. The colonoscopy showed evidence of hyperplasia⁵ with no active colitis. Id. Lower GI biopsies done at the same time showed no diagnostic abnormalities in either the transverse or descending colon and rectum (Tr. 154).

¹Cyanosis - Slightly bluish, grayish, slatelike or dark purple discoloration of the skin due to the presence of reduced hemoglobin in the blood. Taber's Medical Dictionary (15th Ed., 1986) p. 49.

²Post-prandial hypermotility syndrome - An unusual, quick spontaneous movement of food through the colon. Tabers at p. 799, 1356.

³Bradycardia - Slow heartbeat characterized by a pulse rate under 60 beats per minute. Taber's Medical Dictionary (15th Ed., 1986) p. 225.

⁴Colonoscopy - A long flexible narrow endoscope used to look into the colon, inserted rectally. Vol. 4 Social Security Practice Guide, App. 33-A.

⁵Hyperplasia - Excessive proliferation of normal cells in the normal tissue arrangement of an organ. Taber's, supra p. 802.

The administrative record discloses an additional six hospitalizations during the period April 22, 1989 through August 23, 1990 (See Tr. 155, 159, 161, 163-165, 170-174). These Newton-Wellesley Hospital admissions were for GE-reflux, and further extensive testing was done including GI biopsies and a duodenoscopy⁶ and PH probe. The hospitalization on May 11, 1990 was for diarrhea and dehydration (Tr. 165). It was noted by the treating physician at Newton-Wellesley on August 23, 1990 that her daily medication of cisapride was not effective in controlling the symptomatic irritability (Tr. 174).

During three of the Newton-Wellesley admissions, Plaintiff was transferred to Boston Children's Hospital (See Tr. 183). These transfers/admissions occurred on February 10-14, 1989; November 28-30, 1989 (Tr. 187-191); and February 22-23, 1990 for a sleep study to evaluate evidence of cardiac arrhythmia (fast heartbeats).

Tests performed on the 13 month old female with a history of gastro-esophageal reflux and a history of apneic spells, bradycardia spells included a bronchoscopy, which was within normal limits (Tr. 189). The fiber optic bronchoscopy was undertaken to rule out tracheal webs or other possible anatomic causes for her obstructive events besides the already known GE-reflux (Tr. 191). It was noted that her severe GE-reflux was poorly controlled with medical management. Id. Further medical notes by nurse Joyce Nelson can be found at Tr. 199 dated March 20, 1989. They do not indicate where this facility was. There are other reports by Mary Parsons, R.N. for that period of time (Tr. 200). These notes appear to be from the Visiting Nurse Service of Southern Maine (See Tr. 203) and consisted of assessment and monthly visits to the Rice home. Nurse Parsons noted slow weight gain in March 1989 (Tr. 203). A pulmonary consult was ordered at that time due to an aspiration episode that occurred in the doctor's office. Id. Extremely low weight level was noted on November 7, 1989 by Nurse Parsons where the child's weight had dropped to the 25th percentile (Tr. 204). Visiting nurses notes continue through the remainder of 1989 and 1990 (Tr. 203). Nurse Parsons noted in her skills service report of June 27, 1990 that Jennifer had a new apnea monitor with recorder and that she was being fed

⁶Duodenoscopy - Inspection of the duodenum (first part of small intestine) with an endoscopy (a device consisting of a tube and optical system for observing the inside of a hollow organ or cavity). Taber's, supra pp. 500 and 548.

through a nasogastric (NG) tube⁷ which the mother inserts in order to provide better feeding and nutrition (See Tr. 210).

A New Hampshire State Welfare Children With Severe Disabilities Report of Medical Care report dated August 28, 1990 by Carol L. Wertman, R.N. BSN, found Jennifer, as a toddler, to have problems with bowel habits and bladder control (Tr. 215). Special care provided at that time was a Smart cardiopulmonary monitor used when sleeping and an NG #6 tube feeding, as well as medications which included cisapride, tagamet, donatol, and belladonna. Id. Reports submitted to the New Hampshire Division of Human Services, State Welfare Department from Dr. Alex Flores on August 31, 1990 indicated Jennifer had a pseudo-obstruction and autonomic nervous system⁸ dysfunction and abdominal distention. The medications previously set out were to be continued. Id. Dr. Flores recommended intermittent use of the NG tubes when Jennifer was unable to eat. Id.

In response to a questionnaire solicited by the State Welfare Department dated November 8, 1990, Dr. Flores found that the child was not delayed in developmental age-appropriate matters at that point in time (Tr. 218). Subsequent reports by Dr. Flores to New Hampshire State Welfare to allow for continuing Medicaid assistance noted the motility disorder and gastro-esophageal reflux. His treatment and recommendations included the administration of anti-reflux drugs (Tr. 225). As a result of these reports, Jennifer was found eligible for Medicaid assistance for severely disabled children.

Dr. Flores continued monitoring Jennifer's chronic gastrointestinal problems during 1991 and was in correspondence with the local primary treating physician, Dr. Kathleen Corcoran (See Tr. 226-232). In a letter to Dr. Corcoran dated October 31,

⁷Nasogastric (NG) Tube - A tube inserted through the nose that extends into the stomach; Taber's, supra, p. 1100.

⁸Autonomic nervous system - The part of the nervous system that is concerned with control of involuntary bodily functions. It regulates the function of glands, especially the salivary, gastric, and sweat glands, and the adrenal medulla; smooth muscle tissue; and the heart. The autonomic nervous system may act on these tissues to reduce or slow activity or to initiate their function. Merriam-Webster Medical Dictionary (1995 ed.).

1991, Dr. Flores noted that he had an opportunity to do an intra-esophageal PH probe on February 10, 1991, which showed evidence of a 33.5% reflux, which he felt was quite significant (Tr. 229). He noted that he had put Jennifer back on cisapride and that if her symptoms persist, he was going to have to add H2 blockers. He felt that this was going to be a chronic situation (Tr. 229).

In another report to Dr. Corcoran dated December 19, 1991, Dr. Flores notes that Jennifer was having a lot of bloating, intermittent diarrhea, and discomfort. Because of her ongoing problems and her history, he was going to treat her with flagyl for 10 days (Tr. 230).

A follow-up report on March 24, 1992 to Dr. Corcoran concerned all three of the Rice children who have gastrointestinal and GI problems. He found that while Jennifer was stable, she continues to have episodes of diarrhea and vomiting and she was to continue on pepsid and cisapride (Tr. 231).

A pediatric cardiology evaluation was scheduled at New England Medical Center in July 1992 because of irregular heartbeats. In a letter by Dr. Robert Geggel, an associate professor of pediatric cardiology, to Dr. Corcoran about Jennifer's recent stay and admission in the pediatric cardiology clinic at the Framingham Heart Center on July 23, 1992, he noted that "symptoms of Jennifer's autonomic nervous system dysfunction included: heat intolerance, constipation, fever occurring every six to eight weeks up to 105°, and cold intolerance with lethargy" (Tr. 234).

He noted that Jennifer's mother had stated that intermittently she becomes lethargic with Peri-oral⁹ cyanosis and at other times has a bradycardia with a heart rate 60-70 and at other times a tachycardia¹⁰ with a heart rate of 160. It was reported that her cardiac episodes had occurred six times within the last month (Tr. 234). Id.

⁹Peri-oral - Surrounding the mouth. Taber's, supra, p. 1265.

¹⁰Tachycardia - Abnormal rapidity of heart action, usually defined as a heart rate over 100 beats per minute. Taber's, supra, p. 1688.

Physical examination and electrocardiogram were unremarkable. The electrocardiogram was within normal limits (Tr. 235). Dr. Geggel provided the family with an event monitor for use at home. A handwritten note at the bottom of Tr. 235 dated September 2, 1992 stated that the event monitor showed no primary cardiac arrhythmia, nor significant cardiac arrhythmia detected, and no further follow-up was arranged (Tr. 235). The record also contains other hospitalizations (e.g., Frisbee Memorial Hospital, Rochester, NH on October 7-11, 1989) for similar problems of obstructive apnea and high fever (Tr. 245).

Jennifer was also evaluated by Dr. Dorothy Kelly at Massachusetts General Hospital when she was 18 months old (Tr. 248-249). Dr. Kelly noted that Jennifer had problems with grey spells. She felt that "these tend to occur slowly, but they consist of a color change, basically to gray, then lethargy, decreased appetite, decreased activity, sometimes a cold, clammy diaphoresis¹¹, markedly increased sleep and bradycardiac alarms, and also increased apnea alarm at night." These grey spell episodes can last one day or up to one week (Tr. 248). Dr. Kelly also commented that Jennifer had periods of ataxia¹² which occur three to four times per week, which she did not feel were associated with the episodes of greyness. Id. A follow-up visit on July 7, 1990 showed that there were some episodes of apnea and bradycardia which occurred on July 7, 1990; that her heart rate was very irregular at that time, that she had a pale look to her, and was in a down period. The physical examination was entirely normal. The ongoing problems identified by Dr. Kelly included autonomic dysfunction where she noted that Jennifer had a very good two months with no grey spells and no poor days (Tr. 250).

A follow-up visit on October 3, 1990 disclosed that Jennifer's breathing was very shallow and that she was very lethargic in the morning and her color was very grey for approximately four hours, then became normal (Tr. 251). Dr. Kelly felt that the morning problems identified by the mother are most likely symptoms of autonomic dysfunction which need to be

¹¹Diaphoresis - Profuse sweating. Taber's, supra, p. 457.

¹²Ataxia - Defective muscular coordination that manifested when voluntary muscular movements are attempted. Taber's, supra, p. 148.

followed. It was noted that she hadn't had any problems with heat intolerance, although it was the summertime (Tr. 251).

A follow-up evaluation and Recertification For Children With Severe Disabilities Report of Medical Care was completed by Carolyn L. Carlson, R.N. of the Medical Personnel Pool, on November 27, 1990 (Tr. 252). In her report submitted to the New Hampshire State Welfare Department, she noted that Jennifer's developmental profile was one of delay, a failure to thrive as an infant, and that she needed help eating, but that she was mobile in her walking. Nurse Carlson also noted that she would have trouble walking or any type of mobility when acutely ill as well as trouble bathing, dressing, toileting, and eating. Id. She also noted that bronchial suction was necessary as was O₂ support when the patient was acutely ill; that her diet would change, and she would have to go on a nose tube for feeding. It was her opinion that "Jennifer's functional abilities vary greatly according to her health status". Frequently, and without warning, (approximately every four to six weeks) Jennifer will become acutely ill, "shut down". For a period of 24 hours to 2-3 weeks, this "shut down" will occur. She found that "Jennifer also experiences laryngospasms¹³ due to mal-coordinated swallowing. She becomes cyanotic and requires back blows/chest thrusts and often suctioning to relieve the obstruction." Id. Further medical records concerning in-home nursing care are provided by the Medical Personnel Pool for the period of time April 5, 1991 (Tr. 253) through January 21, 1993 (Tr. 368). In addition to the narrative notation, there are medication lists for that same relevant period (Tr. 369-376). An undated written observation note by Heidi Byra, LPN, who initially cared for Jennifer during the period June 4, 1992 (Tr. 320) through January 21, 1993 (Tr. 368) states that Jennifer had periods of bradycardia with a heart rate dropping to 90 and becoming irregular, and that during those times her color was pale grey and her lips turned blue (Tr. 377). She is lethargic during these periods which pass spontaneously. Frequently, these periods are preceded by hyperactivity. Id.

Besides the extensive medical records and frequent hospitalizations during the period 1989-1991, there was also a psychological evaluation performed by the Strafford Learning

¹³Laryngospasm - Spasm of laryngeal muscles. Taber's, supra, p. 931.

Center in January 1993. This psychological evaluation of Jennifer at age four years and two months was to document her current level of cognitive functioning, to assess her learning style, and to assist parents and educational personnel with programming considerations (Tr. 378).

Testing and observation disclosed that Jennifer had difficulty processing what she heard or following directions and instructions for visual motor tasks. She only understood when shown what was to be done (Tr. 378). She was administered a Stanford Binet Intelligence Scale Test, 4th Edition, and she achieved a test composite score of 114 which was a performance well within the high average range when compared to other children of her age (Tr. 379). A report by Dr. John L. Morse, Ed.D, psychologist, was that her current assessment clearly indicated that her overall learning abilities were well above average when compared to other children of her age. However, a significant profile of cognitive strength and weaknesses is seen. Her verbal reasoning skills when provided with pictures and short-term visual memory abilities were all significantly above average (Tr. 379). Despite these high testing results, Dr. Morse felt that Jennifer possessed learning difficulties which were associated with her medical disorder in the areas of speech and language. He also felt that these difficulties represented an educationally handicapping condition which requires remediation. He did not feel that they were developmental in nature (Tr. 380).

A further developmental screening was performed at the Strafford Learning Center on January 19, 1993. It was conducted by Janna O. McCabe, M.S., CCC/SOP, a speech language pathologist, who noted that an earlier developmental screening on November 12, 1992, reported concerns for speech intelligibility, cognitive and language development. Testing revealed that Jennifer's articulation skills were characterized by developmental errors. Language weaknesses were noted for content, form and use. She had difficulty with language processing such as understanding and responding to "WH" questions and language structures which are complex (Tr. 387). Ms. McCabe recommended that Jennifer receive speech/language intervention in a language based pre-school which offers language modeling and expansion techniques. Id.

In addition to the treatment which Jennifer received at Children's Hospital in Boston and through Dr. Corcoran at the Seacoast, she was also provided, under the Children With Severe Disabilities medical care program at the State of New Hampshire,

daily nursing services that amounted to approximately 16 hours per week. These nursing services and observations were conducted by the Medical Personnel Pool and can be found in the transcript at pages 253 through 605. They cover the treatment period of April 5, 1991 through June 10, 1994. With few exceptions, the primary LPN who handled the care and supervision of Jennifer was Heidi Byra. These are her notes for the relevant time periods. In order not to engage in extensive recitation of these daily notes, monthly summaries and other areas relevant to this claim follow.

During the initial periods of care and observation during April through August 1991, Jennifer was observed to have few periods of distress and the ability to go outside and play up to 20 minutes. Her appetite remained poor at times (Tr. 261), but from Nurse Byra's notes, she interacted well with her brother and sisters and appeared in no apparent distress. Nurse Byra accompanied her on trips to see Dr. Flores in Boston (Tr. 265) and noted that she tolerated the trip well. However, within five days of the September 19, 1991 trip, Nurse Byra noted that Plaintiff's color was pale and her mother reported "Jennifer didn't feel well yesterday" and was vacillating between constipation and explosive diarrhea (Tr. 266).

On October 29, 1991, it was noted that Jennifer's color was grey, her lips were blue, and that this condition lasted for 15 minutes though there was no respiratory distress and her heart rate was 112 and regular. After 15 minutes, her color returned to pale pink (Tr. 271). A similar note on November 7, 1991 indicates that while Plaintiff was watching television, the nurse noted pale skin, dark circles under Plaintiff's eyes, listlessness, and a heart rate of 120 and regular. Plaintiff was taking her medications at that time (Tr. 272). Similar reports of decreased activity, nausea, and vomiting, as well as abdominal distention, occur on November 19, 1991 and November 21, 1991 (Tr. 274-275). Nursing notes for the rest of that year do not indicate any further extreme exacerbations of her condition.

Her daily luncheon diet appeared normal, as was noted on January 2, 1992 (Tr. 283), and there were no episodes of choking or nausea. On January 16, 1992 (Tr. 286), Jennifer was noted to be tired, somewhat lethargic, and after going out to the dentist with her mother, had an episode of nausea with vomiting and returned home. Changes in medication and the addition of pepcid were noted on January 31, 1992. Nurse Byra noted no adverse reactions, although there was still a blue tinge around the lips,

but this improved after a while (Tr. 291). In a summary of care note dated May 16, 1992 by Debra Royce, R.N., home care supervisor, she stated that the primary purpose of this care was to assess Jennifer and provide appropriate interventions depending upon her needs at a particular time. Nurse Royce noted:

Jennifer can become acutely ill suddenly and require supportive care including oxygen administration, maintenance of a clear airway, and providing safety and comfort measures. Because of mal-coordinated swallowing due to laryngospasms, Jennifer experiences episodes that requires maneuvers to relieve airway obstruction. The above level of nursing care will continue to be provided to Jennifer indefinitely.

(Tr. 312).

She noted that Jennifer received an average of 16 hours of LPN care per week since October 1990. It was also noted in her patient care plan from the same providers that she suffered from a hiatal hernia and reflux, periods of erratic irregular heart rate with bradycardia, that she was prone to becoming cyanotic due to vagal response. She had periods of hyperactivity and heat intolerance (Tr. 313). Plans to address a minimal amount of these problems were that her head be elevated for sleeping at night, frequent small meals, medication, monitoring of her heart rate, administration of belladonna, and to offer full strength Nutramigen in bottle at times of difficulty. Further plans were to monitor her respiration rate to assure adequate ventilation and monitor her heart rate and provide a structured, supervised environment, as well as avoiding long exposure to heat to avoid any overheating. Id.

It was also noted in this patient care plan that she has night sweats at times and periods of acute illness with pain and lethargy, as well as incontinence at times due to her ANS disorder (Tr. 314).

Frequent references are made by Nurse Byra to the fact that the child spends a lot of time on the couch watching television, instead of engaging in either play activities with her brothers or her sister. If such interaction occurs, the nurse usually will make a notation that it was a good day (See Tr. 319, 324, 332, 335, 337, 347). The daily nursing notes continue again at page Tr. 445 dated August 23, 1993 where it is noted by Nurse

Byra that Jennifer is prone to irregular heartbeats due to atonic nervous system problems, and that frequent monitoring of her heart rate was being undertaken at that time; her color was good, she appeared in no apparent distress (Tr. 445). The day after that, chronic constipation with abdominal distention and pain in the umbilical region, abdomen soft on palpation was noted. Her eating habits were poor, but after a few hours, her color returned and medication was prescribed (Tr. 446).

A September 1, 1993 note indicates that abdomen was slightly distended, bowel sounds faint, but no complaint of abdominal discomfort at this time. Her mother reported no bowel movement that day, though the child appeared to be comfortable (Tr. 451). During the remainder of 1993, various notes indicated a somewhat hyperactive energy level and that structure was needed for her activities (Tr. 501). Continuing problems with slightly distended abdomen were noted and she was continued on her daily medication and that the supervised structured playtime with intervention was to prevent self-injury. Id. During this same time period (Tr. 480-494), Jennifer was experiencing periods of bradycardia, as well as tachycardia, and was having her heart rate monitored frequently both by the nurse and by a monitor provided by her doctors (Tr. 484-494).

Starting in 1994, Nurse Byra, in addition to her daily notes, prepared monthly summaries. Her January monthly summary noted that Jennifer had missed several days of school due to fatigue and abdominal discomfort with her abdomen being distended. New medication (senakot) was prescribed which had been tolerated well and her bowel sounds had been very faint, but she had difficulty with bowel movements, although her weight had been good at 43 pounds (Tr. 536). Jennifer's heart rate was noted to be stable. Her medical condition required that she sleep with her head elevated, and with small frequent meals and medication as needed for reflux and hiatal hernia. Id. Her heart rate was being monitored carefully and she had been seen by Dr. Flores and her medication, cisapride, had been increased to 8cc due to her growth and weight gain. Id.

A February 1994 summary noted the continuation of episodes of abdominal pain in the umbilical region which was usually relieved following a bowel movement, though it was often difficult for her (Tr. 548). Nurse Byra noted Jennifer's continued problem with abdominal distention, soft, and non-tender on palpation. That month she did have a period of hyperactivity during which careful supervision in a structured environment was

achieved to prevent self-injury. Id. Her weight had remained stable and she did not have any episodes of erratic heart rate. Nurse Byra noted that Jennifer continues "to tire easily due to the ANS dysfunction; as a result will often rest on the couch, and that her appetite has fluctuated at times this month." (Tr. 548).

A March 1994 summary noted a continuation of "bouts of abdominal pain in the umbilical region," as well as "episodes of severe rectal pain" (Tr. 562). Her heart rate continued to be stable this month. She frequently took small meals. Her weight remained stable. She was prescribed a new medication (agoral) on an as needed basis for constipation which remained a problem. She noted that Jennifer enjoys school on the whole, but has some days when she is reluctant to go, and that Jennifer's mother reported that Jennifer is often complaining of being tired; and often when she returns home from school, her energy level is low (Tr. 562).

The April 1994 nursing summary noted Jennifer had problems with a respiratory virus which lasted five to six days and continued to have episodes of abdominal pain in the umbilical region. She had missed several days of school due to colds and abdominal problems and when seen by Dr. Flores for her monthly exam, her cisapride dosage was increased to 9cc due to her weight gain. It was noted that her heart rate has remained stable this month, but that her mother noted that Jennifer frequently complains of being tired (Tr. 583).

There were no monthly summary reports for May and June 1994. However, in a letter dated June 29, 1994, Nurse Byra commented on her observations of Jennifer Rice's case over the past three years. She noted that while all children experience occasional stomachaches due to viruses and flu, that this was a daily occurrence for Jennifer when her face became pale, indicating the umbilical region. Abdominal distention often accompanied this pain and she missed days at school for this reason with her energy level low. In addition, she has chronic constipation with evacuation frequently being painful (Tr. 606).

She also had a lactose intolerance, as well as other food intolerances, so her diet was closely supervised. She had a history of cardiac sinus arrhythmias, so therefore, her heart rate was monitored carefully at the apical and radial pulses. It was Nurse Byra's observation that Jennifer does not always tolerate activity well, necessitating rest periods, while heat

intolerance makes it important to take measures to avoid Jennifer becoming overheated. If not, it would result in her becoming lethargic with her face flushing (Tr. 606).

The record notes a letter dated October 18, 1993 from Dr. Craig W. Lillehei of Children's Hospital, to Dr. John Jolles. Dr. Lillehei noted Jennifer's ongoing difficulties with defecation and her strong family history which made him think a "full thickness rectal biopsy"¹⁴ would be reasonable to further evaluate her dysmotility (Tr. 607-608). This rectal biopsy was done on November 11, 1993. Despite this procedure, no unusual pathology was discovered and no specific diagnosis could be made (Tr. 609).

In a further follow-up letter to the Social Security Administration dated July 12, 1994, Dr. Alex F. Flores noted his long-term care of Jennifer having first seen her in 1988 when she had a problem of gastro-esophageal disease, as well as a pan-gastrointestinal motility disorder. He indicates that this is a chronic condition that affects the nerves and muscles of the gastro-intestinal tract and there is no specific cure for it (Tr. 612). She has been on medication to help the movement of the colon, as well as to help stimulate the motility of the small bowel. This was a chronic problem and it causes her to miss school intermittently. He noted that she had missed 47 days of school in the previous year when ill. Id.

In functional assessment questionnaires sent to Jennifer's parents by the State Disability Service, it was noted that her condition is one which changes constantly depending upon her health, and there are times when she can't get off the couch and she can only eat formula. Her shyness with strangers was noted as was her willingness to cooperate and her failure to communicate any needs such as going to the bathroom or eating. She has had episodes of soiling herself (Tr. 134-135).

A non-examining state agency doctor prepared an individualized functional assessment format in case summary for a child ages 3-16 based on the record evidence. He found that she had no limitation in her cognitive development or communicative

¹⁴Biopsy - A diagnostic procedure in which a small piece of tissue is removed so that it can be examined under a microscope. Vol. 4, Social Security Practice Guide, App. 33-3.

development, nor did he note any motor, social, or personal behavioral development problem. It was noted that Plaintiff had a chronic illness which required adaptations, and noted that the condition had not improved, but required monitoring (Tr. 95). Dr. Nault, the State Disability doctor, noted in his June 4, 1992 report that since early infancy, the claimant has "had episodes of choking spells due to the above disorder" and she has also had apnea/bradycardia spells which have diminished. Currently, she was better regulated on tagamet and cisapride. Frequency and severity of attacks appear to be diminishing. He noted her 16 hours a week of home care monitoring. He felt her height and weight were in the normal range and that her development is considered age-appropriate (Tr. 96).

When the case was sent for reconsideration in July 1993, it was referred to the Bureau of Special Medical Services (Tr. 102) for quality assurance evaluation on April 11, 1993. In that evaluation, it was determined that Jennifer had medically determinable impairments in the areas of motor development and behavioral development (Tr. 103). It noted she had a chronic illness. There were effects from medication, as well as the effects of structured settings, adaptations, multi-disciplinary therapy, and school attendance. Id. The case summary evaluation agreed that this was a severe impairment which did not meet the Listings, either medical or functional, but it was the determination of both DDS and DQB that Jennifer's condition "substantially reduces [her] ability to function in age-appropriate activities independently, appropriately, and effectively" (Tr. 104). This was concurred in by the State Agency and also the Division of Quality Review. Id. It was the opinion of the reviewing doctor that the non-medical evidence had a decisive impact on the DDS MCS assessment (Tr. 105). The record does not reflect that the ALJ asked either Dr. Flores or Dr. Corcoran to complete an Individualized Functional Assessment form such as was used by the State Agency doctors.

Discussion

Pursuant to 42 U.S.C. § 405(g), the court is empowered "to enter, upon the pleadings and transcript of the record, a judgment affirming, modifying, or reversing the decision of the

Secretary, with or without remanding the cause for a rehearing." In reviewing a Social Security disability decision, the factual findings of the Secretary "shall be conclusive if supported by `substantial evidence.'" Irlanda Ortiz v. Secretary of Health and Human Servs., 955 F.2d 765, 769 (1st Cir. 1991) (quoting 42 U.S.C. § 405(g)).¹⁵ The court "must uphold the Secretary's findings . . . if a reasonable mind, reviewing the evidence in the record as a whole, could accept it as adequate to support [the Secretary's] conclusion.'" Id. (quoting Rodriguez v. Secretary of Health and Human Servs., 647 F.2d 218, 222 (1st Cir. 1981)); accord Richardson, 402 U.S. at 401. The record must be viewed as a whole to determine whether the decision is supported by substantial evidence. Frustaglia v. Secretary of Health and Human Servs., 829 F.2d 192, 195 (1st Cir. 1987); Rodriguez, 647 F.2d at 222. Moreover, "[i]t is the responsibility of the Secretary to determine issues of credibility and to draw inferences from the record evidence. Indeed, the resolution of

¹⁵Substantial evidence is "such relevant evidence as a reasonable mind might accept as adequate to support a conclusion.'" Richardson v. Perales, 402 U.S. 389, 401 (1971) (citing Consolidated Edison Co. v. NLRB, 305 U.S. 197, 229 (1938)). "This is something less than the weight of the evidence, and the possibility of drawing two inconsistent conclusions from the evidence does not prevent an administrative agency's finding from being supported by substantial evidence." Consolo v. Federal Maritime Comm'n, 383 U.S. 607, 620 (1966); Benko v. Schweiker, 551 F. Supp. 698, 701 (D.N.H. 1982).

conflicts in the evidence is for the Secretary, not the courts." Irlanda Ortiz, 955 F.2d at 769 (citing Rodriguez, 647 F.2d at 222); see also Burgos Lopez v. Secretary of Health and Human Servs., 747 F.2d 37, 40 (1st Cir. 1984).

I. Lack of Counsel

The plaintiff first challenges the Secretary's denial of benefits on the ground that her pro se status resulted in an unfair hearing. The plaintiff contends that her parents did not knowingly and intelligently waive counsel at the administrative hearing and that the erroneous waiver actually prejudiced her claim for benefits. The government responds that, inter alia, the waiver was legally sufficient, the hearing was fair, and that the ALJ fully developed the record on the plaintiff's behalf prior to rendering her decision.

Claimants have a statutory right to counsel at disability hearings. See 42 U.S.C. § 406; see also 20 C.F.R. § 404.1705; Marsh v. Secretary of Health & Human Servs., No. 93-605-JD, slip op. at 11-12 (D.N.H. Oct. 25, 1994); Lewis v. Secretary of Health & Human Servs., No. 92-252-B, slip op. at 19-20 (D.N.H. Aug. 9, 1993). But see Evangelista v. Secretary of Health & Human Serv., 826 F.2d 136, 142 (1st Cir. 1987) (right to counsel in disability cases "falls well below the Sixth Amendment threshold" found in

criminal cases). Claimants must be properly notified of this right, but may waive it if provided with sufficient information to decide intelligently whether to retain counsel or proceed pro se. See Evangelista, 826 F.2d at 142; see also Edwards v. Secretary of Health & Human Serv., 937 F.2d 580, 585-86 (11th Cir. 1991); Wingert v. Bowen, 894 F.2d 296, 298 (8th Cir. 1990); Holland v. Secretary of Health & Human Serv., 764 F.2d 1560, 1562-63 (11th Cir. 1985).¹⁶

However, a finding that the plaintiff was denied her right to counsel because of an insufficient waiver or other deficiencies related to the knowing and intelligent nature of the

¹⁶The type of information that must be set forth in a notice to claimants concerning the right to counsel includes:

- (1) a description of the benefits to be derived from representation by competent counsel;
- (2) the identity of legal service organizations that will represent qualifying claimants without charge;
- (3) the fact that attorneys will sometimes agree to represent claimants on a contingency fee basis; and
- (4) the existence of a statutory ceiling of twenty-five percent on attorney's fee payments that may be paid from an award of past benefits and a requirement that such fees be subject to court approval.

See, e.g., Edwards, 937 F.2d at 585-86; Thompson v. Secretary of Health & Human Serv., 933 F.2d 581, 584-85 (7th Cir. 1991); Holland, 764 F.2d at 1563; Smith v. Secretary of Health & Human Serv., 677 F.2d 826, 829 (11th Cir. 1982).

waiver does not automatically require that the case be remanded. Rather, claimants must show that they were prejudiced by their lack of representation. See Evangelista, 826 F.2d at 142; see also Edwards, 937 F.2d at 586; Kane v. Secretary of Health & Human Serv., 731 F.2d 1216, 1220 (5th Cir. 1984); Smith, 677 F.2d at 829-30. When determining whether a claimant has been prejudiced by her pro se status, the court recognizes that social security proceedings are not adversarial in nature, see Heggerty v. Secretary of Health and Human Servs., 947 F.2d 990, 997 (1st Cir. 1991) (citing Currier v. Secretary of Health, Education and Welfare, 612 F.2d 594, 598 (1st Cir. 1980)), and it is the Secretary's duty to "develop an adequate record from which a reasonable conclusion can be drawn." Id. (quoting Carrillo Marin v. Secretary of Health and Human Servs., 758 F.2d 14, 17 (1st Cir. 1985) (per curiam)). This "basic obligation to develop a full and fair record rises to a special duty when an unrepresented claimant unfamiliar with hearing procedures appeals before him." Lashley v. Secretary of Health & Human Servs., 708 F.2d 1048, 1051 (6th Cir. 1983) (quotation marks and citations omitted). In light of the heightened obligation owed to pro se claimants, the failure to fully develop the record with respect to impairments or other considerations apparent from the evidence supports a finding of prejudice. See Lewis, slip op. at 18.

The administrative record reveals that on at least two occasions prior to the administrative hearing the plaintiff's parents were mailed written notices describing, in various degrees of detail, their right to be represented by counsel. See Tr. at 41-44, 46-47. More significantly, at the time of the hearing the parents voiced concerns about proceeding pro se, which were acknowledged by the ALJ in her opening statement:

ALJ: The claimant child is not present, but her parents, David Rice and --

WIT1: Maureen.

ALJ: -- Maureen Rice are here. They have indicated that they would like to be represented by an attorney and you certainly have the right to that.

Tr. 50. Following a description of the hearing process and a brief discussion of the claimant's medical history and past receipt of state benefits, the ALJ addressed the representation issue in earnest:

ALJ: Okay, well, I don't want to go any further than today unless you have questions because I'd like you to have legal counsel to assist you. I will be asking you such things as whether [the claimant's sister] Megan's condition seems to be more severe than Jennifer's, how they compare. Whether you have other children with or without problems.
. . .

WIT 1: I can give you some of that information now. That wouldn't justify -- I mean, or would you rather have the lawyer present?

ALJ: Well, I'd rather have the lawyer review the case with you. I'm not trying to trap you into anything. I was just hoping that we could accelerate today. I know you've waited a long time for this hearing. Okay, so we will --

WIT 1: We just -- were just afraid that if we didn't get legal counsel that if we did lose, we'd always say, what if we'd gotten a lawyer.

ALJ: Well, if you -- if I made a decision that you weren't happy with, you could appeal then and get a lawyer at that point.

WIT 1: Would we be able to submit new evidence?

ALJ: Yes, you could.

Tr. 54-55. After digressing with a series of questions concerning the plaintiff's medical condition, the ALJ again refocused her attention to the plaintiff's lack of counsel:

ALJ: Well, its strictly up to you. We could proceed today or you could -- we can recess and you can get an attorney to help you.

WIT 1: If you do deny us, we'd be able to appeal it from you --

ALJ: Oh, yes, absolutely.

WIT 1: -- and submit any new evidence?

ALJ: And new evidence. And then the Appeals Council, which is part of SSA also, would determine whether or not my -- well, in the case of new evidence, they usually remand it for another hearing if it would show something different from what's already there. Otherwise, they look at my decision and decide whether it's supported by substantial evidence or not. And that means enough evidence that a reasonable person

could conclude this way even though that's not the only possible conclusion. Then from the Appeals Council, if you don't like their decision, you can go to District Court. Then you should definitely have a lawyer.

WIT 1: So the next step though just to see if you had enough material to make your decision? [sic]

ALJ: Right. And then they can remand or reverse or affirm.

WIT 1: What do you think?

WIT 2: Well, if it can be appealed later on, you know, we're here.

ALJ: Okay, lets do it today then.

WIT 2: Is that how you want to do it?

ALJ: Do you want to --

WIT 1: Yeah.

ALJ: -- talk in private?

WIT 1: No.

WIT 2: No.

Tr. 56-57.

The court finds that the parents were well aware of their right to be represented by counsel but, despite this knowledge, did not waive the right in a knowing and intelligent manner. The ALJ acknowledged the parents' concerns about proceeding pro se and properly undertook to explore the issue at some length. However, the ALJ's efforts were blemished by her incomplete and

potentially misleading description of the administrative process and the potential role of counsel in that process. Specifically, the parents twice inquired about their ability to appeal an adverse ruling and to introduce additional evidence to bolster such an appeal. It is plain from the record that the ALJ's responses to these queries largely allayed their initial reluctance to proceed pro se. However, the ALJ's explanation of the appeals process minimized the importance of a properly developed record at the initial hearing by overstating a claimant's ability to correct errors on appeal. For example, although legal errors and, in some instances, factual findings, may be reversed, the appeals council will not disturb those adverse rulings which are supported by substantial evidence but which could have been resolved in the claimant's favor from the same record. The ALJ did not adequately communicate that, even beyond obviating the need for an appeal, a well-developed record at the hearing stage may greatly improve the likelihood of success on appeal because social security claimants, like others litigating through administrative channels, are bound by what transpires at the earlier stages of review. Instead, in the opinion of the court the ALJ left the parents with the erroneous impression that the absence of counsel at the initial hearing was insignificant because any adverse consequences could be repaired

by counsel in the course of a de novo appellate review.¹⁷ The explanation was further misleading to the extent it created the impression that claimants are entitled to receive, as opposed to request, another hearing before the appeals council. Finally, the misimpression is apparent from the parents' statements at the hearing. See, e.g., Tr. 57 ("well, if it can be appealed later on, you know, we're here"). Given these circumstances, the court concludes that the parents' waiver of counsel is legally insufficient because it was based in part or in whole on information provided by the ALJ which was incorrect, incomplete, or otherwise misleading.¹⁸

The court also finds that the plaintiff was prejudiced by the inadequate waiver of counsel. The administrative record contains a variety of evidence probative of the plaintiff's limited ability to function at an age-appropriate level and the effects of living in a structured or highly supportive setting,

¹⁷The ALJ's explanation of the substantial evidence standard of review, although technically correct, in all likelihood did not cure any mistaken impression given the overall context of the explanation, the parents' failure to manifest any real understanding of the standard, and the fact that standards of review are legal concepts foreign to non-lawyers.

¹⁸The court notes that, from the face of the transcript, the ALJ's failure to properly describe the administrative process and the function that an attorney could be expected to perform was inadvertent and, perhaps, may be attributed to the somewhat disjointed sequence of the hearing.

appropriate disability considerations for children, see, e.g., 20 C.F.R. §§ 416.924(f), 416.924(g), 416.924c (1996). However, in some instances the ALJ failed to take full cognizance of these materials. For example, the ALJ's final decision indicates full consideration of "other persons' statements about how symptoms affect the ability to function independently, appropriately and effectively," yet makes no direct reference to the literally hundreds of pages of caregiver notes maintained by nurses who cared for and observed the plaintiff in her home over the course of three years. See Tr. 36-40. These notes bear directly on the relationship between the plaintiff's medical difficulties and her ability to engage in the level and type of activity expected of a girl her age and the effects of living in home environment with the aid of regular medical care. See, e.g., Tr. 536 (in January, 1994, noting several school absences due to fatigue and abdominal discomfort and distension); Tr. 583 (in April 1994, noting school absences related to 5-6 day respiratory virus, colds, and abdominal problems and noting lethargy); 606 (on June 6, 1994, noting school absences and lethargy related to constant constipation, abdominal distension, and lactose intolerance). The court finds that a searching analysis of this evidence may have resulted in a different result.

In other instances the ALJ failed to supplement the record with additional relevant evidence that she indicated a desire to consider but never obtained. For example, the plaintiff was repeatedly absent from school for reasons her parents and others attributed to her medical condition. The ALJ apparently recognized the potential significance of such absenteeism and explicitly asked for more evidence:

ALJ: Are there any other documents that you would like to have in the file? I think all I'd asked you for is the --

A: School records.

ALJ: -- school record. Yeah, attendance.

A: I didn't even think of those.

ALJ: I was particularly interested in the attendance records itself and sometimes like on a little report card, they summarize that for the year. But if there are notes in her school file that would show that she's unable to sustain participation in school activities or has to miss certain kinds of activities and so forth, that would be helpful too.

Tr. 77. Although the administrative record ultimately reviewed by the ALJ contained a list of the plaintiff's more than 40 school absences during the academic year 1993-94, see Tr. 614, the record is devoid of any of the requested narrative evidence from school officials or teachers indicating the extent to which this absenteeism affected the plaintiff. Moreover, there is no evidence that the ALJ sought to obtain directly such potentially

significant evidence in the face of the parents' apparent failure to do so. Despite this potentially significant gap in the evidentiary record, the ALJ based the denial of benefits on the subsidiary factual conclusion that the plaintiff's repeated absences from school "did not interfere with her school progress, but she continues to miss school in more advanced grades at such a rate, it seems inevitable that she will require additional assistance to maintain performance." Tr. 39. The court finds that a thorough examination of the school attendance issue may have resulted in a different result.

The ALJ failed to weigh evidence, such as that related to extended home health care and school attendance, which if fully explored may have favored a finding of eligibility. These deficiencies constitute the level of prejudice that would not have been present but for the plaintiff's unrepresented status. See Lewis, slip op. at 21-22. Moreover, the prejudicial taint has not been overcome by the ALJ's own efforts to develop the record which, although diligent in many instances, at times fell short of the heightened level necessary to safeguard the rights of pro se claimants. Accordingly, the plaintiff has demonstrated

that the waiver of counsel was not knowing and intelligent and resulted in actual prejudice.¹⁹

The court vacates the Secretary's decision. The matter is remanded for a new hearing consistent with this order.

Conclusion

The plaintiff's motion to remand the Secretary's decision (document no. 9) is granted. The defendant's motion to affirm the Secretary's decision (document no. 10) is denied.

The Secretary's decision is vacated. This matter is remanded for a new hearing consistent with this order.

SO ORDERED.

Joseph A. DiClerico, Jr.
Chief Judge

April 23, 1996

cc: David L. Broderick, Esquire
Raymond J. Kelly, Esquire

¹⁹In light of this ruling, the court need not address the other issues raised by the plaintiff, such as whether the record contained substantial evidence to support the ALJ's denial of benefits.