

BEFORE THE OFFICE OF STATE ADMINISTRATIVE HEARINGS
STATE OF GEORGIA

██████████,
Petitioner,
v.
DEPARTMENT OF COMMUNITY
HEALTH,
Respondent.

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: Docket No.:
: OSAH-DCH-ICWP-██████████-Miller
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INITIAL DECISION

I. INTRODUCTION

The hearing in this matter was held over two separate days on May 13, 2013, and May 30, 2013,¹ before the undersigned administrative law judge of the Office of State Administrative Hearings. The hearing's purpose was threefold: first, to review the budget developed for the Petitioner, ██████████, by the Georgia Department of Community Health ("Department"), for his participation in the Independent Care Waiver Program ("ICWP"), a section 1915(c) Medicaid waiver; second, to determine whether the Petitioner may negotiate compensation rates with his personal support providers if he elects to direct his own care under ICWP's Consumer Directed Care delivery option; and, finally, to consider the Petitioner's request for a ninety-day transition period from the Georgia Pediatric Program ("GAPP"), the program in which he currently participates, to ICWP. The Petitioner was present at the hearing and was represented by C. Talley Wells, Esq. The Department was represented by Tara Dickerson, Esq.

After careful consideration of the evidence and the arguments of the parties, and for the reasons set forth below, the Petitioner's ICWP budget is **AMENDED**, the Petitioner's request to

¹ The hearing record closed on June 21, 2013, following submission of the parties' post-hearing briefs. By Order dated July 11, 2013, the deadline for issuance of this Initial Decision was extended to August 19, 2013.

negotiate caregiver reimbursement rates is **GRANTED**, and the Petitioner's request for a ninety-day transition period is **GRANTED**.

II. FINDINGS OF FACT

A. Petitioner's Background and Medical Condition

1.

The Petitioner was born on May 9, 1991, and he is presently twenty-two years old. He lives at home with his parents, [REDACTED]. At age three, he was diagnosed with a severe, hereditary, and progressive form of muscular dystrophy known as Duchenne muscular dystrophy, for which the life expectancy is approximately twenty-four years. Because the condition affects both voluntary and involuntary muscles, it impacts the Petitioner's heart and lung function as well as his mobility. (Stipulations ¶ 1; Testimony of Petitioner, [REDACTED], [REDACTED], James Logan, and Teresa Painter; Exhibits R-12, R-13.)

2.

In May 2011, the Petitioner was hospitalized due to respiratory failure and underwent a tracheostomy ("trach"). As a consequence, he uses a ventilator ("vent") to breathe, and he requires frequent suctioning of his trach tube. The Petitioner has also been diagnosed with primary cardiomyopathy, a deterioration of the heart which is related to his muscular dystrophy and likely to cause heart failure. (Stipulations ¶ 1; Testimony of Petitioner, [REDACTED], and Dr. Logan; Exhibits R-9, R-12, R-13.)

3.

The Petitioner ambulates using a wheelchair. Although his joint mobility is severely limited, he can move his head, fingers, and toes, as well as his right arm to some degree. With assistance, he can feed himself using an adaptive fork. He is unable to perform any of his vent or

trach care independently, and he must remain within earshot of a caregiver at all times. However, he is intelligent, articulate, and generally able to alert his caregivers to problems. In addition, alarms on his vent and other monitoring devices will sound in the event of an emergency. (Testimony of Petitioner, ██████████, Ms. Painter, and Donna Rose; Exhibits R-12, R-13.)

B. Petitioner's Participation in GAPP

4.

Since June 2011, the Petitioner has received in-home skilled nursing care through the GAPP program. GAPP currently provides twelve hours of skilled nursing services each day, for a total of eighty-four hours per week. These services are paid at a rate of \$35.00 per hour for a licensed practical nurse and \$40.00 per hour for a registered nurse. Although the Petitioner aged out of GAPP on May 9, 2012, when he turned twenty-one, his services have continued pending the resolution of the present appeal. Unfortunately, because GAPP services must be delivered within the home environment, the Petitioner has few opportunities to participate in the community so long as he remains enrolled in GAPP.² (Stipulations ¶¶ 2, 5-6; Testimony of Petitioner, ██████████, Catherine Ivey, Xan Gatling, and Sharron Kirby; Exhibits P-63, R-8, R-9, R-10.)

5.

When a GAPP nurse is not present, ██████████ assume responsibility for the Petitioner's care needs. ██████████ works full-time outside the home, while ██████████ is currently enrolled part-time as a nursing student. The Petitioner's skilled nursing hours are

² Prior to his GAPP enrollment and ventilator dependence, which increased his need for skilled nursing care, the Petitioner received non-skilled personal support services through a different program administered by the Department. During this time, he was able to attend college and lead a more active and independent life. (Testimony of Petitioner.)

scheduled each week to fit his needs and the needs of his family caregivers. (Testimony of Petitioner, ██████████, Ms. Painter, and Ms. Rose; Exhibits R-12, R-13.)

1. Petitioner's Care Needs

6.

The Petitioner's care needs are centered on his trach and vent, and his caregivers must frequently monitor and assess the Petitioner's breathing to ensure that his airway is clear. His caregivers' primary responsibilities include the following:

- providing the Petitioner with respiratory therapy;
- suctioning and assessing secretions;
- caring for the Petitioner's trach;
- operating his vent and responding to alarms;
- monitoring his lung sounds, oxygen levels, and vital signs; and
- assisting with his activities of daily living.

Both the Petitioner's family members and his GAPP nurses perform these duties. The Petitioner's care needs are described in more detail below. (Testimony of Ms. Painter and Ms. Rose.)

7.

The Petitioner's caregivers administer several types of respiratory treatments each day. The first respiratory treatment, chest physiotherapy ("CPT"), utilizes a vest that vibrates the Petitioner's chest to loosen secretions stuck to the sides of his airway. The second treatment is performed with an in-exsufflator or "cough assist" device, which alternately inflates and deflates his lungs through a hose connected to his trach. The cough assist draws the secretions loosened during the CPT treatment into the Petitioner's trach for suctioning. The device must be

monitored to ensure that it remains on the prescribed setting, because an improperly high setting can damage the Petitioner's lungs. (Testimony of Ms. Painter, Ms. Rose, and Kenneth Mobley; Exhibit P-52.)

8.

Suctioning the Petitioner's trach tube is a crucial component of his respiratory care, and it is essential that this task is performed correctly. During suctioning, the caregiver takes an inline suction catheter and pushes it down into the trach tube to extract secretions. Measuring marks on the suction catheter help ensure that it is not pushed in too far, which could result in bradycardia and respiratory failure. After suctioning, secretions are examined for color and viscosity. Dark secretions may need to be addressed by a doctor, while thick secretions should be thinned. Depending on the level of secretions, suctioning is performed anywhere between two and fifty times per day. (Testimony of Petitioner, Dr. Logan, Ms. Painter, Ms. Rose, and Mr. Mobley.)

9.

On rare occasions, the Petitioner's trach becomes blocked and suctioning is unsuccessful. When this occurs, an emergency trach change must be performed immediately. An emergency trach change requires the caregiver to remove the original tube and replace it before the Petitioner's oxygen supply is depleted. If a trach tube of the same size cannot be inserted for any reason, a smaller tube is available. Other emergency measures, such as an Ambu bag for manual ventilation, may also be employed. The Petitioner has required three emergency trach changes since he enrolled in the GAPP program. (Testimony of Petitioner, Dr. Logan, Ms. Painter, and Ms. Rose; Exhibit P-52.)

10.

The Petitioner's caregivers must also be able to provide basic trach care, including changing the trach collar, cleaning around the neck and trach site, and replacing the drain sponge that collects excess secretions and blood from the trach site. During showers, a filter must be connected to his trach tube to keep out water, dust, bacteria, and other contaminants. The Petitioner undergoes a routine trach change approximately every two weeks. [REDACTED] often assists a GAPP nurse with routine trach changes. (Testimony of Petitioner, [REDACTED], Ms. Painter, and Ms. Rose; Exhibit P-52.)

11.

The Petitioner's vent also requires care and attention. Although the vent settings are pre-set and sealed pursuant to his physician's orders, his caregivers check the settings to ensure that no malfunction has occurred. The vent must be monitored to ensure that water does not enter the tubes. The Petitioner is, therefore, disconnected from the vent before he showers. He is able to remain off the ventilator for up to two hours at a time, three to four days per week. (Testimony of Petitioner, Ms. Painter, Ms. Rose, and Mr. Mobley; Exhibit P-52.)

12.

In addition to monitoring the vent, a caregiver must respond to all vent alarms. Alarms may sound for high pressure, low pressure, high minute volume, low minute volume, or low battery. Each alarm has a different pitch and length. The Petitioner's caregivers must be trained to identify which alarm is sounding and to respond appropriately. (Testimony of Petitioner, Ms. Painter, Ms. Rose, and Mr. Mobley; Exhibit P-52.)

13.

The Petitioner's caregivers monitor his vital signs for oxygen saturation, pulse rate, blood pressure, and temperature. They also monitor his bodily functions and provide assistance with other basic needs. This care may include repositioning him, manually manipulating his extremities to keep his joints flexible, and transferring him to a wheelchair or shower chair. The transfer to the wheelchair involves the use of a Hoyer lift to get him out of bed. (Testimony of Petitioner, Ms. Painter, and Ms. Rose; Exhibit P-52.)

2. Training of Petitioner's Caregivers

14.

Through the GAPP program, the Petitioner receives skilled care provided by one of three assigned nurses who work in shifts. One of his nurses, Donna Rose, is a registered nurse, while the two others, Teresa Painter and Kenneth Mobley, are licensed practical nurses. Each of these nurses completed additional training before they assumed independent responsibility for the Petitioner's care. Their training included the classroom and practical instruction offered during their nursing programs, as well as continuing education provided by their current employer, Bayada Home Health Care, and supervised on-site training in the Petitioner's home. In addition, prior to caring for the Petitioner, all three nurses had prior experience caring for patients who were trach- and/or vent-dependent. (Testimony of Ms. Painter, Ms. Rose, and Mr. Mobley.)

15.

In keeping with generally accepted standards of medical practice, the caregivers for a hospitalized vent- and/or trach-dependent individual must be trained in proper care techniques before the individual may be discharged. While the individual is hospitalized, his or her caregivers are trained and evaluated to ensure that they are competent to perform all necessary

care. Hospital personnel use training checklists to assist with this process. (Testimony of Dr. Logan, Gwendolyn Rollins, and Ms. Gatling; Exhibits R-12, R-25, P-53.)

16.

Mr. and Mrs. [REDACTED] were trained to provide the Petitioner's trach and vent care over the course of four to five days during his May 2011 hospitalization. During their training, they received specific instruction from hospital personnel and were required to provide hands-on, supervised care of the Petitioner. Prior to his release from the hospital, they assumed responsibility for his care for a period of twenty-four hours to ensure that they were fully prepared to meet his needs. (Testimony of [REDACTED].)

17.

Dr. James Logan is a board-certified pediatric pulmonologist with extensive experience in the treatment of vent- and trach-dependent patients, including patients with Duchenne's muscular dystrophy. He is also an associate professor of pediatrics at Mercer University and Emory University. Dr. Logan testified that a competent caregiver for a trach- and vent-dependent individual need not be a skilled nurse or family member. Instead, the two essential characteristics of a competent caregiver are: (1) the willingness to learn; and (2) the ability to overcome fear in order to manage a patient's critical airway. Dr. Logan's testimony was both credible and reliable. (Testimony of Dr. Logan.)

C. ICWP Eligibility and Participation

1. Program Overview

18.

ICWP, as a distinct and separate Medicaid waiver program, operates under different parameters from the GAPP program. First, while GAPP serves only children under age twenty-

one, ICWP serves only adults between the ages of twenty-one and sixty-four. To participate in ICWP, an individual must have "a severe physical impairment and/or traumatic brain injury that substantially limit[s] one or more activities of daily living and require[s] the assistance of another individual." Participants must also be medically stable, have the ability to direct their own services, and require the level of care provided in a hospital or nursing facility. (Testimony of Ms. Ivey, Ms. Kirby, and Brian Dowd; Exhibits R-1 at 3, R-3 at § 701.)

19.

ICWP offers a multitude of services to its members, including enhanced case management, personal support services, respite care services, adult day services, emergency response systems, behavioral support, counseling, specialized medical equipment, and vehicle adaptation. However, continuous or in-home skilled nursing care is not available under ICWP. The waiver expressly offers skilled nursing on an episodic basis only, defining the scope of skilled nursing care as follows:

Providers of skilled nursing provide treatments and health care procedures ordered by a physician and required by standards of professional practice to be performed by nursing personnel[;] monitoring [of] the member's health care condition[;] and training [of] other Independent Care service providers in the areas within the scope of nursing such as dietary practices, sanitation and use of emergency services.

Further, "[t]he waiver pays for a nurse visit per day, not to exceed 31 days a month,"³ which is billed at a rate representing approximately one hour of the nurse's time. Due to this restriction, vent- and trach-dependent individuals in the program receive most of their care from trained personal support providers who are not skilled nurses. (Testimony of Ms. Ivey, Ms. Rollins, Ms. Gatling, and Mr. Dowd; Exhibit R-1 at 42, 103.)

³ Skilled nursing visits are available only after a participant has exhausted the fifty skilled nursing visits per year provided under the state Medicaid plan. (Testimony of Mr. Dowd; Exhibits P-71, R-1 at 103.)

20.

Cost-effectiveness is an important goal established in the ICWP waiver. Consequently, participants must be able to execute a plan of care within an annual line-item budget that does not exceed the cost limit established by the waiver. Along with the budgetary ceiling on total waived services, restrictions are also imposed on the quantity and cost of the itemized services provided through ICWP. The budget is determined based on the participant's care needs, as identified by the nursing assessment, and includes the costs of medical supplies, durable medical equipment, and all waived services. The compensation rates for individual services are established in the waiver and the ICWP policy manual. To calculate a participant's budget, the Department multiplies the payment rate for each itemized service by the number of hours allocated to the service, then adds the cost of necessary medical supplies and equipment. (Testimony of Mr. Dowd; Exhibits P-37, R-1 at 3, 18, 189-91; R-3 at § 701.)

21.

For an ICWP participant who meets the hospital level of care, the maximum allowable yearly budget under the waiver is \$108,605.00.⁴ This is significantly less than the state-established payment rate for a vent-dependent patient in a nursing home, which is \$463.87 per day or \$169,312.55 per year. (Testimony of Ms. Ivey and Mr. Dowd; Exhibits P-39, P-40, P-41.)

22.

ICWP provides participants with the option to direct their own services, thereby fostering greater independence in accordance with the program's goals. This consumer-directed care option allows an individual to hire and train his or her caregivers and to negotiate hourly pay rates within the confines of the established budget. Under this option, the participant is free to

⁴ The maximum allowable budget for a participant who meets the less-intensive standard for the nursing facility level of care is set lower, at \$53,561.00 per year. (Testimony of Mr. Dowd; Exhibit R-1 at 189.)

administer the budget as he or she chooses; the Department does not micromanage the participant's expenditures, provided that the expenditures do not exceed the overall budget.⁵ In addition to ICWP budgetary constraints, no single caregiver may work more than forty hours per week. (Testimony of Mr. Sargent and Mr. Dowd; Exhibits R-1 at 147-49, R-3 at Appx. P.)

23.

ICWP works in tandem with the Georgia Nurse Practices Act, which was amended in 2010 to allow individuals to consent to the provision of "health maintenance activities" by unlicensed "proxy caregivers."⁶ The proxy caregiver statute allows ICWP participants to hire unlicensed personnel to provide care that would otherwise be provided by licensed professionals. This option helps to control the cost of the waiver and ensures that ICWP serves as many individuals as possible. (Testimony of Ms. Ivey, Ms. Rollins, Ms. Gatling; Exhibit P-50.)

24.

ICWP participants who elect to utilize proxy caregivers must sign a consent form that tracks the requirements of the statute and provides, in pertinent part, as follows:

Georgia law now permits me, as an individual with a disability[,] to choose to allow unlicensed proxy caregivers who have been properly trained to perform health maintenance activities for me. Health maintenance activities are those health-related things I would normally do for myself, but for my disability. . . . Health maintenance activities are defined as those activities that have reasonably precise and unchanging directions, reasonably predictable outcomes and do not require complex observation skills or critical decisions.

A participant who gives informed consent for a proxy caregiver expressly acknowledges that "there may be additional health risks in having unlicensed proxy caregivers do health

⁵ In this way, the participant may negotiate lower rates for services, thereby gaining the flexibility to obtain additional respite care. The participant may also choose to pay his or her service providers more than the established rate. Although this action would reduce the service hours that could be provided within the budget, the Department will not penalize the participant with a reduction of hours simply because he or she made additional use of outside, informal caregiving in order to pay a higher rate. (Testimony of Mr. Dowd.)

⁶ See O.C.G.A. § 43-26-12 (a)(9)(A).

maintenance activities for me since they may not recognize an important change in my medical condition that needs to be assessed or treated by a licensed healthcare professional.” (Testimony of Ms. Ivey, Ms. Rollins, and Ms. Gatling; Exhibit P-50.)

25.

Because proxy caregivers are not necessarily licensed healthcare professionals, they must receive specific training before they perform health maintenance activities for ICWP participants. The cost of training is covered by the Department and takes place after the particular caregiver has been chosen by the participant. (Testimony of Ms. Ivey, Ms. Rollins, and Ms. Kirby.)

2. Transition Planning

26.

Because a GAPP recipient ages out of the program on his or her twenty-first birthday, the Department follows a transition timeline to reduce the risk of a break in care that could endanger the individual. However, the policy manuals governing the GAPP and ICWP programs establish somewhat different timelines. (Exhibits R-2 at § 807, R-3 at § 701.)

27.

Under Part II, Policies and Procedures for the Georgia Pediatric Program (GAPP) In-Home Skilled Nursing (“GAPP Manual”), the timeline begins between nine months and one year prior to the participant’s twenty-first birthday. At that time, the individual’s file is reviewed to determine if he or she meets the eligibility criteria for adult services through another program. Subsequently, and at least three months prior to the date of ineligibility, a Georgia Medical Care Foundation (“GMCF”) nurse assesses the individual, provides information to the family about

adult waiver or other services, and allows the family to choose a case manager to coordinate services. (Exhibit R-2 at § 807.)

28.

Under Part II, Policies and Procedures for Independent Care Waiver Services (“ICWP Manual”), GMCF uses the GAPP medical record to review an applicant for ICWP eligibility nine months prior to his or her twenty-first birthday. If the applicant meets program criteria, a GMCF review nurse sends an introductory letter and application that must be returned to GMCF seven months before the applicant’s birthday. At six months prior, the nurse completes an assessment of the applicant and explains the services offered through ICWP. Within thirty days of the completed assessment, GMCF notifies the applicant in writing whether he or she has been approved for ICWP participation. If the applicant is accepted into the program, GMCF provides a list of case manager candidates, and the applicant has two weeks to notify GMCF of his or her choice. The selected case manager then coordinates services to begin on the applicant’s twenty-first birthday. (Exhibit R-3 at § 701.)

29.

As suggested by the explicit, albeit potentially inconsistent, timelines set out in both manuals, ICWP frequently accepts individuals who have exceeded the age limit for GAPP. Many GAPP participants, including individuals dependent on trachs and/or vents, have successfully transitioned to ICWP. (Testimony of Ms. Rollins and Ms. Gatling; Exhibits R-1, R-2, R-3, R-12, R-13.)

3. The Petitioner's ICWP Assessment and Budget

30.

In the Petitioner's case, the transition from GAPP to ICWP did not proceed in a timely or predictable manner. First, GMCF did not send him the introductory letter and application for ICWP until December 15, 2011, less than five months before his twenty-first birthday. The Petitioner completed the application and returned it on December 21, 2011. However, the nursing assessment did not take place until February 16, 2012, less than three months before his twenty-first birthday. Based on the assessment, the Petitioner was determined eligible for ICWP under the hospital level of care. (Testimony of Ms. Rollins and Ms. Gatling; Exhibits P-42, P-43, P-45.)

31.

By letter dated April 6, 2012, approximately one month before his birthday, GMCF notified the Petitioner of his proposed plan of care under the ICWP waiver. The plan of care established a total budget of \$65,779.24 and authorized the following services:

- ten hours per month of case management services, at \$6.25 per hour;
- eight hours per day of level III personal support services, at \$14.07 per hour;
- four hours per day of level II personal support services, at \$12.20 per hour; and
- medical supplies totaling \$1350.84 per year.

(Testimony of Ms. Rollins and Ms. Gatling; Exhibits P-37, P-48, P-49, R-1 at 190-91.)

The Petitioner's plan of care was subsequently revised to increase his budget and provide for additional services. Under the final plan of care, issued on March 25, 2013, the following services were authorized:

- enhanced case management services, at \$461.00 per month;
- twelve hours per day of level III personal support services, at \$14.07 per hour;
- four visits per week (208 visits per year) by a registered nurse, at \$49.79 per visit; and
- medical supplies totaling \$1350.84 per year.

The total budget for the revised plan of care is \$78,865.76. The Petitioner is dissatisfied with this proposal, and he prefers that his care be provided by licensed nurses. (Testimony of Petitioner, ██████████, Ms. Rollins, and Ms. Gatling; Exhibit P-37, P-71, R-1 at 190-91.)

4. The Petitioner's Caregiver Search

Despite his concerns with the plan of care, the Petitioner selected Shepherd Care to provide his case management services. Shepherd Care manages a number of ICWP participants with vent and trach needs whose care is provided by proxy caregivers rather than skilled nurses. Some of these individuals are served through traditional nursing agencies, while others use the consumer-directed care model. The Petitioner will require three or more caregivers, in addition to his parents, to meet his needs and staff the eighty-four hours per week that have been allocated in his plan of care. (Testimony of ██████████, Ms. Kirby and Mr. Sargent.)

34.

Upon his approval for ICWP, Sharron Kirby, the program coordinator at Shepherd Care, met with the Petitioner and [REDACTED] and explained the services provided through the program. Thereafter, Ms. Kirby and the Petitioner's assigned case manager, Martin Sargent, attempted to assist the Petitioner in locating potential caregivers. However, the Petitioner's desire to have skilled nurses provide his care undermined his efforts to locate acceptable proxy caregivers. (Testimony of Petitioner, [REDACTED], Ms. Kirby, and Mr. Sargent.)

35.

Initially, the Petitioner sought to employ his caregivers through a traditional nursing agency. Ms. Kirby provided the Petitioner and [REDACTED] with a list of agencies to contact,⁷ several of which were known to provide care to vent-dependent individuals. However, when the Petitioner and [REDACTED] spoke with the agencies, they expressed reservations regarding the qualifications and training of potential caregivers and inquired about the agencies' liability. Unsurprisingly, they were unable to locate an agency that would accept the Petitioner as a client. (Testimony of Petitioner, [REDACTED], and Ms. Kirby; Exhibit P-55B.)

36.

After multiple nursing agencies had rejected the Petitioner's case, Martin Sargent, the Petitioner's case manager at Shepherd Care, suggested consumer-directed care as an alternative to the traditional agency service delivery model. The Petitioner placed online and newspaper advertisements,⁸ and he identified one potential caregiver who was a respiratory therapist.

⁷ One of the goals of ICWP is to promote the independence of its participants. Consistent with this goal, Ms. Kirby and Mr. Sargent sought to support the Petitioner as he arranged his own care, rather than arranging it for him. (Testimony of Ms. Kirby.)

⁸ Later in the search, Catherine Ivey, the Department's former deputy director of Medicaid, identified two training programs for nurses and respiratory therapists that were nearby the Petitioner's residence. Ms. Ivey suggested that

However, the Petitioner did not hire her because he had been unable to locate other necessary caregivers, she could not begin work immediately, and his budget remained uncertain at that time. (Testimony of Petitioner, ██████████, and Mr. Sargent.)

37.

The Petitioner has researched how much his care will cost, utilizing the assumption that he requires a caregiver with the skills of at least a licensed practical nurse. Based on this research, he has concluded that hiring licensed practical nurses as caregivers will cost at least \$20.00 to \$21.00 per hour. (Testimony of Petitioner.)

III. CONCLUSIONS OF LAW

1.

This matter concerns an application for ICWP participation and services; therefore, the Petitioner bears the burden of proof. Ga. Comp. R. & Regs. 616-1-2-.07. The standard of proof is a preponderance of the evidence. Ga. Comp. R. & Regs. 616-1-2-.21.

A. Medicaid Overview

2.

Medicaid is a joint federal-state program that provides comprehensive medical care for certain classes of eligible recipients whose income and resources are insufficient to meet the costs of necessary medical care and services. Social Security Act, 42 U.S.C. §§ 1396-1396v (the "Act"). The Medicaid program was created in 1965 "for the purpose of providing federal financial assistance to States that choose to reimburse certain costs of medical treatment for needy persons." Skandalis v. Rowe, 14 F.3d 173, 175 (2nd Cir. 1994) (quoting Harris v. McRae, 448 U.S. 297, 301 (1980)). Each state is required to designate a single state agency to

the Petitioner contact these programs for potential proxy caregivers. The Petitioner has not yet done so. (Testimony of Petitioner and Ms. Ivey.)

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.

If a state elects to participate in the Medicaid program, it must obtain approval from the Secretary of the Department of Health and Human Services (“Secretary”) of the programs and services it will offer using Medicaid funds. 42 U.S.C. § 1396a; see also Susan J. v. Riley, 254 F.R.D. 439, 445 (M.D. Ala. 2008). Certain services, such as inpatient hospital care and laboratory and X-ray services, are mandatory under the Act, while other services may be funded through Medicaid “at the option of the State.” 42 U.S.C. §§ 1396a(a)(10)(A)(i)-(ii), 1396d(a)(1), (3), (4); see Skandalis, 14 F.3d at 175; Susan J. v. Riley, 254 F.R.D. at 446.

B. Medicaid Waiver Programs

4.

Home and community-based (“HCB”) services are optional services intended to help individuals avoid institutionalization. To encourage states to make these services available, the Act empowers the Secretary to waive statutory requirements relating to “statewideness,” comparability,⁹ and income and resource limits. 42 U.S.C. § 1396n(c)(3). A state that wishes to provide HCB services through a waiver program must “submit a proposal prepared in accordance with regulations promulgated by the Secretary.” Skandalis, 14 F.3d at 176 (citing 42 C.F.R. §§ 435.217, 441.180 and 441.300 *et seq.*) The federal regulations require, *inter alia*, that a state’s application for a waiver include an assurance that services will be furnished only to recipients who in the absence of such services would otherwise require Medicaid-covered care in

⁹ The term “comparability” refers to the Act’s section 1902(a)(10)(B) mandate that medical assistance for any particular individual “shall not be less in amount, duration, or scope than the medical assistance made available to any other such individual.” 42 U.S.C. § 1396a(a)(10)(B); Susan J. v. Riley, 254 F.R.D. at 455.

a hospital, a nursing facility, or an intermediate care facility for the mentally retarded. 42 C.F.R. § 441.301(b)(1)(iii).

5.

The purpose of section 1915(c) waivers, such as ICWP, is to “provide the flexibility needed to enable States to try new or different approaches to the efficient and cost-effective delivery of health care services, or to adapt their programs to the special needs of particular areas or groups of beneficiaries.” 42 C.F.R. § 430.25(b) (emphasis added). Thus, within the broad federal rules applicable to Medicaid, the Department is authorized to determine “eligible groups, types and range of services, payment levels for services, and administrative and operating procedures.” 42 C.F.R. § 430.00 (emphasis added).

6.

The Department is further authorized under Georgia law to adopt and administer the state plan for Medicaid, including establishing “the amount, duration, scope and terms and conditions of eligibility for and receipt of such medical assistance” O.C.G.A. § 49-4-142(a). In making these determinations, the Department has discretion in choosing (1) what services will be offered through its Medicaid waiver programs, (2) which individuals will be included in the intended target group for the waiver services, and (3) whether to “limit the individuals provided benefits under such waiver to individuals with respect to whom the State has determined that there is a reasonable expectation that the amount of medical assistance provided with respect to the individual under such waiver will not exceed the amount of such medical assistance provided for such individual if the waiver did not apply.” 42 U.S.C. § 1396n(c)(4); see Susan J. v. Riley, 616 F. Supp. 2d 1219, 1240 (M.D. Ala. 2009).

7.

Federal regulations specify the types of HCB services that may be provided under a waiver. The list of authorized services includes: case management services, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, respite care services, and day treatment for individuals with chronic mental illness. 42 C.F.R. § 440.180(b). Although there is no specific mention of skilled nursing services, a catch-all provision authorizes “other services requested by the agency and approved by CMS [the Centers for Medicare and Medicaid Services] as cost effective and necessary to avoid institutionalization.” 42 C.F.R. § 440.180(b)(9).

8.

A state requesting waiver approval must assure CMS that safeguards exist to protect “the health and welfare” of waiver program beneficiaries. 42 U.S.C. § 1396n(j)(2)(A); 42 C.F.R. § 302(a). These assurances focus on meeting standards of licensure or certification as required by state law, as well as meeting “adequate standards for all types of providers that provide services under the waiver.” 42 C.F.R. § 441.302(a)(1).

C. Georgia’s ICWP Waiver

9.

Through its ICWP waiver, the Department offers HCB services to physically disabled Medicaid recipients who, in the absence of such services, would require Medicaid-covered care in a hospital or nursing facility. § 1915(c) Home and Community Based Waiver, Independent Care Waiver Program (“Waiver”) at 2 (eff. Apr. 1, 2011) (Exhibit R-1); see 42 C.F.R. §§ 441.300, 441.301(b)(1)(iii), 441.302(c),(g), 430.25(c)(2). In this case, it is undisputed that the

Petitioner is eligible for ICWP due to his physical disability and that he would require Medicaid-covered care in a hospital in the absence of HCB services.

1. Services Provided

10.

The scope of the waiver limits the services that may be provided through ICWP. Susan J. v. Riley, 616 F. Supp. 2d at 1240 (“Once approved, the [w]aiver application becomes the controlling document”). Georgia’s ICWP waiver authorizes the provision of specified services, including enhanced case management, personal support services, emergency response systems, behavioral support, counseling, specialized medical equipment, and vehicle adaptation. Waiver (Exhibit R-1) at 43-112. In addition, Georgia requested and received CMS approval to provide skilled nursing on an episodic basis, under the catch-all provision of 42 C.F.R. § 440.180(b)(9). Id. at 103. In contrast to GAPP, however, the ICWP waiver does not authorize participants to receive continuous skilled nursing services. Id. at 43-112.

11.

Through proxy caregiving, the personal support services offered under the waiver may include health maintenance activities that would otherwise require skilled personnel. Georgia law expressly allows an individual in need of services to select an unlicensed person as a proxy caregiver, “provided that such person shall receive training and shall demonstrate the necessary knowledge and skills to perform documented health maintenance activities, including identified specialized procedures, for such individual.” O.C.G.A. § 43-26-12(9)(A), (C). The proxy caregiver may perform “[h]ealth maintenance activities . . . that, but for a disability, a person could reasonably be expected to do for himself or herself.” O.C.G.A. § 43-26-12(9)(C)(ii). However, health maintenance activities “do not include complex care . . . ; do not require

complex observations or critical decisions;¹⁰ can be safely performed and have reasonably precise, unchanging directions; and have outcomes or results that are reasonably predictable.” O.C.G.A. § 43-26-12(9)(C)(ii). Proxy care must be provided under the orders of a physician, advanced practice registered nurse, or physician’s assistant, and training is essential. O.C.G.A. § 43-26-12(9)(A), (C).

2. Plan of Care and Budget

12.

To provide waiver services, a state uses “an independent assessment . . . to establish a written individualized care plan.” 42 U.S.C. § §1396n(i)(G). The plan specifies the HCB services that will be furnished and may allow the individual to self-direct care, as Georgia has done through its consumer-directed option. 42 U.S.C. §1396n(i)(G), (j); Waiver (Exhibit R-1) at 141-154. Self-direction allows the individual to “choose to use any individual capable of providing the assigned tasks” as an aide. 42 U.S.C. § 1396n(j)(4)(B)(i), (k)(1)(A)(iv)(III) (services must be provided by qualified individuals). Such a plan must include “appropriate risk management techniques that recognize the roles and sharing of responsibilities in obtaining services in a self-directed manner.” 42 U.S.C. §1396n(i)(G)(iii)(III)(ee). Relatedly, the state must ensure that the health, welfare, and financial accountability of participants are safeguarded and that there are “mechanisms . . . to ensure continuity of services and supports.” 42 U.S.C. 1396n(j)(2)(A), (k)(1)(B)(ii).

¹⁰ At the hearing, the Petitioner presented testimony suggesting that his condition requires his caregivers to make complex observations and critical decisions. This Court makes no findings on this issue, in light of Dr. Logan’s testimony and the parties’ agreement that the Petitioner is medically stable and eligible for ICWP. Further, because no proxy caregivers have been identified and no training has taken place, it is as yet unclear whether the Petitioner’s medical needs can be met through proxy caregiving. However, it must be noted that if the Petitioner’s caregivers are, in fact, required to make complex observations and critical decisions, use of a proxy caregiver in place of a skilled nurse is likely not authorized under O.C.G.A. § 43-26-12(9). In that event, the Petitioner may become ineligible for ICWP, as continuous skilled nursing is not available through ICWP.

13.

A self-directed plan may also “include an individualized budget which identifies the dollar value of the services and supports under the control and direction of the individual.” 42 U.S.C. §1396n(i)(G)(iii)(III)(ff), (j)(4)(A) (under the “self-directed personal assistance services” option, an individual exercises some control over aides “within an approved self-directed services plan and budget”), (j)(5)(D) (state creates budget based on assessment and plan). The “method for calculating the dollar values in such budgets” is set out in the waiver. 42 U.S.C. § 1396n(i)(G)(iii)(IV).

14.

Thus, the Department creates budgets for consumer-directed ICWP participants, like the Petitioner, based on their plans of care and the rates for individual services that have been established in the waiver. Waiver (Exhibit R-1) at 190-203; ICWP Manual, Appx. O (Exhibit P-37). The waiver explains further, as follows:

The contract agency uses the same criteria for determining a consumer-directed plan of care as it does the traditional model. The individual must be assessed by the contract agency us[ing] the same assessment and level of care determination tools. As the member and/or representative develop the plan of care, consumer-directed care options are presented. Based on the individual needs the contract agency and the member will determine how many personal support hours are needed and the cost to provide the services in a safe plan. Members [] use this plan of care and the budget developed through assessment to determine the hours of personal support service available. The member is able to negotiate hourly rates after deducting payroll taxes and expenses and begin interviewing and hiring staff.

Waiver (Exhibit R-1) at 153 (emphasis added). Contrary to the Petitioner’s argument, then, the Department is not authorized to establish a budget that exceeds the cost of the services identified in the plan of care.

15.

While the budget is calculated based on the participant's individual needs, he or she may still "exercise[] choice and control over the budget." 42 U.S.C. § 1396n(j)(5)(A), (D). Accordingly, under the waiver, the participant can negotiate hourly rates with his or her provider, so long as he or she remains within the parameters of the approved budget. Under the waiver, participants are "responsible for setting the rates for paying their employees within the established approved budget." Waiver (Exhibit R-1) at 148. The Waiver further provides that the consumer may "[d]etermine staff wages and benefits subject to State limits" and "[d]etermine the amount paid for services within the State's established limits." Id. at 151-52.

16.

Finally, the participant may request adjustments to the budget through his or her case manager. Id. at 153. Georgia has opted to require that "[m]odifications to the participant directed budget . . . be preceded by a change in the service plan." Id. at 153-54. The Department provides safeguards, including monitoring by a case manager and financial support provider, to ensure that self-directed participants remain within budget. Id. at 154. Participants in the self-directed option may negotiate hourly rates with caregivers. This allows participants to pay a higher rate if they can arrange to receive more care through informal (e.g., familial) supports.

C. The Petitioner's ICWP Plan of Care and Budget

17.

In this case, the Court must determine: (1) whether the Department established an appropriate budget for the Petitioner; (2) whether he has the right to negotiate the hourly rates paid to personal support aides; and (3) whether he is entitled to a ninety-day transition period from GAPP to ICWP. In resolving these questions, the Court recognizes that the State has

flexibility to establish the parameters of its waiver programs, subject to CMS approval. A comparison of GAPP versus ICWP demonstrates that the state has made a policy decision to provide medically fragile children with more protective, expensive, and rigorous services than it has chosen to provide for similarly-situated adults. This it may do. 42 U.S.C. § 1396n. Thus, the services that the Petitioner currently receives under GAPP do not dictate the services he is entitled to receive under ICWP.

18.

The Petitioner has requested that his budget be set at \$108,605.00, the waiver's ceiling for participants who require a hospital level of care. However, this budget amount is not warranted. Consistent with the current service plan, the Court finds that the Petitioner should receive 12 hours of personal support services per day at the rate of \$14.07 per hour.¹¹ While the Petitioner contends that he is unable to hire a competent caregiver at this rate, his argument is premised on the erroneous assumption that his caregiver must be trained prior to hiring. Contrary to this assumption and as explained above, ICWP allows him to hire virtually anyone whom he trusts and ensure that they receive the same rigorous training as did his parents. The Court expects that this method of hiring, then training, his caregivers will permit him to find aides willing to work at the designated rate. Alternatively, the Petitioner may choose to reduce the number of hours his aides work and use the extra funds to pay them a higher hourly rate.

19.

It is undisputed that due to the Petitioner's extensive needs and the potentially devastating consequences of substandard care, he must have competent caregivers with the skills, training, and reliability to meet his needs. It is further undisputed that the training provided to

¹¹ The Petitioner does not contest the number of hours allocated under his care plan.

unlicensed caregivers is less extensive than the training completed by licensed, skilled nurses. Therefore, the Court concludes that the Petitioner's plan of care understates his need for skilled nursing visits. The Petitioner is entitled to one nurse visit per day, the maximum allowed under ICWP, rather than the four-times weekly visits stated in his existing plan of care.

20.

In accordance with the foregoing findings, the Petitioner's plan of care is amended to authorize the following services:

- enhanced case management services, at \$461.00 per month, for an annual budget of \$5,532.00;
- twelve hours per day of level III personal support services, at \$14.07 per hour, for an annual budget of \$61,626.60;
- one visit per day by a registered nurse, at \$49.79 per visit, for an annual budget of \$18,173.35;¹² and
- medical supplies totaling \$1350.84 per year.

The total budget for the Petitioner's amended plan of care is \$86,682.79.¹³

21.

The Court further finds that the Department bears the responsibility for training the Petitioner's proxy caregivers, once they have been selected. At the hearing, neither party identified a proposed caregiver training program for trach- and vent-dependent patients outside the hospital setting. Although hospital-based programs exist, the evidence was unclear whether

¹² The fifty visits paid under the state Medicaid plan have been included in this amount.

¹³ So long as the cost of the Petitioner's waived services does not exceed \$108,605.00 per year, the state will remain in compliance with its 1915(c) Medicaid waiver program requirements. Waiver (Exhibit R-1) at 189. The Petitioner and the Department debate whether this budget ceiling includes the cost of all Medicaid services, including non-waived services. This question is not necessary to determine in light of this Court's conclusion that the Petitioner's amended budget, which is based on his care plan and the state-established hourly rates for particular services, does not exceed the budget ceiling.

such programs currently offer training on behalf of non-hospitalized patients. Accordingly, the Court concludes that the training provided to the Petitioner's proxy caregivers shall be equivalent to the training provided in a hospital-based program such as the program completed by the Petitioner's parents. If the Department elects to arrange training outside the hospital setting, the training program shall be approved by Dr. Logan or, in the event Dr. Logan is unavailable, another physician with similar education and expertise in the care of trach- and vent-dependent patients.

22.

The Petitioner seeks a court-ordered ninety-day transition period from GAPP to ICWP, to allow him to identify and train proxy caregivers before his GAPP skilled nursing ends. The Petitioner's proposal is reasonable and appropriate, in light of the Petitioner's previous difficulty identifying potential caregivers and the critical need to train such caregivers before they assume responsibility for his care.

IV. DECISION

In accordance with the foregoing Findings of Facts and Conclusions of Law, the Department's determination is hereby **AFFIRMED IN PART**, and the Court further **ORDERS** as follows:

- (1) the Petitioner's annual ICWP budget shall be \$86,682.79, as itemized above;
- (2) the Petitioner may negotiate hourly pay rates with his caregivers under ICWP's self-directed option, so long as he remains within his overall budget; and

- (3) the Petitioner shall be afforded ninety days to transition from GAPP to ICWP, beginning ten days from the entry of this decision, during which time the Department shall provide appropriate training to the proxy caregivers identified by the Petitioner.

SO ORDERED, this _____ day of August, 2013.

KRISTIN L. MILLER
Administrative Law Judge