BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of:

CLAIMANT,

v.

SAN ANDREAS REGIONAL CENTER, Service Agency.

OAH No. 2022050600

DECISION

Administrative Law Judge Juliet E. Cox, State of California, Office of Administrative Hearings, heard this matter on July 14, 2022, by videoconference.

Claimant's parents appeared for him at the hearing. Claimant was not present.

Executive Director's designee James Elliott appeared for service agency San Andreas Regional Center (SARC).

The matter was submitted for decision on July 14, 2022.

FACTUAL FINDINGS

1. Claimant is a young adult who lives with his parents and a minor sibling. Claimant is conserved, and his parents are his conservators. Claimant is eligible under the Lanterman Developmental Disabilities Services Act (the Lanterman Act, Welf. &

Inst. Code, § 4500 et seq.) for services from SARC because claimant is substantially disabled by autism spectrum disorder, a developmental disability.

2. Claimant wishes to arrange to receive his SARC-funded services through the Self-Determination Program (SDP; see Welf. & Inst. Code, § 4685.8.) Claimant and SARC tentatively have agreed (as described more fully in Finding 22, below) on an annual SDP individual budget for claimant. They disagree, however, as to whether SARC may approve the spending plan claimant has proposed for those funds (described below in Finding 25).

3. On May 3, 2022, SARC issued a Notice of Proposed Action (NOPA) to claimant, stating that SARC would deny approval for an SDP individual budget and spending plan that include "funding of the medication/supplements" on an attached list. The NOPA justifies this disapproval on the ground that SARC may fund only services or supports that are "appropriate and cost-effective," but not "treatments, medications, or interventions that are not scientifically valid or clinically proven to be safe, effective, and appropriate." Claimant filed a timely fair hearing request.

Claimant's Developmental Disability

4. Claimant was born in 2002, in Pennsylvania. According to his parents, he first received a diagnosis of autism spectrum disorder when he was 3 years old.

5. Claimant and his family moved from Pennsylvania to Ohio when claimant was young. Claimant received services in Ohio for his developmental disability under a statutory system that is similar but not identical to California's Lanterman Act.

6. In 2019, claimant's family moved from Ohio to California. SARC accepted claimant as a SARC consumer in October 2019, on the basis of claimant's autism

spectrum disorder. Claimant and SARC agreed to claimant's first Individual Program Plan (IPP) in November 2019.

7. According to the IPP and to claimant's parents, aside from a few hand signs claimant does not communicate verbally. His gross motor skills are normal for a young adult, but he was not reliably toilet trained until he was in his teens. He requires constant supervision for his own personal safety, and is unable to perform any age-appropriate self-care activities independently.

8. Claimant's parents testified, and reported to SARC during claimant's IPP development, that claimant has numerous food allergies and sensitivities as well as problems with digestion and sleep. They describe claimant as suffering from "nutritional deficiency, metabolic disorder, and heavy metal toxicity" in addition to autism spectrum disorder. They offered no medical evidence supporting these additional diagnoses or connecting them with claimant's developmental disability.

Claimant's Nutritional Regimen

9. In Ohio, in approximately 2008, claimant began seeing Phillip C. DeMio, M.D., a physician whose website states that he "focuses on the medical testing and treatment for your loved one with autism, AD/HD, Lyme and other related diseases." Claimant provided a letter from Dr. DeMio, dated March 29, 2022, stating that claimant is Dr. DeMio's patient. Dr. DeMio did not testify.

10. Dr. DeMio's letter states that claimant "is taking a number of daily supplements and it is necessary to continue to take these on an ongoing basis." The letter includes a chart listing the supplements, sorted according to the primary condition Dr. DeMio asserts that each substance treats and including the protocol for administering each substance to claimant.

a. For "autism," the chart lists 19 substances. Some, such as "Doctor's Best Serrapeptase" and "Calcium D-Glucarate" are for oral consumption. Others are for use on the skin or in the nose. To explain these substances' link with autism treatment, Dr. DeMio states, "Complications of autism can include a broad range of medical conditions such as indigestion, immune dysfunction, allergy, gastrointestinal disorders, malnutrition, detoxification, and virus/yeast/parasite issues."

b. For "nutritional deficiency," the chart lists 21 substances. Some are foods, such as honey, coconut water, and olive oil. Others are vitamin and mineral supplements, such as Vitamin C and magnesium citrate. Still others are freeze-dried beef products in capsule form, including heart, liver, and brain tissues. To explain these substances' value to claimant, Dr. DeMio states, "People with nutritional deficiency are at risk for serious complications that can lead to a variety of health problems. These can include problems of digestion, skin problems, stunted or defective bone growth, and even dementia."

c. For "metabolic disorder," the chart lists 28 substances. They include probiotic tablets, garlic and ginger extracts, vinegar, medicinal mushrooms, and "Hyland's homeopathic remedies." About this category, Dr. DeMio states, "Complications of metabolic disorder include health problems such as blood vessel and heart disease, which can lead to heart attacks and strokes. Metabolic disorder also increases your risk of diabetes."

d. Finally, for "heavy metal toxicity," the chart lists 7 substances, including citrus pectin, zeolite (an aluminum-silica compound), and "Dr.

Tobias Colon Cleanse." Dr. DeMio explains these compounds' role in claimant's treatment by stating, "Heavy metals such as [lead] and [mercury] have serious health consequence and a wide range of damages."

e. Some of the supplements on Dr. DeMio's chart appear to overlap in composition or function; for example, the chart includes several digestive enzyme preparations. Nevertheless, no product appears on the chart twice. Some of the 75 products are for once-daily dosing, but the chart states that claimant should take or apply many of them two, three, or four times per day.

11. Claimant follows a gluten-free, casein-free, and sugar-free diet, and uses most or all of the substances listed on Dr. DeMio's chart in the manner the chart describes.

a. Claimant's father testified that claimant's current, actual diet and supplement regimen reflects Dr. DeMio's recommendations. He also testified, however, that he and claimant's mother have altered claimant's supplement regimen and diet over the years, adding and removing substances in response not only to Dr. DeMio's recommendations but also to recommendations from parents of similar children.

b. Claimant's father testified further that although Dr. DeMio did regular blood testing[1] of claimant in the past, claimant's parents have relied more recently on their own observations of claimant's behavior and condition to determine whether changes in claimant's supplement regimen and diet have been helpful or harmful.

c. The evidence did not establish exactly which supplements claimant currently uses, in what quantities, or following what protocols. The evidence did not establish that anyone other than claimant's parents knows exactly what foods and dietary supplements claimant consumes, or monitors his responses to those substances.

12. On February 28, 2022, claimant saw Dr. Sanford C. Newmark, M.D., a pediatrician at the University of California, San Francisco, whose practice emphasizes care for "children with autism, attention-deficit/hyperactivity disorder (ADHD) and other developmental or chronic childhood conditions." Claimant presented a note by Dr. Newmark recommending an amino acid supplement or a prescription drug to improve claimant's sleep, and directing claimant to "Continue other supplements." The evidence did not establish whether Dr. Newmark knew claimant's entire supplement regimen when he gave this advice, and Dr. Newmark did not testify. Claimant has seen Dr. Newmark only once.

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[1] Claimant's parents did not identify any specific laboratory tests. Dr. DeMio's letter states only, "I have ordered repeated lab tests as needed to continue to monitor [claimant's] progress on an ongoing basis (eg: CMP, CBC/Diff, Urine Toxic Metals, Red Blood Cell Elements, etc.)."

Self-Determination Program Principles

13. The Legislature added the SDP to the Lanterman Act "to provide participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their IPP." (Welf. & Inst. Code, § 4685.8, subd. (a).)

14. An IPP for an SDP participant is subject to the same requirements as for Lanterman Act consumers who do not participate in the SDP. (Welf. & Inst. Code, § 4685.8, subd. (c)(4).) Just as for Lanterman Act consumers who do not participate in the SDP, the SDP consumer's IPP identifies the consumer's needs and goals, and describes services the regional center will provide or fund to meet those needs and goals. (*Id.*, §§ 4646, 4685.8, subd. (b)(2)(H)(i).)

15. In the SDP, the consumer directs spending from an "individual budget," representing "the amount of regional center purchase of service funding available to the participant for the purchase of services and supports necessary to implement the IPP." (Welf. & Inst. Code, § 4685.8, subd. (c)(3).) An SDP participant's initial annual individual budget is "the total amount of the most recently available 12 months of purchase of service expenditures," adjusted to reflect changes such as "prior needs or resources that were unaddressed." (*Id.*, subd. (m)(1).) The total budget may not exceed the amount that "would have been expended using regional center purchase of service funds regardless of the individual's participation in the" SDP. (*Id.*, subd. (m)(1)(B)(ii).)

16. The SDP consumer directs spending from this individual budget according to an approved "spending plan," which must "identify the cost of each good, service, and support that will be purchased with regional center funds." (Welf. & Inst.

Code, § 4685.8, subd. (c)(6).) All such goods, services, and supports must be "necessary to implement" the consumer's IPP. (*Id.*, subds. (c)(6), (d)(3)(C).)

17. Services and supports that an IPP identifies for a regional center to purchase must conform to "the regional center's purchase of service policies, as approved by" the California Department of Developmental Services (DDS). (Welf. & Inst. Code, § 4646.4, subd. (a)(1).) Further, and "[n]otwithstanding any other law or regulation," a regional center may not

> purchase experimental treatments, therapeutic services, or devices that have not been clinically determined or scientifically proven to be effective or safe[,] or for which risks and complications are unknown. Experimental treatments or therapeutic services include experimental medical or nutritional therapy when the use of the product for that purpose is not a general physician practice.

(*Id.*, § 4648, subd. (a)(17).) SARC's DDS-approved policy governing purchase of health care goods and services that are not available to a consumer through other sources states that SARC will fund only goods and services that are "generally recognized by clinical professionals as safe [and] effective."

18. Because the SDP is new, DDS has not yet developed formal regulations to govern it. DDS has issued directive memoranda, however. (Welf. & Inst. Code, § 4685.8, subd. (p)(2).) A directive DDS issued on January 13, 2022, integrates the principles summarized in Findings 13 through 17 by stating that "[b]efore including any good or service in an individual budget or SDP spending plan, the planning team must first be clear about how the good or service addresses an identified need or goal

in the IPP." The IPP must identify "the type and amount of all the needed goods and services to achieve the planned outcomes and ensure the participant's health and safety." Despite the SDP's flexibility, "[e]xperimental or prohibited treatments shall not be provided."

Claimant's SDP Budget and Proposed Spending Plan

19. Claimant's November 2019 IPP notes that claimant requires constant supervision, which he received at the time from his parents at home and from school staff members at school.[2] The IPP identifies respite services through a SARC vendor as services claimant and his family need. For various reasons, however, including the COVID-19 pandemic, claimant has never used any such services.

20. Claimant's parents have been eager to participate in the SDP program, because they participated in a similar program in Ohio. They worked with an independent facilitator, Melanie Gonzales, in 2021 to prepare a Person-Centered Plan to supersede claimant's November 2019 IPP as the statement of principles guiding SARC's provision of services to him through the SDP. SARC has not approved claimant's 2021 Person-Centered Plan, because of the issues in dispute at this hearing.

21. As drafted and proposed by Gonzales and claimant's parents, the 2021 Person-Centered Plan continues to emphasize claimant's need for supervision at all times by a responsible adult, and his need for direct assistance with almost every activity of daily living. To meet these needs, the plan states that SARC will "provide a

[2] Claimant was in high school in November 2019.

budget to [claimant] and his family that includes money for 114 hrs [monthly] of Personal Assistant, 24 hrs [monthly] of in-home respite, and social recreation."

22. Claimant and SARC have agreed on an SDP individual budget that would be adequate to cover claimant's needs for personal assistance, parental respite, and recreation, as described in the draft 2021 Person-Centered Plan and summarized above in Finding 21. This budget is approximately $56,600 per year.[3]

23. The draft 2021 Person-Centered Plan also goes into significant detail about claimant's need for a special diet and for an extensive regimen of nutritional supplements. The plan states that "it's important that [claimant's nutritional regimen] is covered under the SDP program in order to maintain [his] maximum wellness."

24. SARC has not agreed that the nutritional program described in the draft 2021 Person-Centered Plan and in Dr. DeMio's March 2022 letter is a "need," within the meaning of the Lanterman Act's requirement that SARC plan to provide services and supports that meet claimant's developmental disability needs. For this reason, SARC has not proposed to include any funding for such supplements in claimant's SDP individual budget. The draft 2021 Person-Centered Plan does not state that SARC's budget for claimant will include funds for any foods, drugs, or nutritional supplements.

25. Claimant has proposed an SDP spending plan to SARC. This spending plan proposes to spend nothing on respite services for claimant's parents or on personal assistance or recreational programs for claimant. Instead, claimant's proposed SDP spending plan would spend the entire $56,600 annual budget on the

[3] The evidence did not establish the exact individual budget amount, but claimant does not contest the amount.

same list of nutritional supplements that Dr. DeMio included in the letter described in Finding 10. (This list, as re-organized by claimant's father with his best reasonable estimate of each item's annual cost, is the list SARC attached to the NOPA described above in Finding 3.)

Evidence Regarding Safety and Clinical Efficiency

26. Robert Wallerstein, M.D., is a board-certified pediatrician and medical geneticist who serves as a physician consultant to SARC. He testified that general practice among pediatricians treating children with autism spectrum disorder does not involve using nutritional supplements to treat any aspects of this disorder. Dr. Wallerstein has reviewed the list of dietary supplements that Dr. DeMio recommends in his letter described above in Finding 10, and knows of no reason to believe that any item on that list, or the entire regimen all together, is clinically effective to treat autism spectrum disorder or any of its symptoms.

27. Julie Lussier, R.N., is the health services coordinator for SARC. Although Lussier is not a physician, her role coordinating and supervising medical services for SARC consumers has made her familiar with general physician practices in treating common developmental disabilities including autism spectrum disorder. Lussier also does not believe that general practice among pediatricians treating children with autism spectrum disorder involves using nutritional supplements to treat any aspects

of this disorder.[4] She noted as well that nutritional supplements, like drugs or foods, may have negative or dangerous effects on people who consume them. Lussier has no basis for concluding that claimant's supplement regimen, in total, is safe, and believes that a person on such an extensive regimen could use it safely, if at all, only with close medical monitoring.

28. Claimant presented evidence that extensive medical and scientific literature exists examining various nutritional interventions for autism. Some of the articles claimant identified had been retracted by their authors or publishers, however, and some stated their authors' conclusions that the nutritional interventions the authors had evaluated were ineffective. Some of the articles were about conditions that claimant does not have, such as infant malnutrition resulting from famine. No evidence identified which of the many articles in evidence were, and were not, published in reputable, peer-reviewed journals. No expert in medicine, psychology, or nutrition testified that he or she and similar experts consider any of the articles claimant identified to be informative or persuasive with respect to clinical treatment for children or young adults with mental and physical health challenges similar to claimant's.

29. Gonzales testified that she drafted claimant's 2021 Person-Centered Plan to characterize claimant's nutritional supplement regimen as a need, and to advocate its inclusion in claimant's SDP spending plan, because she understands based on her

[4] In particular, and based on her review of medical evidence and her experience as a nurse and as SARC's health services coordinator, Lussier firmly rejects the proposition, implicit in Dr. DeMio's recommendations, that a causal link exists between "heavy metal toxicity" and autism spectrum disorder.

long career with the Regional Center of the East Bay that such supplements are not experimental, and are clinically effective. Although Gonzales described a long career providing supportive services to persons with developmental disabilities, she did not testify to any medical training or to her basis for believing that claimant's supplement regimen is safe or clinically effective. Her non-medical opinion is not persuasive.

30. No physician or other expert testified to contradict Lussier's and Dr. Wallerstein's testimony. Their testimony is persuasive. The evidence does not establish that any of the supplements for which claimant seeks SARC funding are generally accepted in the medical community as clinically effective, in any dose or protocol, as treatments for autism spectrum disorder or any of its symptoms.

LEGAL CONCLUSIONS

1. The Lanterman Act entitles claimant to an administrative fair hearing to review SARC's service decisions. (Welf & Inst. Code, § 4710 et seq.) Claimant bears the burden in this matter to prove that the Lanterman Act requires SARC to deliver the services and supports he requests.

2. The matters stated in Findings 13 through 18 confirm that the SDP permits a consumer or the consumer's parents or conservators to meet the consumer's identified needs in creative, flexible ways. Nevertheless, this flexibility is not limitless. In particular, the SDP does not permit a consumer or the consumer's parents or conservators to ignore the consumer's identified needs in favor of spending public funds on services or supports that do not meet those needs. (Welf. & Inst. Code, § 4685.8, subd. (c).)

3. The matters stated in Findings 9 through 12 do not demonstrate that claimant's supplement regimen, as described by Dr. DeMio and by claimant's parents, meets any need relating to claimant's developmental disability. Moreover, the matters stated in Findings 26 through 30 show that the nutritional supplement regimen described in Findings 9 through 12 is at best experimental. These matters, all together, do not show that this regimen has been clinically determined or scientifically proven to be effective or safe, that it is in general use among physicians, or that any medical or psychological professional knows and monitors its risks to claimant. (See Welf. & Inst. Code, § 4648, subd. (a)(17).) Finally, and in light of the matters stated in Finding 17, the matters stated in Findings 26 through 30 show that the regimen described in Findings 9 through 12 does not conform to SARC's DDS-approved policy governing SARC's purchase of health care services.

4. SARC has not erred either by declining to identify Dr. DeMio's supplement regimen as a need SARC must arrange to meet, or by declining to approve an SDP spending plan that funds that supplement regimen in lieu of personal assistance and recreation for claimant and respite for claimant's parents.

ORDER

Claimant's appeal from SARC's NOPA dated May 3, 2022, is denied.

DATE:

JULIET E. COX
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.