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

In the Matter of	)	
	)	
K H	)	OAH No. 19-0015 MDS
	)	Agency No.

DECISION FOLLOWING REMAND

I. Introduction and Procedural History

K H is a youth who receives a variety of Medicaid services, including Home and Community-Based Waiver services (Waiver) and Personal Care Services (PCS). The Department of Health and Social Services, Senior and Disabilities Services Division (Division) notified K's team that some PCS hours were being reduced because the Division concluded some were duplicative of services K received through the Waiver program. K's guardian, N X challenged the Division's decision.

A telephonic hearing took place on February 4, 2019. Ms. Gagne appeared on behalf of the Division. She presented Health Program Manager, Mary Mean, and Susan Kubitz, RN as witnesses. Mr. X testified, and he presented E X, K's Family Habilitation provider and M Z, K's prior physical therapist as witnesses. The Division's Exhibits A-E, Mr. X' Exhibit 1 and three videos of K were admitted. The record closed following the hearing.

On March 4, 2019, a proposed decision was distributed to the parties. Each party had until March 18, 2019 to submit a proposal for action to the Office of Administrative Hearings (OAH). The Division submitted a proposal for action on March 13, 2019. The decision, along with the Division's proposal for action, was forwarded to the Commissioner's designee, on March 26, 2019.

Mr. X contacted OAH on April 17, 2019, inquiring about the proposal for action he faxed to OAH on March 18, 2019. Due to the inaccurate case number on the document submitted by Mr. X, and a clerical error at OAH, at the time the proposed decision was sent to Laura Russell, OAH did not know Mr. X submitted any paperwork. OAH requested a copy of the timely filed proposal for action from Mr. X and advised the Commissioner's office of the mix up. The Commissioner's designee remanded the matter to permit each party to submit literature on the definition of Allan-Herndon-Dudley Syndrome and to address any other relevant arguments raised in both proposals for action.

Following the remand order, the Division's position remains that the services are duplicative. Mr. X maintains the services are not duplicative because more than one person is needed at all times to assist with K's needs. The evidence in this case shows that while some of the proposed reductions are not redundant, some of the services are duplicative, so a reduction is reasonable. Accordingly, The Division's decision to reduce services is affirmed in part and denied in part.

II. Facts[1]

A. Background

K, now ten, was placed in the home of N and E X when he was just a baby. K became part of the X' home because his birth parents were not able to meet his high needs and placed him in foster care. N X is his guardian, and E X is his Family Habilitation provider.

K's primary diagnosis is Allan- Herndon- Dudley Syndrome.[2] Allan- Herndon- Dudley syndrome is a congenital malformation of the brain. It is a "rare disorder of brain development that causes moderate to severe intellectual disabilities and problems with movement."[3] People with this syndrome have impaired speech and a limited ability to communicate.[4] Most children with the syndrome have weak muscle tone (hypotonia). and underdevelopment of many muscles (muscle hypoplasia).[5] As they get older, they often develop joint deformities called contractures, which restrict the movement of certain joints. Abnormal muscle stiffness, muscle weakness, and involuntary movements of the arms and legs are also symptoms.[6] As a result, many people with Allan- Herndon- Dudley syndrome are unable to walk independently and use a wheelchair in adulthood.[7] As explained by Ms. X, K is unable to control his movements. He is confined to a wheel chair and unable to speak.[8] The condition affects his ability to eat and swallow, so he receives sustenance through a feeding tube. He goes from soft, relaxed muscles, to extreme rigidity.[9]

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1 The facts in this case are based on the admitted exhibits and testimony from Ms. X, Mr. X, Ms. Mead, Ms. Z and Ms. Kubitz.

2 Exhibit D p. 16; Ms. X testimony. Exhibit E p. 7.

3 Exhibit C.

4 *Id.*

5 *Id.*

6 *Id.*

7 Exhibit C; http://ghr.nlm.nih.gov/condition/allan-herndon-dudley-syndrome

8 Ms. X testimony.

9 M.s X testimony.

K’s daily routine is as follows: He awakens at 7:00 a.m. Ms. X spends the better part of the first hour on muscle percussion and clearing out his lungs. Ms. X starts feeding K through the G-tube and gives him his medication around 8:00 am.[10] Because he urinates frequently, and it is easier to not have to change him repeatedly, he remains only partially dressed. Following breakfast, he works on range of motion and other skills. He is then placed in his wheel chair. K has lunch around noon and then gets dressed so he can get to school, which begins at 1:00 p.m. K attends school from 1:00 p.m. to 3:30 p.m. While he is intellectually cognitive, he is unable to communicate. Ms. X said he does not attend school every day, but because he is cognitively aware and he enjoys school, they try to normalize as much as possible, provided he is feeling up to it. K gets home around 3:45 p.m. He has a third G-tube feeding around 4:00 p.m., and then he has family time. After that, K rests. After family activities, Ms. X gets K ready for bed, which consists of bathing him and putting on his pajamas. After his bath, Ms. X feeds K again and gives him his medication. Then he goes to sleep around 9:30 p.m. A night nurse is present with K all night.

On January 2, 2019, the Division notified K’s team that it was reducing some of the PCS hours as K was receiving duplicative services through the Waiver program. K’s guardian, N X challenged the Division’s decision.

B. Service Determination Processes

Medicaid provides a variety of in-home support, based on the need of the individual. To qualify for home and community-based waiver services, a recipient must require the level of care provided in a nursing facility.[11] The level of care requirement is determined by an assessment which is documented by the Consumer Assessment Tool (CAT).[12]

The Medicaid Waiver program pays for specified individual services to Waiver recipients, if each of those services is “sufficient to prevent institutionalization and to maintain the recipient in the community.”[13] The Division must approve each specific service as part of the Waiver recipient’s plan of care.[14]

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[10] Ms. X feeds K through his G-tube for each meal. Although he does not eat meals orally, Ms. X said, under the instruction of the physical therapist, she will supervise him with a lollipop or a taste of frosting. This helps him with his swallowing but is also enjoyable for K because of the sweetness.

[11] 7 AAC 130.205(d)(4).

[12] 7 AAC 130.215(4).

[13] 7 AAC 130.217(b)(1).

[14] 7 AAC 130.217(b).

PCS is a Medicaid program that provides help for an individual's functional limitations that are a result of a physical condition.[15] PCS services are not provided for activities that can be performed by the recipient.[16] Further, PCS will not pay for services "if a recipient receives residential habilitation services as in-home support habilitation services under 7 AAC 130.265(h)."[17]

Residential habilitation services are for children with complex medical conditions.[18] It provides services to "assist recipient to acquire, retain and improve self-help, socialization and adaptive skills to maximize independence…"[19] The Division will consider residential habilitation services to be family home rehabilitations services if

> (1) the family home habilitation services site
> > (A) is a residence licensed as an assisted living home or foster home under AS 47.32; and
> > (B) provides 24-hour care;
>
> (2) the recipient's primary caregiver
> > (A) lives with the recipient in the same residence;
> > (B) is not a member of the recipient's immediate family, or an individual with a duty to support the recipient under state law; and
> > (C) provides the oversight, care and support needed by the recipient to prevent risk of institutionalization of that recipient…"[20]

C. K's Waiver and PCS Services

K is eligible for home and community-based waiver services because he is a child with a complex medical condition (CCMC).[21] K receives services based on his needs. K's Plan of Care (POC) is managed by a care coordinator who oversees the plan and evaluates the services in the home.[22]

On October 19, 2018, K was reassessed, using the CAT, to determine his level of needs and services. It calculated his personal care services time by taking each eligible Activity of Daily Living (ADL) and Instrumental Activity of Daily Living (IADL) and assigning a score.[23]

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15 7 AAC 125.010-050.
16 7 AAC 124.040 (a)(4).
17 7 AAC 127.045 (b).
18 7 AAC 130.265 (A).
19 Exhibit B p. 54.
20 7 AAC 130.265.
21 7 AAC 130.205 (d (1).
22 Exhibit E.
23 7 AAC 160.900. In accordance with AAC 125.040 (14), K is a child and therefore is not eligible for IADL services. IADLs are services under AAC 7 AAC 125 (030) that are the responsibility of a parent or guardian to provide.

Because K received home and community-based waiver services, the Division determined that he reached an institutional level of care, and PCS is part of the plan that allows K to remain in his home.

K receives the following Waiver services:[24]

Care Coordination	2 times per month
Hourly respite	10 hours per week
Daily respite	14 daily units per year
Family Habilitation	365 daily units per year
Day Habilitation	6 hours per school week/ 8 hours per non-school week
Nursing oversight	140 units per year

K also receives physical therapy, occupational therapy, speech therapy and aquatic therapy.[25]

In addition to Medicaid services, K receives natural supports from his legal guardian N X. Grandparent F X also lives in the home.[26] PCS will not provide services to a minor whose parent or guardian has a legal obligation to provide those services.[27]

K has a positional wheelchair and feeding chair. He has many assistive devices, including: a specialized car seat, a sleep-safe bed, a bath chair, a suction machine, a pulse oximeter, an electric wheelchair, a hoyer lift, a cough assist machine, and stairlift platforms.[28]

Prior to the proposed reduction, K was receiving 37.00 hours per week of PCS.[29] Following the most recent CAT, the Division proposed a reduction of PCS hours to 7.00 per week.

There is no dispute that K is assessed by the CAT as totally dependent. The only issue is whether the proposed reduction in PCS hours will result in a risk of institutionalization to K. The X assert it will. The Division asserts the reduction will not result in risk of institution because K will receive the same care provided, albeit through one of the other services, as described below.

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24 Exhibit D p. 3

25 Exhibit E pp. 19 and 22.

26 Exhibit E at 22.

27 7 AAC 127.015. Mr. X is K's legal guardian so has obligations to provide for some of his needs. Ms. X is paid as the Family Habilitation person. She has an obligation to provide those services under that role.

28 Exhibit D p. 3.

29 *Id*.

D. Appeal

K's guardian, N X requested a hearing to challenge the Division's decision to reduce K's PCS hours. A telephonic hearing took place on February 4, 2019. Division hearing representative, Terri Gagne appeared on behalf of the Division. She presented Health Program Manager, Mary Mean, and Susan Kubitz, RN as witnesses. Mr. X testified, and he presented E X, Family Habilitation provider and M Z, prior physical therapist as witnesses. The Division's Exhibits A-E, Mr. X' Exhibit 1 and three videos of K were admitted. The record closed following the hearing.

On March 4, 2019, a proposed decision was distributed to the parties. Each party had until March 18, 2019 to submit a proposal for action to the Office of Administrative Hearings (OAH). The Division submitted a proposal for action on March 13, 2019. The decision, along with the Division's proposal for action, was forwarded to the Commissioner's designee, on March 26, 2019.

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OAH gave the parties until May 2, 2019, to submit responsive documents to the remand order. The Division responded on April 23, 2019. Mr. X responded on April 24, 2019. With his submission, Mr. X provided four exhibits. He marked them as Exhibits A-D. Because the Division's exhibits had previously been marked with letters, and to avoid any confusion, the documents submitted by Mr. X are marked 2-5, respectively.

Mr. X' Exhibit 4 is responsive to the remand order for literature on Allan-Herndon-Dudley Syndrome. Mr. X asked that Exhibits 2, 3, and 5 replace the Division's previously admitted documents because they contain more current information. But the scope of this case is limited to evaluating the correctness of decisions made by the Division based on the October 19,

2018 CAT, the POC for February 19, 2018 to February 19, 2019, and only until the date of notice on the assessment determination (February 2, 2019). Exhibits 2, 3, and 5 are outside of the relevant timeframe, and thus, are not responsive to the remand order.[30]

On April 26, 2019, Mr. X requested a status hearing. He and Ms. Gagne each appeared telephonically. Mr. X inquired as to whether he would be able to present testimony regarding the new plan of care. He was advised of the limited scope of this appeal. However, he was also advised each side's proposal for action and subsequent findings, to the extent they were responsive to the remand instructions, would be considered to address this decision.

III. Discussion

When the Division seeks to reduce or eliminate a benefit a recipient is already receiving, it bears the overall burden, by preponderance of the evidence to show the recipient's level of eligibility changed.[31]

The Division cannot reduce any service that is likely to result in K being relocated to an institution within the next 30 days.[32] The X argue that the reduction of 5.53 hours per day places K at risk of institutionalization. The Division asserts the reduction will not result in risk of institutionalization because the services are duplicative of other services he is receiving. Supported living services "may not duplicate other services provided to a recipient, which includes PCS services."[33]

K has significant needs. However, K receives comprehensive Waiver services. He has E X, in the role as Family Habilitation, twenty-four hours a day, seven days a week. He also gets hourly respite, daily respite, Day Habilitation and nursing oversight. Among other assistive devices, the family also has a bath chair, an electric wheelchair, a hoyer lift, and stairlift platforms, to assist with K's care. He receives physical therapy, occupational therapy, speech therapy and aquatic therapy.[34]

K's team contends that none of these services are duplicative because he needs two people to assist him in his activities. While, as described below, this is true in some tasks, the

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30 This may seem a harsh or curious conclusion to not consider all current information, but this is the nature of these appeals. K's team can challenge any new plan of care in a separate proceeding. This decision has a limited scope. Not considering that information now, does not affect the ability to challenge it in the other case.

31 AAC 47.135.

32 7 AAC 127.095 (c).

33 7 AAC 130. 265 (e)(2); *In re N. X.* 17-0935/09410 MDS.

34 Exhibit E pp. 19 and 22.

evidence does not show it true for all activities. To justify the Division's reduction in PCS, it must show that K will have the same services available elsewhere.

A. Risk of Institutionalization

It is undisputed that K is assessed at totally dependent in each category of the CAT. K qualifies for Waiver services because, among other things, he requires a level of care provided in a nursing facility.[35] K requires all the services he is receiving. The Division does not dispute this—instead, it argues the reduction in the actual number of minutes does not place K at risk of institutionalization because it is not a reduction of services; it is merely a matter of reducing the minutes of duplicated services.[36]

To the extent that the reduction in minutes cuts duplicative services, it is appropriate and does not place K at risk of institutionalization. To the extent that those services are not duplicative, it would place K at risk to reduce the number of minutes he is currently receiving. Any reduction, and the basis for it, are set forth below.

B. Activities of Daily Living (ADL)

K's Consumer Assessment Tool (CAT) assesses K as totally dependent for all categories. The Division proposes to reduce K's PCS services from 45.75 per week to 7.00 per week, as duplicative of other services he is receiving.[37] Below are the proposed changes:

1. Bed Mobility

The ADL of bed mobility refers to the ability of a person to move to and from a lying position or turn from side to side in bed.[38] The July 2017 revisions to the personal care services program regulations added the phrase "for a recipient who is non-ambulatory" to the description of this ADL, effectively limiting its application to that group of recipients.[39]

K's February 5, 2015 CAT assessed him as total dependence with one-person physical assist 4 times a day, 7 days per week for a total of 140 minutes weekly. His October 19, 2018 CAT assessed him as the same. Per the CCMC Waiver Plan for February

[35] 7 AAC 130.205(d)(1).
[36] *Id*.
[37] Exhibit D p. 1.
[38] 7 AAC 125.030(b)(1).
[39] *Id*.

19, 2018 through February 18, 2019, K receives Family Habilitation services. Goal 4, objective 1 of that plan states "K will be repositioned every 10 to 15 minutes. . . ."[40]

There is no question that K needs assistance with his bed mobility. He does not have control over his muscles. Ms. X described how he can jerk himself into positions that he cannot get himself out of. She testified that he can inadvertently jerk himself into positions that impede his breathing and put him at risk of aspirating on his own saliva. Because of the communication issues, he is unable to call out for help. However, K has a night nurse who is with him all night and provides movement every 10-15 minutes as part of his Waiver services. Because the night nurse is with him, and he receives services through her, the Division determined it is duplicative to have Bed Mobility services through PCS. The Division decreased the 140.00 minutes weekly. Because K will be repositioned every 10 to 15 minutes by his night nurse, the reduction by the Division is for duplicative services.

*2. **Dressing***

The regulation permits the Division to authorize personal care services for a person who needs physical assistance with "the putting on, fastening, unfastening, and removal of the recipient's clothing, support hose, or prosthesis."[41] On K's February 5, 2015 CAT he was assessed as totally dependent with one person physical assist 2 times a day, 7 days a week, for a total of 210 weekly minutes. On his October 19, 2018 CAT, he was assessed the same. Per the CCMC Waiver Plan February 19, 2018 through February 18, 2019 Family Rehabilitations Services Goal 4, Objective 5 states "K will remain clean with diaper and clothing changes as needed up to 3 times per day for clothing, with 100% physical assist success rate."[42] The Division thus removed 210.00 minutes per week for this service as duplicative.

There is no question that K is totally dependent when it comes to dressing. He cannot dress himself. The goal of CCMC Waiver plan to "remain clean with diaper and clothing changes" does not address the twice-a-day ritual of getting dressed as one starts the day and getting ready for bed at night. Testimony showed K needs to be changed several times throughout the days because he soils himself. Also, as part of his condition, K suffers

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[40] Exhibit D p. 3.
[41] 7 AAC 125.030(b)(4).
[42] Exhibit D p. 4.

from "overactive sweat glands. K soaks through his clothes numerous times per day…".[43] The need to be changed up to three times a day is intended to address the goal of remaining clean. This service is not duplicative of getting K dressed in the morning and getting him ready for bed at night. The Division's removal of 210.00 minutes per week is in error.[44]

3. Eating

The program regulations for eating address whether a person can eat and drink regularly, regardless of skill. K is fed through a G-tube.[45] On the February 5, 2015 CAT K was assessed as totally dependent with one person physically assisting him with eating three times a day, 7 days a week for a total of 315.00 minutes per week. [46] His October 19, 2018 CAT assessed him as eating 4 times a day, 7 days a week with a feeding tube. Per his CCMC Waiver plan for February 19, 2018 through February 18, 2019 under Family Rehabilitations Services Goal 4 "K will meet daily nutritional requirements by following bolus feeding schedule via G-tube up to 4 times a day." The Division thus decreased K's services by 315.00 weekly minutes as duplicative. An individual does not need feeding assistance when you have a feeding tube.[47] K does not require 315.00 weekly minutes of feeding with PCA services because he is receiving the G-tube feeding as part of his goal with Family Rehabilitation. He is also a child whose parent or guardian is responsible to help him with eating.[48] The Division properly concluded a reduction of 315.00 weekly minutes is duplicative.

4. Toileting

The program regulations for toileting focus on how a person uses the toilet, transfers to the toilet, cleans oneself and adjusts one's clothes. K's February 5, 2015 CAT assessed him as totally dependent with a one-person physical assist 6 times a day, 7 days a week for a total of 504.00 weekly minutes.[49]

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[43] Exhibit E p. 19.
[44] The POC also claims, in Exhibit E p. 39, K requires 2 persons to dress him. This is not examined because it should remain for other reasons.
[45] *See* 7 AAC 125.030(b)(5).
[46] Exhibit D p. 5.
[47] *In re D T*, OAH No. 17-1106-MDS, https://aws.state.ak.us/OAH/Decision/Display?rec=3325
[48] 7 AAC 125.010 (c) (8).
[49] Exhibit D p. 5.

K's October 19, 2018 CAT assessed him as totally dependent with a one-person physical assist 6 times a day, 7 days a week for a total of 504.00 weekly minutes.[50] Per the CCMC Waiver plan Goal 4 "K will remain clean with diaper and clothing changes, as needed up to 8 times per day for diapers…" The Division reduced this as duplicative with the Family Rehabilitation Services by 504.00 minutes weekly. The Division properly concluded a reduction of the 504.00 weekly minutes is duplicative.

5. Bathing

The Division may authorize personal care services if a person needs physical assistance with bathing. The assessor must assess how a person takes a full-body bath/shower, and transfers in an out of the tub/shower. K's February 5, 2015 CAT assessed him as totally dependent with a one-person physical assist once a day 7 days a week, for a total of 210.00 weekly minutes. On the October 19, 2018 CAT, he was assessed the same. The February 19, 2018 through February 18, 2019 CCMC Waiver plan states that K will participate in bath time 45 minutes per day. Because he is receiving daily baths up to 45 minutes per day, the 210.00 minutes were removed as duplicative.

The X maintains this task is not duplicative because in order to bathe K, two people are required. The plan of care recognizes that he needs 2-person assist because of his weight and size.[51] This conflict with the CAT recommendation. Ms. X was seen on video lifting K with a second person.

At his present weight of 59 pounds, K can be lifted by one person. The family also has a lift to assist with this. This situation is likely to change as he gets larger and heavier. However, his current size and weight, based on the video, is that K can be lifted by one person.

However, because of the description of K's erratic movements, and the slippery nature of a wet person, should K jerk while attempting to get in or out of the tub, he would be seriously injured. He does not have the muscle control to brace himself for a fall. Further, it is unpredictable when he will have the rigidity in his muscles, and it is not reasonable to expect him to be laid out naked on a bathroom floor or in the tubful of water

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[50] Exhibit D p. 5.

[51] Exhibit E p. 18. The plan of care has a lot of contradictions. For example, on p 18, it refers to the "great success" of the new tub, but on page 20, it refers to looking into getting him a tub. The plan of care also refers to Ms. X as a legal parent, but she is the Family Habilitation person. Mr. X is the guardian.

while he is in a rigid state. Because it is unpredictable when this will occur, there always needs to be two people in order to ensure his safety. Because K's bathing requires two people, the reduction of PCS is not duplicative, and removing 210.00 minutes is in error.

6. Other Covered Activities

On the February 5, 2015 CAT, and per the Fair Hearing Resolution of June 15, 2017, K was authorized for 350.00 weekly minutes of passive range of motion. His October 19, 2018 CAT assessed him needing range of motion for all four extremities 10 minutes per extremity 4 times per day, 7 days per week.[52] Per his CCMC Waiver plan February 19, 2018 through February 18, 2019, "[a]s prescribed in K's home physical therapy plan, FHP will physically assist K in performing passive/acting range of motion exercises using the harness." The Division reduced by 350.00 weekly minutes as being duplicative. The evidence presented did not demonstrate passive/active range of motion using a harness were equivalent to range of motion for all four extremities for 10 minutes four times a day, seven days a week. Therefore, the reduction of 350.00 minutes weekly as duplicative is in error.

7. Need for Two Person

The X opined that for all activities, K needs two people assisting him. This is not supported by the evidence. In the video presented, Ms. X was able to lift K's weight on her own. In addition, the family has assistive devices, such as a hoyer lift assist with moving K. While there was discussion about him being difficult to move when rigid, Ms. Kubitz, RN, testified attempts to transport K when he is in a rigid state should be avoided. He should be left flat until his muscles relax. For K's safety, his caregiver should wait for the rigidity to pass.[53] He can be placed on the floor to avoid rolling.[54] Some of the needs perceived by the X to have two people assist in transport, may be avoided by not attempting to move him in certain circumstances. K will get bigger, and as he ages, his needs may change. But the X will need to present that evidence at that time.

IV. Conclusion

The Community First Choice (CFC) program did identify some duplicative services; however, not all services were duplicative. The Division has asked for a reduction of 1729.00

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52 Exhibit D p. 6.
53 Ms. Kubitz testimony.
54 Ms. Kubitz testimony.

minutes, in total. 770.00 of those are not duplicative. For the reasons described above, as well as the admissible evidence submitted on remand, the reduction should be 959.00 weekly minutes. However, as noted, this decision is limited to a finite time frame and if there has been a change of circumstances or change of documented need outside the time frame, there are remedies available by way of future appeals.

Dated: June 7, 2019

Signed
Hanna Sebold
Administrative Law Judge

Adoption

The undersigned, by delegation from 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 7th day of June 2019.

By: *Signed*
Name: Jillian Gellings
Title: Project Analyst
Agency: Office of the Commissioner, DHSS

[This document has been modified to conform to the technical standards for publication. Names may have been changed to protect privacy.]