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

In the Matter of:	)	
	)	
F D	)	OAH No. 15-0540-MDS
	)	Agency Case No.

DECISION

I. Introduction

The issue in this case is whether F D (age nine) is entitled to an additional 4,032 units of Residential Habilitation services (in-home supportive services) during the period from February 23, 2015 through July 19, 2015.[1] The Division of Senior and Disabilities Services (DSDS or Division) denied F's request to add these additional services, which request had been submitted in the context of a Plan of Care (POC) amendment request.

The Division denied the services at issue on two bases. First, the Division asserted that F had not demonstrated that he had already made use of resources available from sources other than the Medicaid Home and Community-Based Waiver Services program.[2] Second, the Division asserted that F's health has improved, and that the level of waiver services already approved for F, in conjunction with F's other supports, are sufficient to meet his needs, allow him to remain in his community, and avoid placing him in an institution.[3]

This decision concludes that the Division's determination was correct based on the information available to the Division *at that time*. However, additional information was obtained, through the hearing process, that was not previously available to the Division. This new information demonstrates, by a preponderance of the evidence, (1) that F's mother and care coordinator made reasonable efforts to seek and utilize third party / non-waiver services, but that such services are not available in F's community; and (2) that, because of his declining condition, F's existing level of support is insufficient, and F is at risk of being institutionalized if he does not receive the services requested. Accordingly, the Division's denial of that portion of F's proposed Plan of Care amendment, which requested an additional 4,032 units of Residential Habilitation (in-home support) services, for the period from February 3, 2015 through July 19, 2015, is reversed.

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[1] All findings in this paragraph are based on Ex. D.
[2] Ex. D3.
[3] Ex. D2.

II. Facts[4]

A. F's Medical Condition, Behavioral Problems, and Care Needs

F is nine years old.[5] He has been diagnosed with advanced Infantile Neuronal Ceroid Lipofuscinosis (hereafter "INCL"), sometimes called Batten's Disease.[6] INCL is a rare genetic disorder of the nerve cells which causes visual impairment,[7] abnormally increased muscle tone, lack of muscle control, intellectual disability, dementia, and seizures. The disorder is progressive, degenerative, and fatal. The life expectancy of a child with INCS is only nine to eleven years. F is now almost ten. An October 2014 letter from F's geneticist, Dr. J, M.D., indicates that F is currently in a plateau state of his disease, but that soon the disease will begin to affect his cardiorespiratory control.

F is a quadriplegic and weighs about 75 pounds.[8] Due to the severity of his condition and his poor prognosis, F needs around-the-clock care to ensure his health, safety, and well-being.[9] He does not have any muscle control and must be repositioned frequently in order to maintain skin integrity. He is dependent on his caregivers for every aspect of his life. He is also dependent on certain medical equipment, including a car seat, wheelchair, bath chair, Posey bed, two saliva suctioning machines, and a cough-assist machine to help him clear his throat / lungs.

F is virtually completely incapacitated.[10] He has cortical blindness, so he cannot see. He cannot speak, so he is unable to communicate what he wants or how he feels. If asked a question he may make faint sounds and/or smile, but otherwise he cannot respond. He has no control over his arms and legs. To be moved he must be lifted from his specialized bed and placed in his wheelchair. He is fed a liquid formula that is pumped through a foot long tube into his intestines. He must be fed continuously from 6:00 a.m. until 10:00 p.m.

F was hospitalized five times between February 2014 and May 2014 due to viral infections and aspiration pneumonia.[11] In February 2014 F had to be flown to Anchorage on an emergency basis because his condition was so severe that he could not be treated in No Name. In March 2014

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[4] To avoid duplication, discussion of some facts, specifically relevant to the legal issues raised, has been deferred until the discussion of those issues in Section III, below.

[5] Ex. 1 p. 1.

[6] All factual findings in this paragraph are based on Ex. 2 p. 7 unless otherwise stated.

[7] F was diagnosed with cortical blindness in 2011 (Ex. 3. P. 9).

[8] Ex. 4 p. 2.

[9] All factual findings in this paragraph are based on Ex. 2 p. 7 unless otherwise stated.

[10] All factual findings in this paragraph are based on Ex. 7 unless otherwise stated.

[11] All factual findings in this paragraph are based on Ex. 2 p. 7 unless otherwise stated.

F's feeding tube was replaced with a different type to reduce his frequency of aspiration. However, even with the new tube, F became ill and had to be hospitalized.

Due to his frequent hospitalizations, and on the recommendation of F's primary physician, F's mother decided to homeschool her son for the 2014-2015 school year in order to avoid exposing him to illnesses from other children at school.[12] This strategy appears to have been successful, in that F has gained 15 pounds and has not been hospitalized since May 2014.

Under F's individual education plan (IEP), F currently receives in-home education services from his local school district.[13] The school district has assigned a case manager for F, who visits each month and ensures that F's IEP is being followed. F's physical therapist visits monthly to assess F and to educate his caretakers / service providers on appropriate exercises. An occupational therapist visits F on a quarterly basis to assess and monitor his progress. F also undergoes sacral-cranial massage every other week.[14]

F lives with his mother, who is his primary caregiver.[15] His mother works 10 hours per day Monday through Thursday, with a 30-minute commute to and from work. F's mother also works at a second, part time job for four hours each Friday. Because F has sleep problems, his mother must attend to him as needed throughout the night, then work 10 hours per day at her job, and then come home and care for F for the rest of the evening and overnight. F's four page care log for April 10 - 12, 2015 shows that F's mother is extremely busy caring for F; during one day, F required assistance, on average, once every 20 minutes.[16]

During the course of F's 2013 - 2014 POC year, tests were performed which showed that F's brain had shrunk.[17] Since that time F has started having numerous grand mal seizures,[18] and has had an increase in involuntary body twitching.

On April 23, 2015 one of F's doctors, Dr. C, M.D., wrote a letter describing F's current condition; the letter states in relevant part as follows:[19]

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[12] All factual findings in this paragraph are based on Ex. 2 p. 7 unless otherwise stated.

[13] All factual findings in this paragraph are based on Ex. 2 p. 7 unless otherwise stated.

[14] Ex. 3 p. 9.

[15] All factual findings in this paragraph are based on Ex. 2, pp. 8 and 10 unless otherwise stated.

[16] Ex. 4. Because this average includes night-time hours, F's daytime frequency of assistance is actually much higher. In addition, F's mother also has one other child to care for.

[17] All factual findings in this paragraph are based on Ex. 3, p. 9 unless otherwise stated.

[18] F has had grand mal seizures lasting nearly two minutes (Ex. 7 p. 1). He also has petit mal seizures lasting about 20 seconds (Ex. 7 p. 1). He has had up to eight such seizures in a two hour period (Ex. 7 p. 1). Following these seizures F often coughs / spits up saliva, which then needs to be suctioned from his lungs so it does not get into his lungs (Ex. 7 p. 1).

[19] Ex. 5 p. 1 (original formatting of letter modified for brevity).

> [F's] disease has progressed to the point where he is no longer able to be cared for in a school setting . . . . F's medical state is so fragile that a typical childhood illness . . . could be life threatening to [him] at this point . . . . At home F has constant medical needs that cannot be provided by a single person. He requires 24 hour per day care . . . . He requires oral pharyngeal suctioning with a machine multiple times per hour in order to maintain secretion control and his airway. He requires seizure and myoclonus monitoring and care. He requires frequent repositioning to maintain his skin integrity and prevent skin sores. He is incontinent of both urine and stool and requires diaper changing and care. He is fed only with a tube that is hooked up continuously and requires care for feeds and mixing of specific feeds. He requires 3 times daily medication administration. He requires positioning, range of motion and skin care . . . . His continuous care needs are more than one person can provide in a 24 hour a day manner . . . . His only other options for care would be institutionalization or hospitalization.

An amendment to F's IEP dated August 22, 2014, titled "Evaluation Summary and Eligibility Report," indicates that, due to the progression of F's disease, he is no longer able to obtain much benefit from the school he previously attended; the report states in relevant part:[20]

> Cognitive: Due to the severity of F's seizure disorder and related health impairments this area was not assessed at this time.
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> Behavioral, Social, and Emotional: Due to the severity of F's seizure disorder and related health impairments this area was not assessed at this time.
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> Educational: Due to the severity of F's seizure disorder and related health impairments this area was not assessed at this time.
> . . . .
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> Hearing: Due to his limited communication abilities and the frequency of his seizures, a screening . . . was unable to be completed.
>
> Gross Motor: Standardized testing could not be completed due to the severity of F's seizure disorder and related health impairments.
>
> Fine Motor: Standardized evaluation was not completed due to the severity of F's seizure disorder and related health impairments.
> . . . .
>
> Developmental / Medical History: . . . Due to the intensity and frequency of his illness and other related health issues he has regressed . . . .
>
> Pre-academic School Readiness: Due to the severity of F's seizure disorder and related health impairments this area was not assessed at this time.

[20] All factual findings in this paragraph are based on Ex. 6, pp. 3 - 9 unless otherwise stated.

F's mother and care coordinator made inquiries to various business and/or organizations in No Name who might be able to provide services to substitute for the in-home supportive services at issue in this case.[21] One agency responded that "[w]e do not provide any PCA care for consumers under the age of 18."[22] A local hospital, which provides some home health care services, responded that "[w]e do not provide PCA services, nor do we provide pediatric care."[23]

At hearing, F's mother, Ms. D, an adjunct professor with No Name, credibly testified in relevant part as follows:

1. She and her son's care coordinator have explored other potential substitutes for the in-home supportive services requested in this case. Unfortunately, to the best of her knowledge, no viable options are available in the No Name area.
2. Her son's physician has told her that, without the waiver services requested, her son's only other care options would be hospitalization or institutionalization.

B. Relevant Procedural History

F has received Medicaid Home and Community-Based Waiver Services ("waiver services") since 2013 or before.[24] As of October 9, 2014 F was authorized to receive 2,080 units of hourly respite services (520 hours over 52 weeks), 14 units of daily respite services (14 days over 52 weeks), 169 units of nursing oversight and care management services (0.8 hours per week for 52 weeks), and 5,392 units of residential habilitation services - in-home support (20 hours per week for 41 weeks, and another 48 hours per week for 11 weeks).[25]

On March 3, 2015 F submitted a POC amendment request for the period from February 23, 2015 through July 19, 2015.[26] The Plan of Care amendment sought 2,080 units of hourly respite services, 14 units of daily respite services, 312 units of nursing oversight and care management services, and 9,424 units of residential habilitation services - in home support.[27]

On April 7, 2015 the Division approved F's POC amendment request as to 10 hours per week of hourly respite services, 14 days of daily respite services, 312 units of nursing oversight and care management services, and 4,160 units of residential habilitation services - in-home support, but

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[21] Ms. D's hearing testimony; J N's hearing testimony.
[22] Ex. 8.
[23] Ex. 9.
[24] Ex. F.
[25] Exs. F1 - F2.
[26] Exs. E2 - E14.
[27] Exs. D, E. The Division had previously approved 5,392 units of day habilitation services - in home support; F requested an additional 4,032 units of day habilitation services - in home support.

denied that portion of the POC amendment request seeking an additional 4,032 units of residential habilitation services - in-home support.[28]

On May 1, 2015 F's mother, Ms. D, requested a hearing to contest the Division's determination.[29] Ms. D's hearing request stated in relevant part as follows:[30]

> [F] had previously been enrolled in public school . . . and [therefore] required fewer hours of care . . . . He has always been granted additional hours in the summer months (48 hours per week) when school is out of session. We removed F from public school after the spring 2014 semester at the recommendation [of] his doctors . . . .
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> F has a neuro-muscular degenerative disease, which means that he will never improve medically and his health, including his immune system, will continually decline . . . . [H]is disease . . . has a life expectancy of 10-12 years. F is currently 9 years old and we are requesting additional at home support (48 hours per week, which was previously allowed in the summer months) to keep him as healthy as possible for as long as possible.

F's hearing was held on June 23, 2015. F did not participate, but was represented by his mother, Ms. D; she participated by phone and testified on her son's behalf. F's care coordinator, J N, and C T, also participated by phone and testified for F. The Division was represented by Medical Assistance Administrator Victoria Cobo, who participated by phone. Health Program Manager Barbara Rodes participated by phone and testified on behalf of the Division. The record closed at the end of the hearing.

III. Discussion

A. Medicaid Home and Community-Based Waiver Services Program - Overview

1. Relevant Federal Medicaid Statutes and Regulations

States participating in Medicaid must provide certain mandatory services under a state medical assistance plan.[31] States may also, at their option, provide certain additional services, one of which is the Home and Community-Based Waiver Services program.[32] Congress created the

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[28] Ex. D1.

[29] Ex. C.

[30] Ex. C. Because it captures and summarizes some of the testimony Ms. D presented at hearing, Ms. D's hearing request is quoted here at length. Some of the formatting in the original hearing request has been modified here for brevity.

[31] *See* 42 USC §§ 1396a(a)(10)(A); 1396d(a)(1) -(5), 1396a(a)(17), and 1396a(a)(21); *see also* 42 CFR 440.210 & 440.220.

[32] *See* 42 USC § 1396a(a)(10)(A). The program is called a "waiver" program because certain statutory Medicaid requirements are waived by the Secretary of Health and Human Services. *See* 42 USC 1396n(c).

waiver services program to allow states to offer long-term care, not otherwise available through Medicaid, to serve recipients in their own homes and communities instead of in nursing facilities.[33]

Federal regulations require that both mandatory *and* optional Medicaid services "be sufficient in amount, duration, and scope to reasonably achieve [their] purpose."[34] However, a state may "place appropriate limits on a service based on such criteria as medical necessity or on utilization control procedures."[35]

2. *Relevant State Medicaid Regulations*

The information which must be submitted in support of a POC renewal or amendment request, and the substantive standards for their approval, are specified by 7 AAC 130.217, which provides in relevant part as follows:

> (b) The department will approve a plan of care if the department determines that
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> > (1) the services specified in the plan of care are sufficient to prevent institutionalization and to maintain the recipient in the community;
> >
> > (2) each service listed on the plan of care (A) is of sufficient amount, duration, and scope to meet the needs of the recipient . . . and
> >
> > (3) if nursing oversight and care management services are to be provided, a nursing plan in accordance with 7 AAC 130.235 is included.

The specific type of waiver services at issue in this case, "Residential Habilitation Services," are defined by 7 AAC 130.265 in relevant part as follows:[36]

> (h) The department will consider residential habilitation services to be in-home support habilitation services if they are provided on a one-to-one basis to a recipient younger than 18 years of age living full-time in that recipient's private residence where an unpaid primary caregiver resides.
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> (i) The department will pay for in-home support habilitation services under (h) of this section, subject to the following limitations:

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33 *See* 42 USC 1396n(c)(1); 42 CFR §§ 435.217; 42 CFR §§441.300 - 310. Federal Medicaid regulation 42 CFR 440.180, titled "Home or Community-Based Services," provides in relevant part:

> (a) Description and requirements for services. "Home or community-based services" means services, not otherwise furnished under the State's Medicaid plan, that are furnished under a waiver granted under the provisions of Part 441, subpart G of this chapter . . . .
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> (b) Included services. Home or community-based services may include the following services . . . (1) Case management services. (2) Homemaker services. (3) Home health aide services. (4) Personal care services. (5) Adult day health services. (6) Habilitation services. (7) Respite care services. (8) Day treatment . . . (9) Other services requested by the agency and approved by CMS *as cost effective and necessary to avoid institutionalization*. [Emphasis added].

34 42 CFR 440.230(b).

35 42 CFR 440.230(d); *see also DeLuca v. Hammons*, 927 F. Supp. 132 (S.D.N.Y.1996).

36 7 AAC 130.265.

> (1) the department will not pay for more than 18 hours per day of in-home support habilitation services from all providers combined unless the department determines that the recipient is unable to benefit from (A) other home and community-based waiver services; or (B) services provided by family members or community supports;
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> (2) when in-home support habilitation services are authorized for the recipient, the department will not make separate payment for (A) personal care services under 7 AAC 125.010 - 7 AAC 125.199; (B) chore services under 7 AAC 130.245; (C) transportation services under 7 AAC 130.290; (D) meal services under 7 AAC 130.295; or (E) services provided by another resident of the home or by the primary unpaid caregiver.

The regulation requiring Medicaid recipients to seek out and utilize non-Medicaid services where available is 7 AAC 160.200. The regulation provides in relevant part as follows:

> (a) The department will pay for a service, prescription drug, or supply only to the extent it is a covered service under AS 47.07.030 and 7 AAC 105 - 7 AAC 160 and only after the recipient has made full use of any other third-party resources available to pay for that service, prescription drug, or supply . . . .
> . . . .
>
> (e) In this section, "has made full use of" means the recipient has applied for, reasonably cooperated with, and to the extent possible has maintained eligibility for, a third party that will pay for a service, prescription drug, or supply otherwise covered under AS 47.07.030 and 7 AAC 105 - 7 AAC 160.

B. Applicable Burden of Proof and Standard of Review

Pursuant to applicable state and federal regulations, F, as the party seeking additional services, bears the burden of proof in this case.[37] The standard of review in a Medicaid "Fair Hearing" proceeding, as to both the law and the facts, is *de novo* review.[38] In this case, evidence was presented at hearing that was not available to the Division's reviewers. The administrative law judge may independently weigh the evidence and reach a different conclusion than did the Division's staff, even if the original decision is factually supported and has a reasonable basis in law. Likewise, the Commissioner is not required to give deference to factual determinations or legal interpretations of his employees.

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[37] 42 CFR § 435.930, 7 AAC 49.135.

[38] *See* 42 CFR 431.244; *Albert S. v. Dept. of Health and Mental Hygiene*, 891 A.2d 402 (2006); *Maryland Dept. of Health and Mental Hygiene v. Brown*, 935 A.2d 1128 (Md. App. 2007); *In re Parker*, 969 A.2d 322 (N.H. 2009); *Murphy v. Curtis*, 930 N.E.2d 1228 (Ind. App. 2010).

C. The Bases for Denial as Framed by the Division's Notice

The bases for denial of F's plan of care amendment request are limited to those expressed in the Division's notice of April 7, 2015.[39] A fair reading of the Division's notice of adverse action reveals two asserted bases for denial of the additional in-home supportive services:[40]

1. "The amendment does not describe the alternative services to waiver supports that were researched to address F's current needs" (Ex. D3).
2. "It appears that F's health has improved since he has remained at home, and medical documentation does not indicate that he is in need of a higher level of services in order to gain or maintain skills or to remain living at home" (Ex. D2).

Each of these asserted bases for denial is addressed separately below.

D. Has F Shown that he has Satisfied 7 AAC 160.200(a) and (e)?

The Division's first basis for denying the additional residential habilitation / in-home supportive services requested by F asserts that his "amendment does not describe the alternative services to waiver supports that were researched to address F's current needs."[41] Review of F's plan of care amendment request indicates that this basis for denial was well-taken at the time F's amendment request was originally submitted.[42] However, during the hearing process, F's mother and care coordinator submitted additional information, in the form of F's Exhibits 1 - 9, and Ms. D's and Ms. N's hearing testimony. This information shows that Ms. D and her son's care coordinator explored other potential non-waiver substitutes for the in-home supportive services requested in this case, but that no viable options appear to be available in the No Name area.[43] The Division did not provide any evidence to contradict this at hearing.

In summary, the preponderance of the evidence demonstrates that the requirements of 7 AAC 160.200, (which requires Medicaid recipients to seek out and utilize non-Medicaid services where available), has now been satisfied in this case. Accordingly, although this regulation may originally have been an appropriate basis for denial, it no longer is.

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[39] *See Algonquin Gas Transmission Company v. FERC,* 948 F.2d 1305, 1312 n. 12 (D.C.Cir.1991) (an administrative determination "must stand or fall on the grounds articulated by the agency" in that determination); *In Cherokee Nation of Oklahoma v. Norton,* 389 F.3d 1074, 1078 (10th Cir. 2004*), cert. denied*, 546 U.S. 812, 126 S.Ct. 333, 163 L.Ed.2d 46 (2005), (agency action must be upheld, if at all, on the basis articulated by the agency); *American Textile Manufacturers Institute, Inc. v. Donovan*, 452 U.S. 490, 539, 101 S.Ct. 2478, 69 L.Ed.2d 185 (1981) (an agency's *post hoc* rationalizations are an insufficient basis for agency action); 2 Charles H. Koch, Jr., *Administrative Law & Practice* § 8.22 (2nd Edition 1997) ("[t]he number of cases rejecting agency efforts to justify actions after the fact shows the strength of the prohibition against post hoc rationalization"); *compare* 42 CFR 431.241(a) (only matters to be considered at a Medicaid hearing are those pertaining to the agency's action).

[40] Exs. D2, D3.

[41] Ex. D3.

[42] *See* Exs. E3 - E11.

[43] *See* factual findings at pages 2 - 5, above.

E. Has F Demonstrated That a Higher Level of Support is Necessary to Remain at Home and Avoid Institutionalization?

The Division's second and last basis for denial of the additional services at issue asserts that F's health has improved since he has remained at home, and that F's medical documentation does not indicate that he is in need of a higher level of services in order to gain or maintain skills or to remain living at home.[44] However, although it may not have been clear at the time F's amendment request was originally submitted, this is actually not the case. During the hearing process, F's mother and care coordinator submitted additional information, in the form of F's Exhibits 1 - 9, and Ms. D's and Ms. N's hearing testimony, showing that F's medical condition is progressive and terminal (*i.e.* that his condition is getting worse).[45] In addition, one of F's physicians has opined that "[h]is continuous care needs are more than one person can provide in a 24 hour a day manner" and that his "only other options for care would be institutionalization or hospitalization."[46]

The opinion of an examining physician is generally entitled to substantial weight in a Medicaid case.[47] Further, an administrative law judge may generally reject the opinion of a treating or examining physician *only* "for specific and legitimate reasons that are supported by substantial evidence in the record."[48] The opinion of a Division medical reviewer who has never examined F is not the sort of substantial evidence which could be considered sufficient to overcome the opinion of a physician who has personally examined F.

In summary, the preponderance of the evidence clearly indicates that F's medical problems *have gotten worse* under his existing level of service, and that, in fact, F's existing waiver services *are not* of sufficient amount, duration, and scope to meet F's needs. Accordingly, F's amendment request satisfies the requirements of 7 AAC 130.217(b).

IV. Conclusion

The Division's determination was correct based on the information available to the Division at that time. However, additional information was obtained, through the hearing process, that was not previously available to the Division. This new information demonstrates, by a preponderance of the evidence, (1) that F's parents and care coordinator made reasonable efforts to seek and utilize third party / non-waiver services, but that such services are not available in F's community; and (2)

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[44] Ex. D2.

[45] *See* factual findings at pages 2 - 5, above.

[46] Ex. 5 p. 1.

[47] *See Rush v. Parham*, 625 F.2d 1150, 1156 (5th Cir. 1980); *Weaver v. Reagan*, 886 F.2d 194, 200 (8th Cir. 1989); *Holman v. Ohio Dept. of Human Services*, 757 N.E.2d 382 (Ohio App. 7th Dist. 2001).

[48] *See Lester v. Chater*, 81 F.3d 821, 830 - 831 (9th Cir.1996).

that, because of his declining condition, F's existing level of support is insufficient, and F is at risk of being institutionalized if he does not receive the services requested. Accordingly, the Division's denial of that portion of F's proposed Plan of Care amendment, which requested an additional 4,032 units of Residential Habilitation (in-home support) services, for the period from February 3, 2015 through July 19, 2015, is reversed.

DATED this 14th day of July, 2015.

Signed
Jay Durych
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 29th day of July, 2015.

By: *Signed*
Name: Jay D. Durych
Title: Administrative Law Judge, DOA/OAH

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