

unable to break down cell substances known as glycosaminoglycans, which build up to toxic levels and inhibit proper cell functioning. Because the disorder impairs the functioning of all cells, the impact of the disorder is wide-ranging, harming the heart, lungs, brain, bones, and muscles. The Petitioner has also been diagnosed with mitral valve prolapse, osteomyelitis, obstructive sleep apnea, pancreatitis, and hypertension. (Testimony of Sharon Collins and Michael Papciak; Exhibit R-4.)

2.

Hurler's Syndrome is a progressive disorder. In individuals with the severest forms, the disease may be fatal within several years after birth. Those with less severe forms of the disease may live into their twenties and thirties. Individuals with Hurler's Syndrome experience deterioration of organ functioning, developmental disabilities, and impaired mobility. (Testimony of Dr. Papciak.)

3.

Although treatment options for Hurler's Syndrome are limited, some individuals are candidates for bone marrow or stem cell transplants. Enzyme replacement therapy is another method of treatment that may slow the progress of the disease but cannot reverse existing damage. Because the lungs are particularly vulnerable, respiratory care is crucial. (Testimony of Dr. Papciak.)

4.

The Petitioner is dependent on a tracheostomy ("trach") tube to breathe. During his waking hours, he also uses a heated trach collar, which helps prevent build-up of thick secretions. When he is sleeping, he uses a ventilator and a continuous positive airway pressure ("CPAP") machine. He requires frequent suctioning of the trach tube to maintain his airway. He

also has a gastrostomy tube ("G-tube"), which delivers medication and supplemental nutrition directly to his stomach. The Petitioner is severely intellectually disabled and unable to complete many self-care tasks. He is able to walk, with some difficulty, for short distances, but he also uses a wheelchair at times. (Testimony of Dr. Papciak, Melissa Holloway, and _____; Exhibits R-3, R-4, R-7, R-8, R-9, R-10, R-11.)

5.

The most important component of the Petitioner's care centers on his respiratory status, which must be monitored constantly. The Petitioner had an emergency tracheostomy on January 26, 2011. Until recently, he was able to breathe on his own for short periods without his trach tube. The situation changed in February 2013, however, when the Petitioner accidentally pulled out his trach tube. Ms. _____ was in the room at the time and, although she acted swiftly, he had turned blue from lack of oxygen in the short time it took for her to replace the tube. Following this incident, the Petitioner's physician determined that his trachea had deteriorated to the point that it would collapse without the trach tube in place. Consequently, Ms. _____ currently changes the Petitioner's trach tube two to three times per week. (Testimony of Dr. Papciak and Ms. _____.)

6.

The Petitioner's prescribed medications include the following: Albuterol, which is inhaled or administered over the trach, to relax his airway; Prevacid, to decrease stomach acid; Flonase, a nasal spray, for seasonal allergies; Melatonin, to regulate his sleep-wake cycles; various topical ointments for fungal infections; and vitamins. (Testimony of Ms. Holloway and Ms. _____.)

7.

The Petitioner's mother and primary caregiver, Ms. _____, is also a registered nurse. When she is not at work or sleeping, she provides almost constant nursing care and monitoring of the Petitioner. Every four hours, she assesses his vital signs and his respiratory system. Following the nursing assessment, she administers nebulizing, vest, and saline treatments. She also suctions secretions from his trach tube approximately every fifteen minutes. The Petitioner obtains most of his nutrition orally. He also takes his vitamins and Prevacid orally, but he receives water and other medications through his G-tube, which is also sometimes used for supplemental nutrition. (Testimony of Ms. _____.)

8.

At night, the Petitioner is monitored either directly by a nurse or electronically, using a baby monitor with audio and video capabilities. In addition to his ventilator and CPAP machine, the Petitioner uses a pulse oximeter that measures the oxygen saturation level of his blood. At times, the Petitioner detaches the ventilator tubing from his trach, and he often resists efforts to replace it. An alarm on his pulse oximeter sounds two to three times per night, on average, requiring intervention each time. (Testimony of Ms. _____ and Ms. Holloway.)

9.

Ms. _____ also provides much of the Petitioner's personal care. She brushes his teeth and bathes him regularly. During baths, she inspects him from head to toe, examining nodules on his skin to ensure they have not been irritated. She checks incision lines on the back of his neck and back, which have come open and become infected multiple times. She also checks an open area on his pubic bone that is prone to draining. When the Petitioner is bathing, she must ensure that no water enters his trach tube. She changes his diapers and cleans his

bottom, where his skin is sensitive and excoriated. The Petitioner's room is cleaned with Clorox and Pine Sol, as he is susceptible to infection. (Testimony of Ms. _____, Ms. Holloway, and Dr. Papciak.)

10.

As part of the Petitioner's toilet training regimen, Ms. _____ takes him to the bathroom every two hours. She helps him walk back and forth in his room several times a day and encourages him to ride a tricycle. To develop and maintain his fine motor skills, she gives him blocks and stickers to manipulate. (Testimony of Ms. _____.)

B. The Petitioner's Caregivers and Care Schedule

11.

Ms. _____ and _____, the Petitioner's father, have been divorced for eleven years. Although Mr. _____ is the Petitioner's secondary caregiver, he resides outside the home. Ms. _____ testified that Mr. _____ generally stays with the Petitioner for a few hours on the days she works to fill the gap between her departure and the arrival of the GAPP nurse. According to Ms. _____, Mr. _____ is unemployed and does not pay child support. Therefore, Ms. _____ income is the household's primary means of support. (Testimony of Ms. _____; Exhibit R-6.)

12.

The Petitioner has two brothers, ages fourteen and eighteen, both of whom reside with the Petitioner and Ms. _____. _____, his younger brother, is able to assist with the Petitioner's personal care, but he cannot meet his skilled nursing needs. His older brother, _____, has recently obtained a full-time job and is unable to provide more than occasional supplementary care. (Testimony of Ms. _____; Exhibit R-6.)

13.

Ms. _____ currently holds two employment positions. She works full-time on an overnight shift as a registered nurse at Northeast Georgia Medical Center. In that capacity, she works every Saturday and Sunday and alternate Thursdays and Fridays from 7:00 p.m. to 7:00 a.m. She also works part-time as a registered nurse at Habersham County Medical Center. Her part-time hours vary each week, although she generally works either Monday, Tuesday, or Wednesday night. At the present time, she has been unable to find a job that would permit her to work a daytime schedule. (Testimony of Ms. _____.)

14.

Due to Ms. _____'s work schedule, she has arranged for the Petitioner's GAPP nurses to maintain a constant presence on weekends, from 8:00 a.m. on Saturday morning until 8:00 a.m. on Monday morning. GAPP nurses are also present overnight from 8:00 p.m. to 8:00 a.m. during the week on the days that Ms. _____ works. (Testimony of Ms. _____.)

15.

During the school year, the Petitioner goes to school five days a week for seven hours a day.¹ He receives services under an individualized education plan and is accompanied by a nurse, who is paid by the school district. This nursing care is in addition to the hours of skilled nursing services the Petitioner receives through the GAPP program. (Testimony of Ms. Holloway and Ms. _____; Exhibit R-7.)

¹ The Court presumes that the Petitioner is on summer break at the present time.

C. The GAPP Program

16.

The Department implemented the GAPP program in 2002 as part of Georgia's Medicaid plan. GAPP serves children under age 21, living at home, who are medically fragile and require the type of continuous skilled nursing services that are usually provided in an institutional setting. A skilled nursing service is one that "is so inherently complex that it can be safely and effectively performed only by, or under the supervision of, technical or professional personnel such as registered nurses, licensed practical (vocational) nurses, physical therapists, and speech pathologists or audiologists." (Testimony of Ms. Collins; Exhibits R-1 at §§ 601, 701, and Appx. R; R-2.)

17.

In addition to providing skilled nursing services, GAPP serves as a teaching program, wherein a child's home caregivers learn to perform the necessary medical services when a skilled nurse is not present. As the medical condition of the child stabilizes, the skilled nursing services are reduced to give greater responsibility to the child's caregivers. The Department reassesses a child's eligibility and need for skilled nursing services under GAPP every three to six months. (Testimony of Ms. Collins; Exhibits R-1 at §§ 701, 801 and Appx. R; R-11.)

18.

In January 2013, the Petitioner's physician requested authorization from the Department for a continuation of nursing services through the GAPP program. The Petitioner's physician recommended that he continue to receive eighty-four hours per week of in-home skilled nursing care for the upcoming certification period. (Testimony of Ms. Holloway; Exhibits R-3, R-4, R-5.)

19.

The Department has contracted with the Georgia Medical Care Foundation (“GMCF”) to review applications for admission and continued stay in the GAPP Program. GMCF’s GAPP review team, which consists of a pediatrician and four GAPP review nurses, evaluated the Petitioner’s request for skilled nursing services. After reviewing the authorization request, the supporting documentation, and the Petitioner’s nursing notes from the three previous months,² the team recommended that the Petitioner’s skilled nursing services be reduced from eighty-four hours per week to fifty-four hours per week, with a four-week weaning period. (Testimony of Ms. Holloway and Dr. Papciak; Exhibits R-3, R-4, R-5, R-6, R-7, R-8, R-9.)

20.

On February 27, 2013, GMCF issued a Final Determination, stating that the Petitioner’s skilled nursing services would be reduced from eighty-four hours per week to fifty-four hours per week for the following reasons:

- The nurses['] notes reviewed for the past 3 months document the stability of your child’s condition.
 - Oxygen saturations are documented to be 96%-98% while on room air.
 - The nursing note on 12/25/13 states that “is able to turn and reposition self while asleep.”
 - It is consistently documented throughout the notes that respirations are “even, clear and unlabored.”
- Your child’s condition has remained stable with no exacerbations in disease process or hospitalizations since last pre-certification period.

² However, the nursing care provided to the Petitioner is more extensive than is reflected in the nursing notes. (Testimony of Ms. _____.) This Court gives greater weight to Ms. _____’s testimony regarding the extent of her son’s needs, in light of her nursing background and intimate familiarity with the Petitioner’s care, than to the testimony of the Department’s witnesses, whose knowledge was based primarily on a paper review. See Hunter v. Cook, 1:08-CV-2930-TWT, 2011 U.S. Dist. LEXIS 109775, at *21, 26 (N.D. Ga. Sept. 27, 2011).

- There is no evidence from the documentation submitted that the current hours are medically necessary to correct or ameliorate the child's medical condition (*see* 42 USCS § 1382h)(b)[sic], O.C.G.A. § 49-4-169.1) and GAPP Manual § 702.2(A)).
- G-tubes are not so inherently complex to require a professional licensed person on a daily basis. This does not require GAPP nursing hours which require continuous skilled nursing care or skilled nursing care in shifts (GAPP Manual § 601) and it does not meet medical necessity and require the level of care provided in a nursing facility or hospital (*See* 42 CFR § 409.31-409.34 and 42 CFR § 440.10).
- While _____ is trach and ventilator (CPAP) dependent, his respiratory status appears stable based on the information submitted.
- _____ is able to attend school 5 days per week.
- _____ is able to receive all nutrition orally and uses his g-tube for medications. The 60 day summary states: "Bolus feeds have not been required due to PO tolerated well."
- Skilled nursing hours cannot be granted for projected potential problems. It is to provide for the current skilled need of the child.
- Skilled nursing is granted, based on the medical necessity of the child's condition.

The Petitioner timely appealed the Final Determination. (Exhibit R-3; Testimony of Ms. Collins.)

III. CONCLUSIONS OF LAW

1.

This matter concerns the proposed termination of certain benefits provided to the Petitioner under the Medicaid program; therefore, the Department bears the burden of proof. Ga. Comp. R. & Regs. r. 616-1-2-.07. The standard of proof is a preponderance of evidence. Ga. Comp. R. & Regs. r. 616-1-2-.21.

2.

Medicaid is a joint federal-state program that provides comprehensive medical care for certain classes of eligible recipients whose income and resources are determined to be insufficient to meet the costs of necessary medical care and services. 42 U.S.C. §§ 1396-1396v. Each state is required to designate a single state agency to administer its Medicaid plan. In Georgia, that agency is the Department. 42 C.F.R. § 431.10(a); O.C.G.A. § 49-2-11(f).

3.

The Medicaid Act requires states to provide necessary medical care to eligible recipients under age twenty-one “whether or not such services are covered under the State plan.” 42 U.S.C. § 1396d(r)(5). More specifically, a participating state must provide early and periodic screening, diagnostic, and treatment (“EPSDT”) services to eligible children as needed “to correct or ameliorate defects and physical and mental illnesses.” *Id.*³ The Department cannot choose to disregard federal EPSDT requirements. 42 U.S.C. § 1396c (state Medicaid plans must comply with federal statute or no payments will be made); O.C.G.A. § 49-4-18 (compliance with federal Social Security Act is intended); *Moore v. Reese*, 637 F.3d 1220, 1233-1234 (11th Cir. Ga. 2011) (outlining a state’s “mandatory EPSDT obligations to Medicaid-eligible children”).

4.

Federal statutes and regulations do not define the phrase “correct or ameliorate.” However, Georgia law defines the phrase as “to improve or maintain a child’s health in the best condition possible, compensate for a health problem, prevent it from worsening, prevent the

³ The Eleventh Circuit Court of Appeals has held that “[t]he language of subsection (r)(5) appears to mandate coverage for all medically necessary treatment for eligible recipients under age twenty-one.” *Pittman v. Secretary Fla. Dept. of Health & Rehabilitative Serv.*, 998 F.2d 887, 889 (11th Cir. 1993). Further, “[t]he federal Circuits that have analyzed the 1989 ESPDT [sic] amendment agree that . . . participating states must provide all services within the scope of § 1396d(a) which are necessary to correct or ameliorate defects, illnesses, and conditions in children discovered by the screening services.” *S.D. v. Hood*, 391 F.3d 581, 593 (5th Cir. 2004).

development of additional health problems, or improve or maintain a child's overall health, even if treatment or services will not cure the recipient's overall health." O.C.G.A. § 49-4-169.1(1). See also A.M.T. v. Gargano, 781 F. Supp. 2d 798, 805 (S.D. Ind. 2011).⁴

5.

Private duty nursing, the service at issue in this case, is one type of EPSDT service that must be made available to eligible children. 42 U.S.C. § 1396d(a). Private duty nursing is defined as "nursing services for recipients who require more individual and continuous care than is available for a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility." 42 C.F.R. § 440.80. These nursing services are provided by a registered nurse or nurse practitioner under the direction of the recipient's physician at the recipient's home, a hospital, or a skilled nursing facility. Id. GAPP uses the nomenclature "in-home skilled nursing services" to describe private duty nursing services. Part II, Policies and Procedures for the Georgia Pediatric Program ("GAPP Manual") (Exhibit R-1 § 601.3; see also Moore, 637 F.3d at 1224; Royal v. Cook, 2012 U.S. Dist. LEXIS 84537, at *2 (N.D. Ga. June 15, 2012).

6.

When in-home skilled nursing services are medically necessary for a Medicaid-eligible child, the Department must provide nursing care to the child "that is 'sufficient in amount, duration, and scope to reasonably achieve its purpose,' but 'may place appropriate limits on a service based on such criteria as medical necessity.'" Moore, 637 F.3d at 1234 (quoting 42

⁴ Courts in other states that have interpreted the phrase "correct or ameliorate" have found it to mean "to make better or more tolerable." A.M.T., 781 F. Supp. 2d at 805 (citing Collins v. Hamilton, 231 F. Supp. 2d 840, 849 (S.D. Ind. 2002)). In so finding, the court in A.M.T. considered legislative history showing that Congress intended for EPSDT to function as "a preventative health program for children." Id. at 806 (citing H.R. 3299, 101st Cong. § 4213 (1989)). It held that failing to consider "a disabled child's potential for regression violates federal Medicaid law," finding it unreasonable to put a Medicaid recipient on a "figurative rollercoaster" by requiring that the child regress before continuing Medicaid services. Id. at 807.

C.F.R. §§ 440.230(b) and (d)). Under the GAPP Manual, medical necessity, “taking into consideration the overall medical condition of the member, the equipment and the level of care and frequency of care required for the member,” is used to determine a child’s need for “continuous skilled nursing care in shifts.” GAPP Manual §§ 601; 702.1. The number of nursing hours is determined by the child’s “specific medical treatment needs . . . and the documented training needs of the primary caregiver.” Id. Determining the need for skilled nursing care requires a “common-sense, non-technical consideration of the patient’s condition as a whole.” Aurora v. Sec’y of U.S. Dep’t of Health & Human Servs., 715 F. Supp. 466, 468 (E.D.N.Y. 1989).

7.

In determining the number of skilled nursing hours that are medically necessary, both the treating physician and the Department may introduce evidence of medical need. Id. When the Department and the treating physician do not agree, a factfinder, in this case the undersigned, determines the number of hours that is medically necessary. Id. at 1250; Hunter v. Cook, No. 1:08-CV-2930-TWT, 2011 U.S. Dist. LEXIS 109775, at *8 (N.D. Ga. Sept. 27, 2011).

8.

The GAPP Manual adopts the language and requirements surrounding “skilled services” from federal Medicare regulations. GAPP Manual, Appx. R. Under the regulations, skilled nursing services are those which “[r]equire the skills of technical or professional personnel such as registered nurses . . . and [a]re furnished directly by, or under the supervision of, such personnel.” 42 C.F.R. § 409.31(a), (b)(1). In general, the “inherent complexity of the service, the condition of the beneficiary, and accepted standards of medical and nursing practice” are all factors used to determine whether a particular service is considered skilled. 42 C.F.R.

§ 409.44(a), (b)(1)(i). “The fact that a skilled nursing service can be or is taught to the beneficiary or to the beneficiary’s family or friends does not negate the skilled aspect of the service when performed by the nurse.” 42 C.F.R. § 409.44(b)(iii). Even a service that is customarily considered unskilled may constitute a skilled service if, for instance, “only a registered nurse can ensure that essential non-skilled care is achieving its purpose.” 42 C.F.R. § 409.42(c)(1)(i).⁵ Skilled services specifically include both tracheostomy care and caregiver training. 42 C.F.R. §§ 409.33(b)(3), (7), 409.42(c)(1)(ii).

9.

Here, it is undisputed that the Petitioner requires skilled nursing services to correct and/or ameliorate his medical condition. In addition to frequent skilled assessment of his respiratory status, he requires infrequent medical interventions to maintain his airway.⁶ Therefore, this Court must decide only the number of skilled nursing hours that is medically necessary to correct or ameliorate the Petitioner’s condition.

10.

Because GAPP is, in part, a teaching program, the GAPP Manual contemplates that skilled nursing hours will be reduced when a child’s caregivers have been trained to provide more care. The number of approved hours is based on the “specific medical treatment needs of the member . . . and the documented training needs of the primary caregiver . . .” GAPP Manual § 702.1(D). There is an “expectation that the primary caregiver(s) will become

⁵ On the other hand, if an “average nonmedical person without direct supervision” from medical personnel can perform the care, it is not a skilled service, even if there is no person competent to perform it. 42 C.F.R. § 409.44(b)(ii),(iv). Examples of non-skilled personal care services include “[a]dministration of routine oral medications, eye drops, and ointments”; “[c]hanges of dressings for noninfected . . . conditions”; “[p]rophylactic and palliative skin care, including bathing and application of creams, or treatment of minor skin problems”; “[r]outine care of the incontinent patient, including use of diapers and protective sheets”; “[a]ssistance in dressing, eating, and going to the toilet”; assistive walking; and repetitive exercises to maintain function. 42 C.F.R. § 409.33(d).

⁶ The mere fact that his mother is capable of providing some of this care does not render it unskilled. 42 C.F.R. § 409.44(b)(iii).

competent to assume some responsibility for the care of the child.” GAPP Manual § 702.1(E). Thus, under ordinary circumstances, a reduction of skilled nursing hours is often appropriate after a caregiver has received proper training.

11.

The present case, however, does not present ordinary circumstances, primarily because Ms. _____ is a single parent who works an overnight shift, and her work schedule increases the Petitioner’s need for skilled nursing care. Since Ms. _____ must be absent from the home while the Petitioner is sleeping, she is unable to rely on electronic monitors or alarms on the Petitioner’s ventilator, CPAP machine, and/or pulse oximeter to alert her to a change in his condition. These devices would otherwise allow her to sleep at the same time as the Petitioner. Instead, she must sleep while the Petitioner is awake and in need of direct, one-on-one monitoring by a skilled nurse or trained caregiver. Therefore, Ms. _____’s work schedule must be considered in determining the number of skilled nursing hours that are medically necessary to correct or ameliorate the Petitioner’s medical condition. See M.R. v. Dreyfus, 697 F.3d 706, 729-30, 732-33 (9th Cir. 2012); Moore v. Reese, 637 F.3d 1220, 1228, 1241 (11th Cir. 2011) (GMCF considered caregiver's work schedule and sleeping needs, but not “caregiver convenience” activities such as grocery shopping or attending social functions, when approving skilled nursing hours). Here, the Petitioner requires skilled nursing care both when Ms. _____ is working and when her work schedule requires her to sleep during the day.

12.

The Department failed to prove, by a preponderance of the evidence and for the reasons stated above, that the Petitioner’s skilled nursing hours should be reduced. Under the particular facts presented, the reduction of hours proposed by the Department would compromise what is

medically necessary to correct or ameliorate the Petitioner's condition. 42 U.S.C. § 1396d(r)(5); O.C.G.A. § 49-4-169.1(1).

IV. DECISION

In accordance with the foregoing Findings of Fact and Conclusions of Law, the Department's decision to reduce the hours of skilled nursing care provided to the Petitioner is hereby **REVERSED**. The Petitioner remains entitled to receive eighty-four hours of skilled nursing care per week.

SO ORDERED, this 10th day of July, 2013.

KRISTIN L. MILLER
Administrative Law Judge