BEFORE THE OFFICE OF ADMINISTRATIVE HEARINGS STATE OF CALIFORNIA

In the Matter of the Fair Hearing Request of:

CLAIMANT,

vs.

KERN REGIONAL CENTER,

Service Agency.

OAH No. 2020030908

On September 24, 2020, and October 19, 2020, Robert G. Martin, Administrative Law Judge, Office of Administrative Hearings, heard this matter by videoconference.

Claimant's mother and conservator appeared on behalf of claimant, who was not present.¹

Matthew F. Bahr, Attorney at Law, represented Kern Regional Center (KRC).

Oral and documentary evidence was received. The record was closed, and the matter was submitted for decision on October 19, 2020.

¹ Claimant and her mother/conservator are identified by titles to protect their privacy.

ISSUE

May KRC terminate its monthly stipend for claimant's specialized diet?

EVIDENCE RELIED UPON

Documents: KRC's exhibits 1 through 5, and 5a. Claimant's exhibits A through O, and C-1 through C-6.

Testimony: Celia Pinal, KRC Director of Client Services, Elbia Vargas, KRC Service Coordinator, and claimant's mother.

FACTUAL FINDINGS

Parties and Jurisdiction

1. Claimant is a 34-year-old conserved woman who is an eligible consumer of KRC under the Lanterman Developmental Disabilities Services Act (Lanterman Act; Welf. & Inst. Code, § 4500 et seq.), based on qualifying diagnoses of autism spectrum disorder and severe intellectual disability. Claimant has also been diagnosed with celiac disease, for which she requires a specialized, gluten-free diet.

2. Since at least 2010, KRC has provided claimant a monthly stipend that reimburses claimant a maximum of \$750 per month for her specialized diet.

3. On February 24, 2020, KRC issued a Notice of Proposed Action (NOPA), informing claimant of KRC's proposal to discontinue its monthly stipend for claimant's specialized diet. As authority for its proposed action, KRC cited and attached copies of

Welfare and Institutions Code sections 4512, subdivision (b); 4659, subdivisions (a) – (f); and 4646.5, subdivision (a)(2). KRC also cited to Welfare and Institutions Code section "4689(C)", and attached a copy of section 4689, subdivision (i)(1)(C), which concerns a six-month limitation on certain payments not applicable in this matter. KRC acknowledged at hearing that the reference to section 4689, subdivision (i)(1)(C), was an error, and that KRC meant to cite to section 4689, subdivision (c), which lists examples of supported living services and supports available to developmentally disabled persons living in the community.

4. On March 9, 2020, claimant's mother filed a fair hearing request on claimant's behalf, appealing KRC's proposal to discontinue claimant's specialized diet stipend.

5. On April 14, 2020, Celia Pinal, KRC Director of Client Services, held an informal meeting with claimant's mother by videoconference to discuss KRC's proposed action to terminate KRC's monthly stipend for claimant's specialized diet. During the informal meeting, KRC explained the two bases for its proposed action. First, that claimant's specialized diet did not alleviate her developmental disability of autism, and second, that claimant's specialized diet could be funded by generic funding sources – specifically, CalFresh benefits received by claimant for food purchases. Claimant's mother objected that claimant needed her specialized diet and supplements to be able to live independently, explaining that claimant would be unable to live independently without the diet because she would become physically ill, suffer seizures, and exhibit extreme behaviors. Mother also said the diet was very expensive and claimant did not receive enough income through supplemental security income and food stamps to pay for the diet.

6. KRC declined to change its proposed action at the informal meeting. KRC failed to send claimant a summary of the informal meeting. However, there is no evidence claimant suffered any actual prejudice as a result of not receiving a summary. Claimant filed exhibits for the hearing addressing both bases for KRC's proposal to terminate funding for claimant's specialized diet. Claimant's mother was prepared at the hearing to testify and examine witnesses on both bases.

Claimant's Individual Program Plan

7. Pursuant to her April 11, 2020 Individual Program Plan (IPP), claimant resides in her own apartment with 24-hour supportive living services and protective supervision. Claimant requires assistance to complete each of her activities of daily living such as personal hygiene, dressing, meal shopping, cooking, laundry, and household cleaning. She also requires 24-hour supervision for safety. KRC funds claimant's supported living services and protective supervision.

8. Claimant participates two days per week in a vocational volunteer work program, shredding paper, wiping down tables, and performing other tasks as directed by staff. Claimant also participates in community integration activities, engaging with peers on community outings for social events, movies, bowling, swimming, and other activities.

Claimant's Specialized Diet

9. Claimant exhibited symptoms of gastrointestinal problems at a young age, suffering from chronic diarrhea, vomiting and allergic skin rashes. Testing in 1998 found allergies to milk products, and certain nuts and fruits. Testing in 1999 led to a diagnosis of celiac disease, an autoimmune disease where eating wheat products or any other food containing gluten causes inflammation and damage to the mucosa in

the small intestine, and may cause other conditions including dermatitis herpetiformis (an itchy skin rash) which claimant was diagnosed with in 2003, and potentially severe long-term health effects.

10. Following claimant's diagnosis of celiac disease, her mother researched and developed a specialized, strict gluten-free diet for claimant that allows claimant to eat certain naturally gluten-free foods, washed to remove any possible contamination with gluten, and certified gluten-free foods. Claimant also receives medically prescribed over-the-counter vitamin supplements, although no prescription for the vitamin supplements was offered in evidence.

11. Before starting her specialized diet, claimant exhibited seizures and problem behaviors including non-compliance, tantrumming, eloping in the community, damaging property, and self-injury. These behaviors were severe enough that staff members in her former group home could not manage them, making it difficult or impossible for claimant to live independently in the group home. Mother testified that, after claimant began her specialized diet, her problem behaviors decreased substantially, and her seizures and skin rash outbreaks stopped. Mother also testified that in the few instances where claimant has deviated from her specialized diet by accidentally eating a food item containing gluten, claimant has experienced illness and a resumption of problem behaviors that has prevented claimant from performing activities of daily living, participating in her volunteer work program or community integration activities, or otherwise working towards the objectives of her IPP.

12. KRC does not dispute that claimant suffers from celiac disease, or that claimant requires her present specialized diet to live independently and otherwise follow her IPP. Since at least 2010, claimant's IPP has acknowledged claimant's need

for a specialized diet free from wheat, gluten and nuts, and has provided funding for such a diet.

13. Mother was unable to state the approximate current monthly cost of claimant's specialized diet. Claimant's prescribed vitamins cost approximately \$225 per month. Each month, mother submits to KRC for reimbursement an invoice and attached receipts for claimant's specialized diet and vitamin supplements. Mother invoices KRC for a portion of the vitamin cost, and the difference between the cost of the certified gluten-free items and the cost of comparable non-gluten-free items. Claimant's evidence included a list of 19 food items available in certified gluten free items being from 34 percent to 1,000 percent higher than the cost of the comparable non-gluten free items for an amount slightly over \$700.

14. KRC's evidence included an online article regarding naturally gluten-free foods that could be eaten by someone on a gluten-free diet, and a list of gluten-free products available from one retailer. However, KRC did not offer evidence of what it believed to be an appropriate cost of a specialized gluten-free diet for claimant, or evidence that claimant's maximum reimbursable monthly cost of \$750 was excessive.

Previous Fair Hearings

15. The parties have twice before litigated the issue of KRC's funding for claimant's specialized diet with the Office of Administrative Hearings (OAH). In May 2010, KRC notified claimant of its proposed action to terminate its funding of claimant's specialized diet based on Welfare and Institutions Code section 4648, subdivision (a)(15), which prohibited a regional center from purchasing experimental

treatments, therapeutic services, or devices. At a hearing in May 2011, in addition to contending that claimant's specialized diet was an experimental treatment for claimant's celiac disease, KRC asserted for the first time the alternative argument that KRC was required to terminate funding for claimant's diet because the diet was not a treatment for claimant's developmental disability of autism, or for a medical condition arising as a direct result of claimant's autism. KRC had not included this alternative basis for terminating funding in its May 2010 NOPA provided to claimant.

16. At the May 2011 hearing, claimant presented evidence establishing that a gluten and wheat-free specialized diet such as claimants was a recognized treatment for celiac disease; however, claimant's representative was not adequately prepared to address KRC's alternative argument for terminating funding. In a decision issued May 31, 2011, Administrative Law Judge Humberto Flores held KRC had not established that a gluten and wheat-free diet was an experimental treatment for celiac disease. Judge Flores also found KRC had failed to give claimant adequate notice in accordance with Welfare and Institutions Code sections 4701 and 4710 of its alternative argument that KRC was required to terminate funding for claimant's diet because the diet was not a treatment for claimant's developmental disability of autism, or for a medical condition arising as a direct result of claimant's autism. The May 31, 2011 decision therefore found cause did not exist to terminate funding of claimant's specialized diet based on KRC's alternative argument, and expressly stated it made no factual findings or legal conclusions on the merits of KRC's alternative argument.

17. In May 2014, KRC again notified claimant in a NOPA of its decision to terminate KRC's funding for claimant's specialized diet. KRC based its decision on Welfare and Institutions Code section 4512, subdivisions (a) and (b), which define regional center-supplied services and supports for persons with developmental

disabilities as including, among other things, specialized services and supports directed toward the alleviation of a developmental disability. KRC contended claimant's specialized diet was not directed toward the alleviation of claimant's developmental disability because claimant's celiac disease was unrelated to her autism. At the hearing of claimant's appeal of KRC's decision to terminate funding, the parties submitted conflicting research studies on the issue of whether celiac disease was related to autism, with claimant submitting two research studies suggesting a relationship between the two conditions, and KRC submitting an abstract summarizing a research study that KRC argued indicated the absence of a relationship. Claimant's mother testified that when claimant did not follow her gluten-free diet, she exhibited problem behaviors that her group home staff could not manage, and an extremely painful rash that made her behaviors worse.

18. The hearing was again held before Judge Flores. His August 8, 2014 decision found KRC had not established grounds for terminating funding for claimant's specialized diet. The evidence presented on the issue of whether celiac disease was related to autism was inconsistent, and KRC had not called an expert to address the inconsistent research studies. Judge Flores found that the abstract submitted by KRC did not include a detailed explanation of the findings and conclusions of the research study, and was insufficient by itself to establish the absence of a relationship between celiac disease and autism. Additionally, Judge Flores' decision found claimant's celiac disease had a direct effect on her behaviors that were caused by her autism, and claimant's specialized diet reduced her problem behaviors by reducing the serious physical symptoms of claimant's celiac disease. Finally, Judge Flores concluded that the specialized diet was a service and support appropriately funded by KRC as "physical habilitation" or "specialized medical care" for claimant under Welfare and Institutions Code section 4512, subdivision (b).

Funding Sources Available to Claimant

19. At the time of the present hearing, in addition to her specialized diet stipend, claimant received monthly income of \$944 in federal supplemental security income benefits, \$57 in state supplementary payment benefits, and \$204 in state CalFresh benefits for food purchases. Claimant's mother agreed that the CalFresh benefits should be applied toward the cost of claimant's specialized diet. KRC suggested that a portion of claimant's supplemental security income benefits and supplementary payment benefits should also be allocated to claimant's specialized diet to offset any amounts payable by KRC, but did not offer evidence of the amount of, or bases for, a proposed allocation.

Relationship Between Celiac Disease and Autism

20. As support for its contention that claimant's specialized diet does not alleviate her developmental disability of autism, KRC presented a research study published in 2013 in JAMA Psychiatry, entitled "A Nationwide Study of the Association between Celiac Disease and the Risk of Autism Spectrum Disorders." (Exh. 5a.) The study's purpose was to "examine the association between ASD [autism spectrum disorder] and CD [celiac disease] in individuals grouped by their small intestine histopathological findings at biopsy: (1) VA [villious atrophy] (equal to CD), (2) inflammation without VA, or (3) normal mucosa but a positive CD serological test result." (Exh. 5a, p. 83.) The study noted celiac disease "is associated with substantial comorbidity, including neurologic and psychiatric disorders." (*Id.*) The study also noted, "Most case reports suggest an association between autism spectrum disorders and [CD] or positive CD test results, but larger studies are contradictory." (Exh. 5a, p. 82.) Finally, the study noted at page 86:

The role of gluten and a gluten-free diet in individuals with an ASD is under debate. One study reported that a glutenfree diet in 15 children with ASDs had no effect; however, after the trial, parents of 9 of the children wanted to continue with the diet because they thought their autistic children had improved. A Cochrane review found only a small effect of gluten- and casein-free diets on ASD, whereas a later randomized, single-blind study reported that dietary intervention with a gluten- and casein-free diet had a beneficial effect in some children with ASD.

21. The study found that subjects not diagnosed with autism at the time of their intestinal biopsy had higher-than-expected risks of later being diagnosed with ASD, from 1.4 times the expected risk for subjects whose biopsies found VA, to 2.0 times the expected risk for subjects with inflammation without VA, to 3.1 times the expected risk for subjects with normal intestinal mucosa but a positive serological test result for CD.

22. The study concluded, "Although this study found no association between CD or inflammation and earlier ASD's, there was a markedly increased risk of ASDs in individuals with normal mucosa but a positive CD serological test result." (Exh. 5a, p. 82.) Claimant's 1999 diagnosis of celiac disease was apparently based on a positive serological test result. (See Exh. L.). No evidence was presented of a biopsy of claimant's small intestine.

23. KRC offered no expert testimony to explain the findings of the 2013 study, or how to relate the study's findings to claimant's diagnoses and test results.

LEGAL CONCLUSIONS

Jurisdiction and Burden of Proof

1. The Lanterman Act governs this case. (Welf. & Inst. Code, § 4500 et seq.)² An administrative "fair hearing" to determine the respective rights and obligations of the consumer and the regional center is available under the Lanterman Act. (§§ 4700-4716.) Claimant requested a fair hearing to appeal KRC's decision to terminate funding for her specialized diet. Jurisdiction in this case is established. (Factual Findings 1-4.)

2. A regional center seeking to change a service it has previously approved has the burden to demonstrate its proposed decision is correct. "Except as otherwise provided by law, a party has the burden of proof as to each fact the existence or nonexistent of which is essential to the claim for relief or defense that he is asserting." (Evid. Code, § 500; see also, *McCoy v. Board of Retirement* (1986) 183 Cal.App.3d 1044, at p. 1051, note 5 ("As in ordinary civil actions, the party asserting the affirmative at an administrative hearing has the burden of proof").) Because no other statute or law specifically applies to the Lanterman Act, the standard of proof required of KRC in this case is preponderance of the evidence. (Evid. Code, § 115 ("Except as otherwise provided by law, the burden of proof requires proof by a preponderance of the evidence").)

² All further statutory references are to the Welfare and Institutions Code unless indicated otherwise.

The Lanterman Act

3. The Lanterman Act acknowledges the state's responsibility to provide services and supports for developmentally disabled individuals and their families. (§ 4501.) The state agency charged with implementing the Lanterman Act, the Department of Developmental Services (DDS), is authorized to contract with regional centers to provide developmentally disabled individuals with access to the services and supports best suited to them throughout their lifetime. (§ 4520.)

4. The "services and supports" provided to a consumer include specialized services and supports directed toward the alleviation of a developmental disability, or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with a developmental disability, or toward the achievement and maintenance of independent, productive, and normal lives. (§ 4512, subd. (b).) A regional center is required to secure the services and supports that meet the needs of the consumer, as determined in the consumer's individual program plan (IPP). (§ 4646, subd. (a)(1).) The determination of which services and supports are necessary for each consumer must be made through the IPP process. (§ 4512, subd. (b).) The determination must be made on the basis of the needs and preferences of the consumer or, when appropriate, the consumer's family, and include consideration of a range of service options proposed by individual program plan participants, the effectiveness of each option in meeting the goals stated in the IPP, and the costeffectiveness of each option. (§ 4512, subd. (b).) If the parties cannot agree on the provision of a service after the IPP process, a hearing officer must make the decision after a fair hearing. (§ 4646, subd. (g).)

5. When purchasing services and supports for a consumer, a regional center must ensure, among other things, "[c]onformance with the regional center's purchase

of service policies, as approved by the [Department of Developmental Services] pursuant to subdivision (d) of Section 4434," and "[u]tilization of generic services and supports when appropriate." (§ 4646.4, subd. (a)(1) and (2).) Regional center funds "shall not be used to supplant the budget of any agency that has a legal responsibility to serve all members of the general public and is receiving public funds for providing those services." (§ 4648, subd. (a)(8).) If a service specified in a client's IPP is not available through a generic agency, the regional center may be required to fund the service if the service is necessary for the client to meet the goals set forth in the IPP. (§ 4648, subd. (a)(1); see also, § 4659, subds. (a) and (b).)

KRC's Obligation to Fund Claimant's Specialized Diet

6. Claimant's existing IPP states claimant requires a specialized diet free from wheat, gluten and nuts. The evidence demonstrated claimant requires her specialized diet to maintain an independent, productive, and normal life and pursue her IPP objectives. When claimant has deviated from her specialized diet by accidentally eating a food item containing gluten, she has experienced illness and a resumption of problem behaviors that has prevented her from performing activities of daily living, participating in volunteer work programs or community integration activities, or otherwise working towards the objectives of her IPP.

7. KRC's evidence did not establish that claimant's specialized diet does not alleviate her developmental disabilities of autism or severe intellectual disability. The 2013 study presented by KRC regarding the association between celiac disease and autism spectrum disorder noted an ongoing scientific debate concerning the role of gluten and a gluten-free diet in individuals with autism, and acknowledged most case reports suggest an association between autism and celiac disease. The 2013 study itself found no association between celiac disease or inflammation and earlier autism

spectrum disorders but did find what it described as a markedly increased risk of ASDs in individuals with a positive CD serological test result whose biopsy shows normal small intestine mucosa. This description appears at least somewhat applicable to claimant, whose celiac disease was apparently diagnosed in 1999 through a positive CD serological test result, although no biopsy of claimant was offered in evidence.

8. To establish that claimant's specialized diet does not alleviate her developmental disabilities of autism or severe intellectual disability, expert testimony would be required to resolve the difference between the findings of the 2013 study and other studies it notes regarding the relationship between celiac disease and autism, to clarify the applicability of the 2013 study's findings to claimant, based on her test results and diagnosis, and to establish that claimant's specialized diet does not alleviate her intellectual disability. The 2013 study did not address whether claimant's diet might alleviate her severe intellectual disability, and KRC presented no evidence on that point.

9. Additionally, it was undisputed at hearing that claimant's diet is necessary for claimant to control her behaviors and achieve and maintain an independent, productive, and normal life, as provided in Welfare and Institutions Code sections 4512, subdivision (b). On this basis, the evidence indicated claimant required her specialized diet as a service or support to meet her individual needs and objectives established through the IPP process.

10. KRC established that generic funding for claimant's diet is available from CalFresh in the amount of \$204.00 per month. It is therefore appropriate to reduce the maximum amount of KRC's monthly stipend for claimant's specialized diet by that amount.

ORDER

Claimant's appeal is granted in part. KRC shall continue to provide claimant a stipend funding her specialized gluten-free diet pursuant to her 2020 IPP, except that KRC shall reimburse claimant a maximum amount of \$546 per month. This reimbursement shall continue until changed circumstances or a new IPP warrant otherwise.

DATE:

ROBER G. MARTIN Administrative Law Judge Office of Administrative Hearings

NOTICE

This is the final administrative decision; both parties are bound by this decision. Either party may appeal this decision to a court of competent jurisdiction within 90 days.