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

ΝX

OAH No. 19-0381-MDS Agency No.

FINAL DECISION AFTER REMAND

I. Introduction

N X suffers from spinal muscular atrophy, a condition that severely limits her physical abilities. She resides in her own home and receives Medicaid Home and Community-based Waiver Services (Waiver). She filed to renew her Waiver Plan of Care (POC) and requested a continuation in her Waiver services. She was notified on April 23, 2019 that most of the services requested under her POC, in the category of supported living services, were denied. Ms. X requested a hearing to challenge the Division's determination.

After the hearing, a proposed decision was issued on September 26, 2019, finding that the evidence at hearing demonstrated that Ms. X's care needs can appropriately be provided for under the category of supported living services, and that the Division's interpretation of the regulations governing supported living services is unduly narrow and incorrect. Both parties filed proposals for action (PFAs). The Commissioner's Delegate, Jillian Gellings, remanded the case to the administrative law judge "to review the arguments made in both parties" proposals for action, including untimely and supplemental submissions, and to take any action as deemed necessary to consider them."¹

A review of the parties' post-hearing submissions does not provide a basis for changing the rationale of the proposed decision.² Accordingly, the Division's denial of Ms. X's supported living services is reversed.

II. Facts and Procedural History

The following discussion of the facts is necessary in order to set the context for discussion of the Division's interpretation of the pertinent regulatory standards in this case. There are, however, no material facts in dispute in this case.

¹ Order Remanding Case, October 8, 2019 (distributed October 9, 2019).

² This final decision also corrects a manifest typographical error in footnote 23 (footnote 21 in the proposed decision), pursuant to 2 AAC 64.350.

Ms. X is in her early 30s. She was born with spinal muscular atrophy (SMA), a progressive or degenerative neurologic disorder that affects the motor neurons, with the result that she has significant muscular weakness that impacts her ability to move and use her extremities; she is essentially quadriplegic and is required to use a specialized motorized wheelchair for mobility; she has speech difficulties including hypophonia and dysarthria (essentially slurred and soft speech) which require her to use a head microphone and voice amplifier technology to effectively communicate; and she has dysphagia which requires a PEG tube (a feeding tube).³ In addition, Ms. X's diagnoses include chronic osteomyelitis, osteopenia, nutritional deficiency, and chronic pain syndrome.⁴ She is extremely susceptible to infection. She is unable to sit unsupported, but she can hold her head upright for short periods, after which she must rest her neck.⁵

Ms. X's mental functioning is fully intact, she has attended community college, and she is highly intelligent. Due to her physical limitations, she has been assessed by the Division as completely dependent upon others for her care needs, including feeding herself, bathing, toileting, transferring, etc. She requires frequent repositioning in her wheelchair and while sleeping (bed mobility), often needing such adjustments every 15 minutes throughout the day. Although she is completely dependent on caregivers for repositioning and bed mobility, Ms. X is not a passive recipient of assistance and does physically participate in many of the other activities of daily living, such as personal hygiene tasks, toileting, bathing, suctioning of her PEG tube, and communication tasks via a specialized phone or her computer.⁶

Ms. X's utilization of supported living services has enabled her to continue to live in her own home, and engage in her life activities, despite the progression of the debilitating symptoms and side effects of her SMA.⁷ Her care coordinator testified, emphatically and credibly, that if she does not have access to supported living services going forward, the inevitable result will be that she will need to be institutionalized.⁸

In late 2017, an administrative appeal with some similarities to Ms. X's situation, *Matter of NX*, was decided by the Department of Health and Social Services. In that case, involving a

 $^{^{3}}$ X exh. 6.

⁴ X exh. 4.

⁵ X exh. 7.

⁶ T testimony. 7 Id : V testimo

⁷ Id.; X testimony.
⁸ Id.

⁸ *Id.*

quadriplegic Waiver recipient, an administrative law judge's (ALJ's) proposed decision had reversed the Division's denial of supported living services. The Department reversed the ALJ's decision, disallowing all supported living services for the recipient, and stating as follows: "the purpose of supported living service is for skill development and retention, and personal care services are not an acceptable primary use for supported living services."⁹

In 2018, after issuance of the decision in *Matter of NX*, Ms. X sought to renew her Medicaid Waiver POC. After correspondence back and forth between her care coordinator and a Division representative, some modifications were made to the goals in the POC and her renewal was approved, including her request for 122 hours per week of supported living services and four hours per week of day habilitation services.¹⁰

In 2019, Ms. X again sought renewal of her Waiver POC, including 122 hours per week of supported living services and four hours per week of day habilitation services.¹¹ Discussions and correspondence ensued between her care coordinator and a different Division representative, Tammy Smith. The Division offered to approve a POC that included, on a weekly basis, 74.5 hours of supported living services, 47.5 hours of personal care services (PCS), and four hours of day habilitation services.¹² Ms. X declined that offer because she felt that it would jeopardize her health and would be contrary to the advice of her medical providers.¹³ The Division then issued a letter to Ms. X, denying the entirety of her requested supported living services, while approving the four hours per week of requested day habilitation services.¹⁴

Ms. X appealed the denial of supported living services in early May 2019. The hearing was held on August 7, 2019. Ms. X appeared in person, testified on her own behalf, and was represented by attorney Mark Regan from Disability Law Center. Care coordinator J T also testified on Ms. X's behalf. The Division was represented by Assistant Attorney General Paul Peterson. Health Program Manager I Tammy Smith testified on behalf of the Division. The parties submitted written closing arguments on August 23, 2019, and the matter was taken under advisement.

¹³ X testimony.

⁹ In the Matter of NX, OAH No. 17-0935-0941 (Comm. DHSS, Dec. 26, 2017).

¹⁰ X exh. 1, p. 13.

¹¹ X exh. 2.

¹² To the extent that the Division objected to discussion of this offer on the grounds that it was part of a settlement discussion, that objection was waived when the Division referenced these discussions between the parties during its opening statement.

¹⁴ X exh. 2.

III. Discussion

The sole issue in this case is whether the Division correctly denied Ms. X's request in her Waiver POC for 122 hours per week of supported living services. The Division has the burden of proof on this issue.

It is undisputed that the Division had previously approved 122 hours of supported living services for Ms. X for many years; this included approval of her 2018 POC, after the Department had issued its decision in the *Matter of NX* case. It is also undisputed that although Ms. X is dependent on her supported living caregivers for her activities of daily living, including eating, bathing, toileting, transferring, being repositioned in bed and in her wheelchair, etc., she physically participates in many of these activities.

A. The denial letter

The Division's denial letter stated the primary grounds for denying supported living services, in pertinent part, as follows:

[T]here are major concerns with how and what skills Ms. X is acquiring, building, or retaining because of her degenerative disease. ... Based on the goals/objectives as written, the direct service workers are 100% of the time completing with total physical support which is more in line with providing Personal Care Services (PCS) and not habilitative services. ...

Habilitative services are equal to teaching/training in context to learn, build or keep skills. Ms. X is completely dependent upon service care providers and with her diagnosis of SMA this will never change. Therefore, she is unable to acquire, build or retain skills aimed at increasing her overall level of functioning. ...

The activities that a service provider may provide must be planned with the objective of maintaining or improving the recipient's physical, mental, and social abilities rather than rehabilitating or restoring such abilities. These services must be individually tailored, and may include personal care and protective oversight and supervision, *in addition to skills development*. Even if Ms. X needs assistance with personal care, protective oversight and supervision, she still must require and actively engage with skill development. ... Adaptive skills are defined as practical, everyday skills needed to function and meet the demands of one's environment, including the skills necessary to effectively and independently take care of oneself and to interact with people. ... Ms. X exceeds these definitions based on her intellect and abilities to self-direct her life and care.

Considering the contradicting information, Ms. X's degenerative disease, which will increasingly deteriorate over time, and Ms. X already being completely dependent upon service care providers, Supported Living is not an appropriate service. Realistic, appropriate skills to build and maintain have not been identified. SDS could continue to work on these goals and objectives 24/7 and the outcome would remain the same: physical hands-on [assistance]. Ms. X will

continue to remain fully dependent upon care providers for every aspect of daily living. Based on what is written and described in the plan, PCS is the appropriate service. ...

Based on the progress towards previous goals and the contradicting information throughout the plans, SDS has determined Supported Living Services have exhausted [their] efficacy and [are] no longer an appropriate service. ... After years of Supported Living Services, Ms. X is still completely dependent upon service care providers and always will be; she is also fully cognizant and does not require habilitation services to retain her cognitive functioning. ...

Therefore, the department denies under 7 [AAC] 130.217 and 7 [AAC] 130.265, Supported Living ... (122 hours per week)¹⁵

Thus, the Division's rationale for denying Ms. X's request for supported living services can be summarized as follows: Ms. X's degenerative condition has caused her physical abilities to reach the point where she is totally dependent on caregivers for her activities of daily living, and she will never regain the ability to perform those activities; in addition, her cognitive abilities remain strong, so she does not need her caregivers to help her learn how to perform those activities or make decisions about them; *therefore she is not using her supported living services to build or maintain skills related to those activities*. Although the denial letter does not quote or refer to the *Matter of NX* decision, Ms. Smith's testimony and the Division's briefs make it clear that the decision played a central role in the Division's determination in this case, specifically the Commissioner's statement in *NX* to the effect that "personal care services are not an acceptable primary use for supported living services."¹⁶

B. Regulatory standards and definitions

To assess whether the Division correctly made the determination to deny Ms. X's supported living services, one must review the pertinent standards set out in the Division's regulations. The denial letter quoted above cites 7 AAC 130.217 and 7 AAC 130.265. The first cited regulation simply requires that Waiver services be described in a POC, and sets forth detailed requirements for the content of the POC. The second regulation provides, in pertinent part, that supported living services are a type of "residential habilitation services;" the Division "will consider habilitation services to be supported-living habilitation services" if they are provided on a one-to-one basis, the recipient is 18 years of age or older, and the recipient is

¹⁵ Division exh. D, pp. 4-5 (emphasis in original).

¹⁶ In the Matter of NX, OAH No. 17-0935-0941 (Comm. DHSS, Dec. 26, 2017).

living full time in their own residence; the regulation also provides that in general the Division will pay for a maximum of 18 hours of supported living services per day.

More helpful regulatory definitions are found elsewhere. A Department regulation defines habilitation services, in pertinent part, as "services that ... help a recipient to acquire, retain, or improve skills related to activities of daily living ... and the self-help, social, and adaptive skills necessary to enable the recipient to reside in a noninstitutional setting."¹⁷ Another pertinent standard is found in the *Residential Habilitation Services Conditions of Participation* (Conditions of Participation); these provisions are adopted by reference at 7 AAC 160.900(45), and 7 AAC 160.265(a)(2) explicitly requires that any residential Habilitation program "must be provided in accordance with the department's Residential Habilitation Services Conditions of Participation." Thus, the Conditions of Participation are **mandatory requirements** of any program for supported living services. They provide in pertinent part as follows:

Residential habilitation services may be provided to assist recipients to acquire, retain, and improve the self-help, socialization, and adaptive skills necessary to maximize independence and to live in the most integrated setting appropriate to the recipient's wishes and needs. ...

The activities provided as residential habilitation services must be planned with the objective of maintaining or improving the recipient's physical, mental and social abilities rather than rehabilitating or restoring such abilities. These services must be individually tailored, and **may include personal care and protective oversight and supervision, in addition to skills development**.¹⁸

C. Analysis

Ms. X argues in this matter that she participates in many of her activities of daily living, that she needs supported living services to assist her in maintaining skills that are critical to her management of her own life, and that the Division's decision in this case discriminates against her because she is not cognitively impaired. The Division responds that whether or not Ms. X is able to physically participate in daily living tasks, and notwithstanding her argument that the Division is punishing her or discriminating against her based on her having a high level of cognitive abilities, in reality the only issue here is whether the primary use of her requested

¹⁷ 7 AAC 130.319(6).

¹⁸ Residential Habilitation Services Conditions of Participation, p. 1 (emphasis added). This document is available online at <u>http://dhss.alaska.gov/dsds/Documents/regspackage/ResidentialHabilitationServicesCOP.pdf</u>.

supported living hours is "active skill building."¹⁹ As stated in the Division's closing argument, "the question that is before the ALJ is whether the primary use of the supported living services ... is for skill development."²⁰

The Division's characterization of the question presented for decision in this matter is incorrect. First, the Division overextends the meaning of the operative language of the Matter of NX decision, which does not use the term "primary use" in such a broad manner – it simply states that PCS "services are not an acceptable primary use for supported living services." Second, and more importantly, the term "primary use" does not appear in any of the regulations relating to supported living services or habilitation services. The Matter of NX decision coined that language without citing to any statutory or regulatory authority, other than the definitions discussed above. In addition, the decision failed to square its "primary use" holding with the actual, applicable terms of the Conditions of Participation, including the explicit statement that supported living services "may include personal care and protective oversight and supervision."²¹ For these reasons, the *Matter of NX* decision is of questionable precedential value.22

Nonetheless, even if one were to accept the Division's characterization of the critical question in this case as correct, the Division's determination is not based on the undisputed facts in this case. As discussed above, Ms. X physically participates in many of her activities of daily living, despite being fully dependent on her caregivers for those activities. It is an undisputed fact that her participation in those activities is done with the intention and goal of "maintaining [her] physical, mental, and social abilities."²³ She engages in those activities in order to attempt to "retain ... the self-help, socialization, and adaptive skills necessary to maximize independence and to live in the most integrated setting appropriate to [her] wishes and needs."²⁴ Ms. X's supported living services, in fact, fit squarely within the standards contained within the Conditions of Participation.

¹⁹ Division's Opening Statement.

²⁰ Division's written Closing Argument at 4.

²¹ Conditions of Participation, p. 1.

²² The ALJ agrees with Ms. X's argument that the Division's effort to narrow the definitions of supported living or habilitation services should be accomplished by revising the regulations through standard rulemaking processes under the Administrative Procedures Act.

Conditions of Participation, p. 1. Id.

²⁴

The Division presented no factual testimony to support a contrary conclusion. Rather, the Division's determination in this case appears to be predicated on an interpretation of the supported living standards that assumes that if a recipient's physical disability is such that they will never be able to increase their performance of an activity of living (and in fact their ability to perform the activity is likely to continue diminishing), then by necessity the recipient cannot receive supported living services.²⁵ This interpretation, simply stated, is not supported by the regulations. If a recipient's ability to physically engage in activities of life is decreasing over time, but supported living services are being utilized to **slow the rate of decrease**, that is just as legitimate as using supported living services to increase a recipient's ability going forward. Such an interpretation completely comports with the express language of the relevant regulations.

At the hearing, the Division seemed to focus its arguments on this regulatory definition of habilitation services: "services that ... help a recipient to acquire, retain, or improve skills related to activities of daily living ... and the self-help, social, and adaptive skills necessary to enable the recipient to reside in a noninstitutional setting."²⁶ However, as already discussed, Ms. X's program of supported living is aimed at helping her "retain ... skills related to activities of daily living," and it is aimed at enabling her to "reside in a noninstitutional setting." The entire thrust of her POC is designed to allow her to live in her own home and to participate in all of her life activities to the greatest extent possible.

Ms. X argued at the hearing that decision-making is a skill of daily living that is supported by her supported living services. The Division responded by pointing out that there is no evidence that her decision-making abilities are diminishing, arguing therefore that they are not appropriately considered in the discussion of supported living services. There are two problems here. First, **retaining skills** is explicitly listed as a goal of supported living services; a skill need not be diminishing in order to be retained to prevent diminishment over time. Second, the Division's argument fails to see the forest for the trees. Ms. X's decision-making skills cannot be viewed in an isolated manner; rather, they are part and parcel of an aggregation of skills that constitute living independently. Living independently is one of the explicit goals of supported living services.

²⁵ For example, in the Division's view, if service providers assist Ms. X with brushing her teeth, and her ability to increase her participation in that activity is unlikely to ever increase, then this activity should be provided for through PCS rather than supported living.

²⁶ 7 AAC 130.319(6).

This decision finds that the Division's interpretation of the regulations governing supported living services is unduly narrow and inappropriately focuses only on acquiring or improving skills, to the exclusion of retaining or slowing the rate of loss of skills. It is unclear why the Division has adopted such an interpretation in this case. It is noted that the Division, while acknowledging that supported living services cost a great deal more than PCS services, has asserted that monetary considerations played no role in its determination in this case.²⁷ The ALJ accepts that assertion at face value, and will assume that the Division's determination to deny Ms. X's supported living services was simply based on an incorrect reading or interpretation of the relevant regulations.²⁸

D. The parties' post-hearing submissions

1. The Division's PFA²⁹

The Division's PFA makes two arguments: (1) the issues in this case are "the same" as the "legal and factual issues" in the *Matter of NX* decision, so the Division's decision here to deny supported living services should be upheld; and (2) the administrative law judge committed "clear error" in the proposed decision when he "assume[d] that he has jurisdiction over discrimination or equal protection cases, but decide[d] not to exercise that jurisdiction."³⁰

In subsequent correspondence that was submitted to OAH with respect to an ancillary issue, the Division's counsel characterized the first argument above as "the only real argument" in the Division's PFA; thus one can quickly dispose of the Division's second argument. It is sufficient to note that the argument misses the mark; administrative law judges can and should address allegations of discrimination in state agencies' *interpretation or application* of regulations and statutes. In any event, however, as acknowledged in the PFA, the proposed

http://dhss.alaska.gov/dsds/Documents/pca/PCA-waiver-service-rates201807.pdf (date accessed Sept. 25, 2019). Because this decision finds in favor of Ms. X on the issue of interpretation of the regulations regarding supported living services, it does not reach the question of whether the Division discriminated against Ms. X based on her cognitive abilities.

²⁷ The ALJ takes administrative notice that supported living services cost approximately 75% more than comparable PCS services. PCS is reimbursed at \$6.25 per 15-minute service unit, while Waiver supported living services are reimbursed at \$10.93 per 15-minute service unit. *Department of Health and Social Services Chart of Personal Care Attendant and Waiver Service Rates* effective July 1, 2018 (Anchorage rates – the rates for the Kenai Peninsula are 1 % higher than Anchorage). This document is available online at

²⁹ The Division's PFA was filed after the deadline for doing so, apparently due to a clerical error; normally, an untimely filed PFA will not be considered and will be returned to the filer. In this case, however, the Order Remanding Case requires that "untimely and supplemental submissions" be addressed in this final decision. ³⁰ Division's PFA, p. 1.

decision did not reach Ms. X's discrimination argument.³¹ Therefore, this argument by the Division requires no further response.

As to the Division's first argument (the "real argument"), the problem for the Division is that the *Matter of NX* decision did not involve "the same legal and factual issues" as those presented in Ms. X's case. In the *Matter of NX*, the administrative law judge's proposed decision determined that the claimant should be allowed PCS-type services under the rubric of supported living simply because the Conditions of Participation appear to allow that result, via the language stating that residential habilitation services "may include personal care."³² The proposed decision concluded that "[p]ersonal care services of the type sought by Ms. X clearly fall within the acceptable range of supported living services…."³³

By contrast, this decision's conclusion that Ms. X is eligible for supported living services is predicated in part on factual findings that Ms. X physically participates in many of her activities of daily living, that her utilization of supported living services has enabled her to continue to live in her own home and avoid institutionalization, and that if she does not have access to supported living services going forward, the inevitable result will be that she will need to be institutionalized. It is also predicated on the conclusion that the Division's interpretation of the regulations governing supported living services is unduly narrow and inappropriately focuses only on acquiring or improving skills, to the exclusion of retaining or slowing the rate of loss of skills. Those factual and legal factors clearly distinguish this case from the *Matter of NX*.

For the reasons stated above, the Division's PFA does not present arguments that compel a reversal of the proposed decision in this case.

2. Ms. X's PFA and response to Division's PFA

Ms. X's PFA urges the Department of Health and Social Services to adopt the proposed decision in its entirety. It points out that denial of supported living services to Ms. X would be contrary to the federal Medicaid Act, which defines habilitation services to include skill-building that is designed to retain existing functioning.³⁴ Ms. X is correct that this language of the Medicaid Act further supports the result reached by the proposed decision here.

³¹ See footnote 28, supra.

³² Conditions of Participation, p. 1; see In the Matter of NX, OAH No. 17-0935-0941, pp. 18-20.

³³ In the Matter of NX, OAH No. 17-0935-0941, p. 19.

³⁴ 42 U.S.C. sec. 1396n(c)(5)(A).

Ms. X's PFA also argues that denial of supported living services here would discriminate against her, and thus be in violation of the Americans with Disabilities Act, because her disability "does not affect her intellectual functioning and so gives her both the opportunity and the responsibility to get a somewhat different type of supported living services than people with significant cognitive impairments³⁵ This is essentially equivalent to the discrimination argument raised by Ms. X at the hearing, which, as noted above, the proposed decision did not reach. Therefore, there is no need for this final decision to further analyze the issue.

Ms. X also submitted a "response to [the] Division's proposal for action,"³⁶ in which she argues that the Division's PFA improperly raises two arguments for the first time. She suggests that the first new argument is the Division's contention that the final decision in *Matter of NX* is exactly like Ms. X's case. She is correct that the Division never made this argument in precisely this manner, prior to filing its PFA; however, it was clear at the hearing that the Division believed the *Matter of NX* decision to mandate its denial of supported living to Ms. X. In any event, the substance of this argument by the Division has already been addressed above.

Ms. X contends that the Division also improperly raised for the first time in its PFA the argument that the ALJ's committed "clear error" in supposedly "assum[ing] ... jurisdiction over discrimination or equal protection cases." Ms. X is again correct that the Division did not raise this argument prior to filing its PFA. However, given that the proposed decision did not reach her discrimination claim, there is no need to further belabor this issue.

IV. Conclusion

The Division failed to meet its burden of proof to show, by a preponderance of the evidence, that its denial of Ms. X's supported living services in her POC was correct. Nothing in the parties' post-hearing submissions provides any basis for changing the rationale of the proposed decision issued by the administrative law judge. Therefore, the Division's decision is reversed.

DATED this 25th day of November, 2019.

Signed

Andrew M. Lebo Administrative Law Judge

³⁵ X PFA, p. 2.

³⁶ Under OAH's governing statutes, normally a party is not allowed to file a response to another party's PFA. In this instance, however, as noted above, the Order Remanding Case requires that "untimely and supplemental submissions" be addressed in this final decision.

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 27th day of November, 2019.

By: <u>Signed</u>

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.]