BEFORE THE ALASKA OFFICE OF ADMINISTRATIVE HEARINGS ON REFERRAL BY THE COMMISSIONER OF HEALTH AND SOCIAL SERVICES

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In the Matter of:

ВC

OAH No. 15-0226-MDS Agency No.

DECISION

I. Introduction

B C is a disabled 10-year-old boy who qualifies for Medicaid services under the Children with Complex Medical Conditions program. He receives Medicaid-authorized services 24 hours a day from his family habilitation services provider, E X, who is his foster mother and primary caregiver. He also receives services from a Personal Care Assistant (PCA) to physically assist him with various activities of daily living (ADLs) and other activities covered by Medicaid.

On October 22, 2014, the Division of Senior and Disabilities Services (Division) reassessed B's eligibility for PCA services. It notified him on February 10, 2015 that his PCA services would be terminated because they are duplicative of services provided by his family habilitation provider. The Division also asserted that minors are not eligible for certain PCA services, because those services are a parental responsibility.

Through his legal guardian, N X, B requested a hearing. The hearing was held on July 30, 2015. B was represented by his legal guardian. Testifying on B's behalf were N X, E X, and care Coordinator K J. No Name Services case manager L E also participated on B's behalf. Victoria Cobo represented the Division. Geetha Samuel, R.N., Laura Baldwin, and Olga Ipatova testified for the Division.

The Division has not met its burden to show a material change in B's condition which justifies eliminating PCA assistance. In addition, because B is in foster care, the PCA services do not duplicate services that are parental responsibilities. Therefore, its decision is reversed.

II. Background Facts¹

B C is a 10-year-old boy who is 49 inches tall and weighs roughly 50 pounds. He lives in a licensed foster home with E X. His legal guardian, N X, is E X's son, and he lives next door. The two homes are connected; they share a kitchen and living area.

¹ These facts are based upon Division Ex. D (PCA denial letter), Div. Ex. E and F (2014 and 2013 assessments), Claimant Ex. 1 (SDS Waiver Plan of Care Amendment, eff. date August 29, 2014, signed by all parties in 2014); Cl. Ex. 2 (SDS Waiver Proposed Plan of Care Amendment (signed by B's care providers in July 2015, not signed by Division); Cl. Ex. 3 (E X, letter dated July 16, 2015 and daily care logs); Cl. Ex. 4 (Dr. S M, M.D., letter dated July 28, 2015); Cl. Ex. 5 (Dr. T P, M.D., letter dated July 21, 2015); and Cl. Ex. 6 (physical therapy records; Dr. L V, D.P.T., letter dated April 7, 2015; Dr. B Y, M.D. undated letter; and sample daily care logs), and the testimonies of N X, E X, K J, Geetha Samuel, R.N., Laura Baldwin and Olga Ipatova.

B experiences profound developmental delays due to a birth defect of the brain known as dysgenesis (malformation) of the corpus callosum, and he requires 24-hour care. He is unable to function at an appropriate age level and does not follow directions or instructions. He also has a cleft lip and palate. Other diagnoses include Diabetes Insipidus, hypothyroidism, cortical visual impairment, and unspecified developmental delay.

B speaks only two words; he communicates primarily using squeals, screeches, and grunts. He is working to use a communication system in which he shows choices by grabbing at pictures. He primarily moves around using a maneuver his care providers call "frog hopping," "bunny hopping," or "crunning," in which he crawls and leaps forward at a fast pace.² He can use a walker if he has complete assistance. He also "walks" if a care provider holds him up under his arms and manually moves his legs.³ He does not have the strength and coordination to transfer between surfaces, so he is picked up and carried for this activity.

B makes spastic or ballistic movements of his arms and legs that he cannot control and which can interfere with his care. In addition, he is often uncooperative with his care givers when they are assisting with his daily care needs, and he may thrash or otherwise resist care. He has a number of aversions to physical contact, which also complicate his care. For instance, he does not tolerate having his feet touched.⁴ In addition, he has oral aversions and dislikes having his head touched. This means that tasks like eating, bathing, and personal hygiene take much longer than they normally would.⁵

B also interferes with his care out of playfulness. For example, he pulls hair and grabs glasses, and he grabs his diaper, including whatever may be in it. B's regular playfulness, ballistic movement or resistance to care mean that two people are typically required for diaper changes. One person is needed to hold B's hands and stop him from interfering, while the other person changes the diaper. If someone does not restrain B's hands, he grabs at himself or his dirty diapers and then puts his hands into his mouth or elsewhere.⁶

B cannot distinguish between play and injury-causing events, so he requires constant monitoring to ensure he does not harm himself or others while playing. For example, he enjoys

² *See* Cl. Ex. 3; Div. Ex. E at 7.

³ Div. Ex. E at 7; Div. Ex. F at 7.

⁴ *See* Cl. Ex. 6 at 4.

⁵ *See* Cl. Ex. 1 at 9.

⁶ Cl. Ex. 3; testimony of E X; testimony of N X.

chasing other children by frog-hopping, but he when he catches them, he knocks them over and bites or scratches them.

B is fed four times a day through a gastronomy tube (g-tube) and feeding pump, though he also is fed soft foods orally. Each g-tube feeding requires 45 to 60 minutes. He must be monitored closely during feedings to ensure he does not aspirate his food. His Diabetes Insipidus also requires careful monitoring of his sodium levels.

B is incontinent of bowel and bladder, and he wears diapers that must be changed four to six times per day. Diaper changes require undressing him, because B frequently wears overalls to prevent him from pulling out his g-tube.⁷

At night, B wakes up around midnight every night and often cannot get back to sleep. When this happens, he thrashes around in bed and may kink or pull out his feeding tube, which sounds an alarm. His caregivers must turn off the pump before it pumps food into the bed, then change B's clothes, clean him up and fix the pump or feeding tube. It sometimes takes hours to help B relax back into sleep.

B was assessed on October 22, 2014 by nurse-assessor Geetha Samuel to determine his eligibility for the PCA program. Ms. Samuel's conclusions were essentially identical to those from B's prior assessment in 2013, and B was scored as functionally eligible for PCA services.⁸

The Division terminated B's PCA services, however, because it determined that his needs were already being met by his family habilitation services. The PCA services at issue involve assistance with transfers, locomotion, dressing, eating, toilet use, personal hygiene, bathing, medication and escort.⁹ The Division also contended that, as a minor, B is not eligible to receive PCA services for the activities of eating, medication and escort since these are a parental responsibility.¹⁰ The Division argues that B does not require assistance from two people for the activities in question, so PCA services are duplicative of care already provided by E X or by the day habilitation or respite services that are authorized in B's Waiver Plan of Care.

III. Discussion

The Medicaid program authorizes PCA services for the purpose of providing "physical assistance with activities of daily living (ADL), physical assistance with instrumental activities

⁷ Div. Ex. E at 8.

⁸ Div. Ex. E at 20, 28; Ex. F at 20, 28.

⁹ Div. Ex. D.

¹⁰ Div. Ex. D at 2-5.

of daily living (IADL), and other services based on the physical condition of the recipient."¹¹ PCA services are provided only in a recipient's personal residence or to a Medicaid Waiver recipient who receives residential habilitation services provided in a foster home.¹² However, PCA services are not provided if they duplicate services that are already provided to a Medicaid Waiver recipient as part of that person's Waiver Services Plan of Care (POC).¹³

The Division is seeking to terminate B's PCA services for two independent reasons. The first is that, as a minor, B is not eligible to receive PCA services for activities to provide necessary food, clothing, shelter or medical attention, since these are a parental responsibility. This position does not apply to this situation, however, since B resides in foster care and not in his parents' or guardian's home.¹⁴

The Division's second argument is that PCA services are duplicative of the family habilitation services that are already paid for and provided to B under his Medicaid Waiver Plan of Care.

The Division bears the burden of proof because it is seeking to terminate services that B has been receiving since at least 2009. It must show that B has had a "material change of condition."¹⁵ The Division can meet this burden using any evidence on which reasonable people might rely in the conduct of serious affairs,¹⁶ including sources such as written reports of firsthand evaluations of the patient.

The Division's argument is a major change in its position. B has been receiving PCA assistance, despite living in foster care, for many years. The Division has not pointed to any specific recent regulation changes to support its position that PCA assistance is no longer available to him.¹⁷ Given that there has been no substantive regulation change, the Division's termination of B's PCA benefits must be supported by a material change in his condition. However, the facts of this case do not show any change in his condition.

¹⁶ 2 AAC 64.290(a)(1).

¹¹ 7 AAC 125.010(a).

¹² 7 AAC 125.050 (a), (b)(3).

 $^{^{13}}$ 7 AAC 125.040(a)(12).

¹⁴ It also should be noted that PCA services do not provide food, clothing, shelter, or medical attention. They provide hands-on physical care.

¹⁵ 7 AAC 125.026(a). This is a term of art that encompasses not only changes in the recipient's situation, but also changes in regulations affecting the authorized level of services. *See* 7 AAC 125.026(d).

¹⁷ The regulation cited in the Division's benefit termination letter is 7 AAC 125.040(a)(11), which has remained virtually the same since 2010. There was a slight change, effective November 3, 2012 (Register 204), that made a minor wording revision. This revision did not require PCA termination in this case.

The record includes B's assessments from September 24, 2013 and October 22, 2014.¹⁸ Both assessments code B as being dependent in his activities of transfers, locomotion, dressing, eating, toileting, personal hygiene, and bathing.¹⁹ Both assessments code B as requiring oneperson assistance for the ADLs at issue in this case. Following the 2013 assessment, however, the Division continued to provide B with two-person assistance, as it had for many years prior to that.²⁰ On virtually identical assessment findings in 2014, the Division has terminated PCA services. The Division must explain why such similar findings justify such disparate treatment, and it must show that one-person assistance adequately meets B's needs.

The Division points to a lack of information documenting the need for two-person care. It also relies on the fact that B weighs only 50 pounds which, it argues, means he is small enough for one person to manage. It contends that two-person assistance is authorized only in cases involving quadriplegia or obesity, or, at a minimum, in cases which involve people who weigh substantially more than B.

The evidence about B's care needs, however, amply supports his need for two-person physical assistance, *i.e.*, a PCA assisting the foster care provider. E X has been B's primary caregiver since he was eight months old.²¹ She is most experienced with his day-to-day care needs. Ms. X provided sample daily care logs, wrote and credibly testified that B requires two-person assistance for his care needs, including toileting, walking, transfers, eating, bathing, personal hygiene and administration of medicine/injections. This is because of his spastic movements, his lack of understanding, and his inability to cooperate with his care needs.²² The daily care logs document that B currently receives two-person assistance with these activities.²³

Both E and N X testified that continued two-person assistance is necessary to ensure B's safety and well-being, as well as the safety of his caregivers. They note that B's assistance needs are growing rather than decreasing as he gets bigger and stronger. B's Plan of Care, which the Division signed in December 2014, also documents B's increasing aggression as he gets older.²⁴

¹⁸ Div. Ex. E, F.

¹⁹ Div. Ex. E at 20; Ex. F at 20.

²⁰ Testimonies of E X, N X, and Olga Ipatova; Cl. Exs. 2-6.

²¹ Testimony of E X.

²² Testimony of E X; Cl. Ex. 3 (E X letter and care logs); Cl. Ex. 6 at 9-12 (care logs).

²³ See Cl. Ex. 6 at 9-12 (two-person assist for transfers, walking, toileting, bathing, personal hygiene, and eating); Cl. Ex. 3 (two people for feeding, toileting, medications, injections, dressing, personal hygiene, transfers, bathing, walking). The logs also show that B sometimes receives one-person assistance for eating, walking, medications, and transfers.

²⁴ Cl. Ex. 1 at 8 (POC at 3: "Aggression is worse because he is getting stronger and bigger, not because he is being mean.").

The October 2014 assessment additionally documents safety concerns related to B's eating ADL.²⁵ It shows that B requires aspiration precautions and monitoring while he eats, and he has problems chewing or swallowing, which may justify PCA assistance for feedings.

The record includes letters from four of B's medical providers: three doctors and his physical therapist. Each of the medical providers offers an opinion corroborating B's need for continued assistance at the level he currently receives.²⁶ B's pediatric endocrinologist specifically advised that two people are required to safely provide B's activities of daily living, including bathing, transfers, diaper changes, physical therapy, and other needs. She recommends that B continue to have PCA assistance in addition to care from his primary caregiver.²⁷

Two of B's primary care doctors advised that PCA assistance is medically necessary for his activities of daily living, including feeding, bathing, dressing, skin care, toiletry, walking, transportation, meals, movement, and other activities.²⁸ They also wrote that PCA assistance is imperative to maintain his development and to prevent injuries. In the context of the issue in this case, these opinions are appropriately interpreted to support continuing B's present level of care, including two-person assistance.

B's physical therapist wrote that "[d]aily passive motion and stretching along with functional exercise is required to maintain range of motion and strength."²⁹ She indicates that B currently receives daily PCA services for massage, passive joint mobility and stretching for his upper and lower body. This is provided in two daily sessions of approximately one hour each. In addition to massage and stretching, B's PCA works with him on functional mobility. This requires assistance for all mobility and transfer tasks, since B is at high risk for falls if he is unassisted.³⁰

The physical therapy documents do not specify that two-person assistance is required; nor do they indicate that one-person assistance is adequate. The tone of the letter and accompanying medical records, however, supports the proposition that B's existing level of assistance should be maintained. Ms. Baldwin testified that she had spoken with B's physical therapist, who indicated that B is making progress and that one-person assistance is adequate for transfers and

²⁵ Div. Ex. E at 9, 25.

²⁶ There is no evidence that B's medical condition or assistance needs have significantly changed over time, and the medical providers' letters are viewed as describing B's needs at the time of the assessment as well as at the time the letters were written.

²⁷ Cl. Ex. 4 (Dr. S M, M.D., letter dated July 28, 2015).

²⁸ See Cl. Ex. 5 (Dr. T P, M.D., letter dated July 21, 2015); Cl. Ex. 6 at 8 (Dr. B Y, M.D., undated letter).

²⁹ Cl. Ex. 6 at 7 (Dr. L V, D.P.T., letter dated April 7, 2015).

³⁰ *Id.*; *see also* Cl. Ex. 6 at 2-6 (physical therapy records dated October 20, 2014).

locomotion using assistive devices during his physical therapy sessions. Ms. Baldwin further testified that she had written up a summary of her discussion with the physical therapist and that it had been sent to the therapist for her review and approval. The record was left open for the Division to submit that summary into evidence, but it did not do so.

The record supports the conclusion that B has PCA care needs that are not met by his Medicaid Waiver services. Although he is young and weighs relatively little, there is substantial evidence that his thrashing, uncontrolled spastic movements, and even his misguided playfulness, make it very difficult for one person to safely manage his many care needs. His aspiration risk also presents particular challenges for one-person care. The record supports B's need to continue receiving the same level of assistance that has been provided in past years.

IV. Conclusion

The Division has not adequately explained how B's assistance needs have changed, such that he no longer requires two-person assistance for his ADLs and other covered activities. B has received two-person assistance from a PCA and his family habilitation services provider for many years. The record does not show that his physical care needs decreased between 2013 and 2014. Consequently, the Division did not meet its burden to show that one-person care adequately meets B's needs. The termination of PCA services is reversed.

DATED this 31st day of August, 2015.

Signed

Kathryn A. Swiderski Administrative Law Judge

Adoption

The undersigned, by delegation from of the Commissioner of Health and Social Services, adopts this Decision, under the authority of AS 44.64.060(e)(1), as the final administrative determination in this matter.

Judicial review of this decision may be obtained by filing an appeal in the Alaska Superior Court in accordance with Alaska R. App. P. 602(a)(2) within 30 days after the date of this decision.

DATED this 13th day of October, 2015.

By:

Signed

Name: Deborah L. Erickson Title: Project Coordinator Agency: Office of the Commissioner, DHSS

[This document has been modified to conform to the technical standards for publication.]