

BEFORE THE OFFICE OF STATE ADMINISTRATIVE HEARINGS
STATE OF GEORGIA

[REDACTED] (MINOR), Petitioner,	:	
	:	
v.	:	Docket No.:
	:	OSAH-DCH-GAPP-[REDACTED]-Schroer
DEPARTMENT OF COMMUNITY HEALTH,	:	
Respondent.	:	

INITIAL DECISION

I. Summary of Proceedings

The hearing in this matter was held on October 1, 2013,¹ before the undersigned administrative law judge of the Office of State Administrative Hearings. The hearing's purpose was to determine whether the skilled nursing hours provided to Petitioner under the Georgia Pediatric Program ("GAPP") should be reduced. Petitioner, [REDACTED], was represented by her mother, [REDACTED]. The Department of Community Health ("Department"), Respondent herein, was represented by Yvonne Hawks, Esq.

After careful consideration of the evidence and the arguments of the parties, the Department's decision to reduce Petitioner's skilled nursing hours is hereby **REVERSED**.

II. Findings of Fact

1.

[REDACTED] is eight years old. She lives at home with her mother and her eighteen-year-old brother, who is in high school. [REDACTED]'s parents are divorced, and her father is overseas in the military. In 2007, at age two, [REDACTED] was diagnosed with infantile-onset Pompe disease. Pompe

¹ The hearing was continued from September 3, 2013, at the request of Petitioner's mother. Although both Petitioner and her mother were present on September 3, only Petitioner's mother was present for the hearing on October 1.

disease is a rare genetic condition caused by an enzyme deficiency. Ordinarily, this enzyme, sometimes referred to as "GAA," breaks down glycogen in the body. In a person with Pompe disease, the GAA deficiency results in the buildup of glycogen in the body's cells, especially the muscles. Over time, the build-up of glycogen weakens respiratory, skeletal, and cardiac muscles and results in significantly impaired respiratory function, progressive osteoporosis, and cardiomyopathy. (Testimony of ██████, ██████; Ex. R-4)

2.

Although ██████ receives enzyme replacement therapy, infantile-onset Pompe disease is terminal and there is no cure.² Since being diagnosed, ██████ has had a history of respiratory illnesses and her lungs are very fragile. In 2008, she was hospitalized for over forty days with pneumonia and RSV, with subsequent, multi-day hospital admissions for respiratory distress. She was intubated and on a ventilator during that time. ██████ was hospitalized again in 2010 and 2011 for pneumonia and respiratory failure. In addition to respiratory-related admissions, ██████ was hospitalized in 2009 for infections and for replacement of her port, through which ██████ receives all her nourishment and medicines. In 2011, she was hospitalized again for fever and low oxygen levels.³ In January 2012, ██████ was hospitalized due to complications from a

² According to her mother, ██████. As set forth in the Medical Necessity/Level of Care Statement written by one of ██████'s physicians, ██████, "[d]eath in the infantile onset form [of Pompe disease] is usually related to cardiac or respiratory failure." ██████'s pulmonologist, ██████, is a physician at Children's Healthcare of Atlanta and an Assistant Professor at Emory University School of Medicine. He testified that ██████ is a very complicated patient, and, although he has treated patients with similar conditions, he has had few patients with infantile onset Pompe disease. Both ██████ and ██████'s mother believe that ██████ has reached age eight due in large part to the availability of in-home skilled nurses to provide care for ██████ and train and oversee ██████'s caregivers. (Testimony of ██████; Ex. R-4)

³ During this 2011 admission, ██████'s doctors discovered that she had a left proximal femur fracture. ██████ has extremely fragile bones due to progressively worsening osteoporosis.

pamidronate infusion, which [REDACTED] receives every six months as treatment for diminished bone density. (Testimony of [REDACTED], [REDACTED]; Exs. 4, 11)

3.

Because she cannot cough or swallow on her own, [REDACTED] requires significant daily care to keep her airways clear. [REDACTED]'s physician has ordered that her breath sounds and vital signs be assessed every four hours. An assessment of breath sounds in a child such as [REDACTED] is an extremely complex undertaking that can only be done by someone properly trained to do so. [REDACTED] also requires regular and frequent suctioning with a catheter throughout the day and night to prevent mucous buildup, oxygen desaturation, and respiratory distress. [REDACTED]'s day begins with a comprehensive morning "pulmonary toiletry," which includes (i) deep suctioning using a suction machine and a catheter inserted down her throat to clear secretions, (ii), a chest percussion therapy ("CPT") vest attached to a machine that shakes her chest wall at high frequencies to loosen the secretions in her lungs, and (iii) a cough assist device that provides positive pressure through a mask to expand her lungs and a sucking, negative pressure to pull the air and secretions out her lungs. (Testimony of [REDACTED]; Exs. R-4, R-11, R-12)

4.

In addition to her morning pulmonary treatments, [REDACTED] requires daily cleaning and treatment of her gastrostomy-jejunostomy ("G-J") tube, as well as bathing, moisturizing, diapering, and administration of medications. Because [REDACTED]'s lower body and her left-side upper body are paralyzed, she can only move her right arm and head and must be assisted by a

Recently, [REDACTED] was in the grocery store with her mother, and a stranger accidentally brushed against her. That small, unintentional touching caused deep bruising to [REDACTED]'s foot and required a visit to the physician to rule out a fracture. (Testimony of [REDACTED])

trained adult in all these activities.⁴ ██████'s mother estimates that it takes approximately one-and-a-half hours to complete ██████'s morning treatments and care. (Testimony of ██████; Ex. R-4)

5.

In the past, ██████'s fragile condition and susceptibility to illness prevented her from attending school outside her home. However, in the hopes of enhancing her quality of life, ██████ began attending school for three hours per day this school year. When she goes to school, her mother sends a suction machine with her. Upon her arrival, the school nurse conducts an assessment, including checking ██████'s vital signs, breath sounds, oxygen levels, and temperature. The school nurse monitors ██████ throughout her time at school, and an aide stays with ██████ at all times. If another child arrives sick at school, the teacher calls ██████'s mother before her bus arrives and ██████ stays home. When she arrives home from school, either ██████'s mother or a skilled nurse checks ██████'s vital signs and breath sounds, flushes the G-J tube, and changes her diaper. During the afternoon, ██████ may be visited by a therapist or a teacher who helps write down ██████'s homework answers. She also begins her feeding through the G-J tube and a second round of breathing treatments, including the CPT vest, the cough assist machine and more suctioning. (Testimony of ██████; Ex. R-4)

6.

During the evening and nighttime hours, ██████ receives additional breathing treatments, diapering and an assessment of her vital signs and breathing. ██████'s mother also does range of

⁴ Because ██████'s skin and bones are so fragile, she requires extremely careful handling to prevent new fractures or exacerbation of current injuries. Despite what appears by all accounts to be vigilant and dedicated care, ██████ has sustained fractures being moved by her mother, a nurse, and her aunt. This increased risk of fracture with little to no trauma being reported is consistent with patients with Pompe disease. (Testimony of ██████; Exs. R-4, R-11, R-12)

motion exercises with [REDACTED] before bedtime to prevent further muscle weakness and skin breakdown. [REDACTED] is feed continuously through the night, and uses a BiPAP breathing machine while sleeping to help control her breathing. In addition, [REDACTED]'s extremities must be repositioned or turned at least every two hours even while she is sleeping, which requires extreme care due to her fragile bones.⁵ (Testimony of [REDACTED]; Exs. R-4, R-11, R-12)

7.

Petitioner began receiving in-home skilled nursing care through GAPP in or around 2009. In addition to providing direct care to [REDACTED], the nurses also help train [REDACTED]'s mother to provide skilled care to [REDACTED] when the nurses are not there. Although [REDACTED] has rated herself as competent to do all the skilled tasks necessary to care for [REDACTED],⁶ she is not confident in her ability to consistently do so, especially with the more complex tasks, such as assessment of [REDACTED]'s breath sounds. For example, [REDACTED] has listened to [REDACTED]'s breathing and detected nothing unusual; yet, when the nurse arrives and does her assessment, the nurse has detected breath sounds that indicate that [REDACTED] is in some respiratory distress. Moreover, [REDACTED] testified that her ability to provide quality skilled care to [REDACTED] is compromised when she is fatigued. For example, in early July 2013, during a week when [REDACTED] only received 35 hours of skilled nursing services due to personnel issues at the nursing agency, [REDACTED] provided more of [REDACTED]'s skilled care than is typical, and she became very tired. During that week, [REDACTED] incorrectly attached the

⁵ [REDACTED]'s mother uses a baby monitor through the night so that if [REDACTED] is uncomfortable and needs to be repositioned more frequently than every two hours, [REDACTED] can call out and her mother will go to her. (Testimony of [REDACTED]; Ex. R-12)

⁶ [REDACTED]'s uncle, [REDACTED], has also been rated as "competent" on a Caregiver Teaching Checklist. Nevertheless, [REDACTED]'s mother testified that he is not comfortable caring for [REDACTED] on his own for long periods of time. Similarly, it appears from the nursing notes in the record that [REDACTED]'s teenage brother sometimes cares for [REDACTED] for short periods of time. It is unclear whether [REDACTED]'s brother has been trained to do the complex skilled services [REDACTED] needs. (Testimony of [REDACTED]; Ex. R-6)

tubing to one of the medical devices, causing [REDACTED] to aspirate. [REDACTED], who works fulltime for Boeing in addition to being [REDACTED]'s primary caregiver, attributed this mistake to exhaustion. (Testimony of [REDACTED]; Exs. R-6, R-11, R-12, R-14)

8.

According to [REDACTED], who testified at the hearing, [REDACTED]'s respiratory condition is "dynamic," meaning that it can quickly decline in a matter of minutes or hours if she catches a cold or other illness.⁷ Essentially, [REDACTED] opined that [REDACTED] would benefit from skilled nursing care "24/7," given the complexity of her medical needs and the technologically-advanced medical devices and treatments that her caregivers must administer. Although [REDACTED] [REDACTED] acknowledged that parents can be trained to provide some of the skilled care that children such as [REDACTED] require, he opined that it is not appropriate to have them do so for longer than a typical nursing shift. Thus, although there is no magic formula for calculating exactly how many nursing hours [REDACTED] needs, [REDACTED] opined that [REDACTED] would medically benefit from at least 77 hours per week of skilled nursing care.⁸ (Testimony of [REDACTED]; Exs. R-12, P-1⁹)

⁷ When [REDACTED] gets sick or has any respiratory symptoms at all, her CPT vest treatments are increased to four times per day, cough assist may be as frequent as every ten minutes with frequent suctioning, and nebulized treatments may increase to nine times per day. Consequently, common childhood illnesses, such as a cold, are potentially "disastrous" for [REDACTED]'s respiratory condition and require increased skilled supervision and treatment. (Testimony of [REDACTED]; Ex. P-1)

⁸ [REDACTED]' recommendation of 77 hours was echoed by other physicians following [REDACTED], including the geneticists from The Emory Clinic who treat [REDACTED], [REDACTED], M.D., [REDACTED], M.D., and [REDACTED], MS. (Exs. R-12, P-2) At the administrative hearing, however, [REDACTED] sought only to contest the proposed reduction of [REDACTED]'s skilled nursing hours from 63 hours per week to 40, and did not seek an increase to the physicians' recommended 77 hours per week.

⁹ [REDACTED]'s mother submitted two updated letters of medical necessity from [REDACTED]'s physicians, which were tendered into evidence, but were not marked for identification. The Court has marked the August 7, 2013 letter from [REDACTED] as Exhibit P-1 and the August 1, 2013 letter from [REDACTED] as Exhibit P-2.

9.

The Department requires that ██████'s eligibility for GAPP services be reviewed every three to six months. The Department has contracted with the Georgia Medical Care Foundation ("GMCF") to conduct these reviews and to determine the level and frequency of skilled care that is "medically necessary." In or around February 2013, GMCF conducted such a review of ██████'s case. As an initial step, GMCF first assessed whether ██████ was still eligible for the program. That is, was she "medically fragile with multiple systems diagnoses and [does she] require continuous skilled nursing care in shifts." Specifically, under the Department's GAPP Manual, GMCF must determine that ██████ requires "service which 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 ██████, Collins; Exs. R-1, R-9)

10.

The Department does not argue that ██████ is no longer eligible for GAPP. She clearly is a child with inherently complex medical needs and requires skilled nursing care in shifts. The issue in dispute here is whether ██████'s current allotment of 63 hours of skilled nursing hours per week should be reduced to 40 hours per week. During the most recent review, a GMCF nurse considered a packet of information relating to ██████, including three months of nursing notes, a nursing care plan from the in-home nursing agency, a Letter of Understanding signed by ██████'s mother,¹⁰ a plan of treatment prepared by ██████'s physician, and her individualized

¹⁰ In the Letter of Understanding, which is a form found in Appendix J of the GAPP Manual, ██████'s mother agreed that GAPP was designed to assist her in learning to care for her

educational plan developed by the school system. From the February review, the GMCF nurse, Jennifer Purcell, R.N., determined that ██████'s medical condition was relatively stable, with no hospitalizations or changes in her skilled nursing needs in the past three months. Purcell also considered that ██████'s mother was competent in attending to many of ██████'s skilled needs, such as administering the G-J tube feedings and assessing ██████'s vital signs. Moreover, some of the tasks, although requiring extraordinary care, such as repositioning, diapering, and bathing, were not skilled nursing needs at all, according to Purcell. She acknowledged, however, that at least two of the tasks were so complex that they could only be performed by a skilled nurse: (1) assessment of ██████'s respiratory condition and (2) ongoing education of ██████'s caregiver. (Testimony of Purcell, Collins, Exs. R-4, R-5, R-7, R-8, R-9, R-11, R-12)

11.

Purcell did not physically examine ██████, nor did she consult directly with ██████'s physicians. Rather, she studied the medical records prepared by ██████'s medical providers and consulted with a GMCF medical review team, consisting of several registered nurses and Dr. Michael Papciak, M.D., a GMCF pediatrician.¹¹ The medical review team decided that ██████ should be weaned gradually from 63 hours of skilled nursing hours per week to 40 hours per week. According to Purcell, 40 hours per week is a standard weaning target for GAPP nursing services. Moreover, it was roughly consistent with Purcell's estimate of how many hours per day ██████ required skilled nursing care, a figure she reached by calculating the minutes each skilled nursing task typically takes to perform. For example, Purcell estimated that a "head to

child's medical conditions and that she understood that skilled nursing services may be reduced over time based on ██████'s medical needs. (Testimony of ██████; Ex. R-5)

¹¹ Although Dr. Papciak was identified by the Department as a possible witness, he did not testify at the administrative hearing. Accordingly, the Court is unaware of Dr. Papciak's experience with or understanding of Pompe disease. Purcell testified that she had not encountered a child with Pompe disease prior to reviewing ██████'s case. (Testimony of Purcell)

toe” assessment of [REDACTED] takes approximately thirty minutes, and that such assessment must be done at the beginning and end of each nursing shift. The use of the CPT vest, which must be done at least two times per day, Purcell estimated takes 20 to 30 minutes each time, while the J-G tube feeding takes approximately 10 minutes,¹² the nebulizer treatments takes 20 minutes, and so on. Adding up all these minutes, Purcell arrived at between 5 and 6 hours per day of direct skilled nursing tasks. (Testimony of Purcell; Exs. R-7, R-8)

12.

Based on Purcell’s calculations and GMCF’s general goal of weaning GAPP recipients down to 40 hours per week of skilled nursing services, the medical review team recommended that [REDACTED]’s in-home skilled nursing hours be reduced first to 48 hours per week for six weeks and then to 40 hours per week thereafter. Although [REDACTED]’s mother asked GMCF to reconsider its position, GMCF issued a Final Determination Letter on March 29, 2013, confirming the proposed reduction in hours and notifying her of her right to appeal the decision. (Testimony of Purcell; Exs. R-2, R-3)

III. Conclusions of Law

1.

This matter concerns Respondent’s reduction of Petitioner’s benefits; therefore, Respondent 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.

¹² The nursing notes indicate that the G-J tube sometimes gets blocked, which requires additional time to flush. See, e.g., Ex. R-7, at 11/20/12. It is not clear from the record whether Purcell took this into account in making her rough calculations.

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.

A participating state is required to provide certain categories of care to eligible children, including early and periodic screening, diagnostic and treatment (“EPSDT”) services as needed “to correct or ameliorate defects and physical and mental illnesses.” 42 U.S.C. § 1396d(r)(5). Private duty nursing is an enumerated category of treatment under the Medicaid Act. 42 U.S.C. § 1396d(a)(8).

4.

Georgia law defines “correct or ameliorate” to mean “to improve or maintain a child’s health in the best condition possible, compensate for a health problem, prevent it from worsening, prevent the 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.

5.

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). 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).

6.

GAPP is designed to serve medically fragile children under the age of twenty-one who require skilled nursing care based on medical necessity and “equivalent to the care received in an institutional setting, i.e., hospital or skilled nursing facility.” Part II, Policies and Procedures for the Georgia Pediatric Program (GAPP), pub. Jan. 1, 2013 (“GAPP Manual”) (Exhibit R-9), § 601.1. A child enrolled in the GAPP program is eligible to receive private duty nursing services.¹³ 42 U.S.C. § 1396d(a)(8); id. at § 601.3.

7.

In this case, it is undisputed that [REDACTED] is medically fragile, thereby meeting the first requirement for program participation. In addition, there is no dispute that [REDACTED] meets the standard for the nursing facility level of care. Specifically, to meet the standard for the nursing facility level of care, [REDACTED] “requires service which is so inherently complex that it can be safely and effectively performed only by, or under the supervision of, technical or professional

¹³ Private duty nursing service is defined as “nursing services for recipients who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility.” 42 C.F.R. § 440.80. Through GAPP, these services may be provided only at the recipient’s home. GAPP Manual § 601.3.

personnel such as registered nurses, licensed practical (vocational) nurses, physical therapists, and speech pathologists or audiologists.” GAPP Manual, Appx. R (Exhibit R-9). Additionally, among other requirements, ██████ “must require skilled nursing or skilled rehabilitation services, or both, on a daily basis.” Id. Based on the record, ██████ meets these requirements for participation in GAPP.

8.

The only contested issue is the number of skilled nursing hours that are medically necessary to correct or ameliorate ██████’s particular conditions. A child’s need for GAPP skilled nursing services is determined based on medical necessity, “taking into consideration the overall medical condition of the member, the equipment and the level and frequency of care required for the member.” Id. at § 702.1; see 42 C.F.R. § 440.230(d). However, the skilled nursing care provided must be “sufficient in amount, duration, and scope to reasonably achieve its purpose.” 42 C.F.R. § 440.330(b); see Moore v. Reese, 637 F.3d 1220, 1257-58 (11th Cir. 2011).

9.

The Court has weighed the Department’s position that 40 hours per week are sufficient against the position of ██████’s mother and her physicians’ that 63 to 77 hours per week are medically necessary. In so doing, the Court has considered, among other things, the following factors: (i) ██████’s extremely fragile physical condition, (ii) the progressive diminishment and weakening of her skeletal, cardiac, and respiratory systems, (iii) the ever-present risks of rapid and life-threatening deterioration in ██████’s respiratory functioning due to common illnesses and other causes, (iv) the likelihood that a fatigued caregiver will be unable to provide the complex,

continuous skilled care ■■■■ requires, as was borne out in July of this year,¹⁴ and (v) the rareness of Pompe disease and the respective knowledge and experience of the medical professionals who have expressed their opinions regarding what is medically necessary to prevent ■■■■'s condition from worsening. Having weighed this and all the evidence in the record, the Court concludes that the Department has failed to prove that a reduction of nursing hours to 40 hours per week will fulfill the state's obligation to provide EPSDT services to ■■■■ in the appropriate amount, duration and scope.

10.

The Court further concludes that GMCF's practice of adding up the minimum number of minutes that a skilled nurse, as opposed to someone unskilled, must provide care to ■■■■ throughout the day to be overly simplistic and, in the end, unrepresentative of ■■■■'s true medical needs. As ■■■■ persuasively testified, ■■■■ needs the skilled care of a nurse 24 hours per day, every day. Although a nurse may not be actively providing hands-on services at every minute of every hour, he or she is providing watchful oversight and skillful monitoring of ■■■■'s condition and responding to changes in ■■■■'s condition as needed. In addition, although ■■■■'s mother may be trained and competent to provide skilled care for ■■■■ in the absence of a nurse, the evidence in the record does not support a conclusion that she can safely and properly do so for the 128 hours per week that she would be solely responsible for ■■■■'s

¹⁴ A caregiver whose attentiveness and decision-making are impaired by fatigue may be unable to provide sufficient care to a medically fragile child. See Hunter v. Cook, 2013 U.S. Dist. LEXIS 139963, *21-22 (N.D. Ga. Sept. 27, 2013). If the skilled nursing services provided under GAPP do not account for some degree of caregiver fatigue, particularly where only one trained and competent adult caregiver is present in the home, then the state has not met its duty to offer care that is "sufficient in amount, duration, and scope to reasonably achieve its purpose." See 42 U.S.C. § 440.230(b); Hunter, 2013 U.S. Dist. LEXIS 139963 at *32-37.

complex medical needs if the skilled nursing hours are reduced to 40 hours per week. In fact, the evidence from July 2013 proves otherwise.

11.

Finally, the Court concludes that the Department's attempt to meet its obligations to provide federally-mandated EPSDT services through GAPP fails when the Department chooses to elevate its GAPP weaning goals over its duty under the Medicaid Act to provide services necessary to correct or ameliorate a child's condition. Of course, in some cases the Department's weaning goal and the child's medical needs will align, and the Department can properly reduce skilled nursing hours down to 40 hours per week or less. However, it has not met its burden of proving that it can properly do so in ██████'s case. Rather, the evidence in the record shows that ██████ requires skilled nursing hours at a minimum of 63 hours per week, and that a reduction to 40 hours per week would jeopardize her health and safety and be inconsistent with Georgia's obligation under state and federal law to provide services to ameliorate ██████'s medical conditions.

IV. Decision

In accordance with the foregoing Findings of Fact and Conclusions of Law, the Department's decision to reduce the Petitioner's skilled nursing hours is hereby **REVERSED**.

SO ORDERED, this _____ day of November, 2013.

KIMBERLY W. SCHROER
Administrative Law Judge