

**BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA**

In the Matter of:

CLAIMANT,

vs.

NORTH LOS ANGELES COUNTY REGIONAL CENTER,

Service Agency.

OAH No. 2022030906

DECISION

Glynda B. Gomez, Administrative Law Judge, Office of Administrative Hearings (OAH), State of California, heard this matter on August 17, 2022, by videoconference.

Stella Dorian, Fair Hearing Representative, represented the North Los Angeles County Regional Center (NLACRC or Service Agency).

Claimant's mother represented Claimant. (names have been omitted to protect the privacy interests of Claimant and his family.) Claimant was not present.

Oral and documentary evidence was received. The record was closed, and the matter was submitted for decision on August 17, 2022.

Issue

Is Service Agency prohibited from paying the conference fee for Claimant's mother to attend the "Dear Mom" conference?

Evidence

The ALJ considered the testimony of Dr. Arpi Arabian, Cristina Preuss and Claimant's mother and Service Agency's Exhibits 1-4, and 6-14.

FACTUAL FINDINGS

Jurisdictional Matters

1. Claimant is a seven-year-old boy eligible for regional center services as a person with Intellectual Disability with a secondary diagnosis of Down Syndrome.
2. On January 27, 2022 Claimant requested funding in the amount of \$150 for his mother to attend the April 9, 2022 "Dear Mom" conference in Laguna Beach, California. On March 18, 2022, NLACRC issued a Notice of Proposed Action (NOPA) denying Claimant's request. Claimant filed a timely request for hearing appealing the denial and this hearing ensued. All jurisdictional requirements have been met.

"Dear Mom" Conference

3. Outcome 4 of Claimant's current Individual Program Plan (IPP) provides: "[Claimant's] parents will obtain education in order to assist them in helping their son continue to grow and learn. (May 2019 to May 2021)" The outcome was carried over

from a May 22, 2019 addendum to Claimant's May 2, 2019 IPP. There was no explanation for the time indication in the IPP or through testimony or documentary evidence at the administrative hearing.

4. Claimant's mother had received funding to attend the "Dear Mom" conference in 2019. The "Dear Mom" conference focuses on the community of parents of people who have Down Syndrome and adults who have Down Syndrome. According to Claimant's mother, the conference has been a place for her to feel "part of a community," learn and feel supported. At the Dear Mom conference, Claimant's mother had the opportunity to interact with other similarly situated parents and with adults who have Down Syndrome. She received valuable information on accessing insurance and generic resources at the event and planning for Claimant's future as an individual with Down Syndrome. The "Dear Mom" conference was one of a very few in-person conferences offered in 2022 because of continuing Covid-19 concerns. Claimant's mother paid for and attended the "Dear Mom" conference.

5. The informational brochure that Claimant's mother provided to NLACRC with her request for funding, did not give the names or qualifications of speakers at the conference. Although some professionals were scheduled to present at the conference, the majority of speakers were either people who have Down Syndrome or their parents. There was also an art exhibit featuring the work of people with Down Syndrome. There was no indication from the materials that the conference would focus on any experimental treatments. In fact, the materials made it clear that the focus of the conference was on the shared experience of people with Down Syndrome and their family members, connecting them with each other, building community and self-advocacy. There was no evidence that the conference promoted treatments or treatments that were not research or evidenced based.

6. Arpi Arabian, Psych. D. (Arabian), NLACRC's Behavioral Services Supervisor, is an experienced psychologist with extensive experience working with the developmentally-disabled population.

7. Cristina Preuss (Preuss) is NLACRC's Director of Consumer Services and has worked for NLACRC in various capacities for 10 years.

8. According to the credited testimony of Arabian and Preuss, NLACRC has developed a new internal process to review requests for conference attendance. Written guidance has been provided to NLACRC staff, but has not been added to its purchase of service policy, posted on its public website or distributed to its constituency. Together, Preuss and Arabian review requests for conference funding and determine whether the conference provides evidence and research based content. NLACRC has concerns about the reliability and accuracy of the information that is imparted to parents and consumers at conferences and seeks to avoid events that disseminate information on experimental treatments and treatments that are not evidence or research based. The concern is based upon the statutory mandate contained in Welfare and Institutions Code section 4648 that NLACRC not fund experimental treatments.

9. NLACRC's March 18, 2022 Notice of Proposed Action cites the following as its reason for denying the request:

Based on the information available, the Dear Mom conference is not providing a platform to teach, train, or provide information of [sic] empirical information or research related to Down Syndrome, but rather is a social experience for mothers to listen to other parents speak

about their personal stories and experiences related to having a child with Down Syndrome.

After review of the available conference information, speakers and their topics, NLACRC identified that the overall conference is a social networking opportunity amongst parents rather than a structured training.

Additionally, the speaker-led workshops are not facilitated by licensed professionals or experts in the field of Down Syndrome, but rather family members who are speaking of their personal life experiences. Therefore, NLACRC is denying your request for funding of the Dear Mom Conference admission fee.

(Ex. 11.)

10. According to Preuss and Arabian, generic resources such as Club 21 and Down Syndrome Association conferences provide accurate research and evidence-based information and provide virtual and in-person conferences. Claimant's mother provided credible testimony about her involvement with and research about those organizations. Specifically, Club 21 has a membership fee which must be paid as a prerequisite to participation in any conference, the membership fee exceeds the \$150 cost of the "Dear Mom" conference and neither has a recent in-person conference available for her to attend on a weekend. Events for Club 21 and Down Syndrome Association are typically scheduled during the week during working hours when Claimant's mother must be at work to financially support her family.

LEGAL CONCLUSIONS

1. The Lanterman Act governs this case. (Welf. & Inst. Code, § 4500 et seq.) (Further statutory references are to the Welfare and Institutions Code.) 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 the Service Agency’s denial of his request for funding for his mother to attend the “Dear Mom” conference. Jurisdiction in this case was thus established.

2. Because Claimant seeks benefits or services, he bears the burden of proving the request is proper under the Lanterman Act. (See, e.g., *Hughes v. Board of Architectural Examiners* (1998) 17 Cal.4th 763, 789, fn. 9; *Lindsay v. San Diego Retirement Bd.* (1964) 231 Cal.App.2d 156, 161.) Claimant must prove his case by a preponderance of the evidence, which requires him to present evidence that has more convincing force than that opposed to it. (Evid. Code, §115; *People ex rel. Brown v. Tri-Union Seafoods, LLC* (2009) 171 Cal.App.4th 1549, 1567.)

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 Legislature’s intent in enacting the Lanterman Act was to ensure certain rights of persons with developmental disabilities, including “[a] right to treatment and habilitation services and supports in the least restrictive environment.

Treatment and habilitation services and supports should foster the developmental potential of the person and be directed toward the achievement of the most independent, productive, and normal lives possible.” (§§4502, subd. (a), 4640.7.)

5. Regional centers are responsible for conducting a planning process that results in an IPP. Among other things, the IPP must set forth goals and objectives for the client, contain provisions for the acquisition of services based upon the client’s developmental needs and the effectiveness of the services selected to assist the consumer in achieving the agreed-upon goals, address the cost-effectiveness of the services and supports, contain a statement of time-limited objectives for improving the client’s situation, and reflect the client’s particular desires and preferences. (§§ 4646, subd. (a)(1), (2), and (4), 4646.5, subd. (a), 4512, subd. (b), 4648, subd. (a)(6)(D) & (E).)

6. Individual program plans shall be prepared jointly by the planning team. Decisions concerning the consumer's goals, objectives, and services and supports that will be included in the consumer's individual program plan and purchased by the regional center or obtained from generic agencies shall be made by agreement between the regional center representative and the consumer or, when appropriate, the parents, legal guardian, conservator, or authorized representative at the program plan meeting. (§ 4646, subd. (d).) The regional center shall ensure that Claimant’s designated representative receives written notice of all meetings to develop or revise the individual program plan. (§ 4646, subd. (e).) Regional centers must comply with their IPP process at the time of development, scheduled review, or modification of a consumer's 4646.4. individual program plan. (§ 4646.4, subd. (a).)

7. Several portions of the Lanterman Act address the need for regional centers to identify sources for funding and services, such as the language in Code section 4659, subdivision (a), that the regional center “shall identify and pursue all

possible sources of funding," including governmental programs such as Medi-Cal and school districts, and private entities such as insurance. (*Id.*, subdivision (a)(1) and (2).) Code section 4659, subdivision (c), states a regional center shall not purchase any service available from Medi-Cal, private insurance, or other identified sources and under Code section 4648, subdivision (a)(8).

8. Regional center funds shall not be used to supplant the budget of any agency which has the legal responsibility to serve all members of the general public and is receiving public funds for providing those services.

9. Further, NLACRC is mandated to ensure the effective and efficient use of public resources and detect and prevent waste and abuse in the utilization of public funds. (Code, § 4620.3, subdivision (b).)

10. When purchasing services and supports, regional centers shall (1) ensure they have conformed with their purchase of service policies; (2) utilize generic services when appropriate; and (3) utilize other sources of funding as listed in Code section 4659. (Code, § 4646.4, subd. (a).) NLACRC is also required to consider generic resources and the family's responsibility for providing services and supports when considering the purchase of regional center supports and services for its consumers. (Code, § 4646.4.)

11. Code section 4648 requires regional centers to ensure that services and supports assist individuals with developmental disabilities in achieving the greatest self-sufficiency possible and to secure services and supports that meet the needs of the consumer, as determined by the IPP. Services and supports shall be flexible and individually tailored to the consumer. This section also requires regional centers to be fiscally responsible.

12. Code section 4648, subdivision (a)(16) provides that:

Notwithstanding any other law or regulation, effective July 1, 2009, regional centers shall 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.

Disposition

12. Claimant's request for funding of the \$150 fee for attendance at the "Dear Mom" conference is consistent with the outcomes in his past and current IPP. The request does not call for NLACRC to fund or in any way support experimental treatments or therapies or any treatment or therapy that lacks a research or evidence basis. Instead, the conference provided support, community and camaraderie for Claimant's mother as she navigates the maze of generic resources and attempts to plan for his future as a developmentally-disabled adult. At the conference, Claimant's mother was able to obtain additional information about insurance and generic resources and also learn from professionals, other parents and adults with Down Syndrome. Although the conference did have a social benefit for Claimant's mother in that she was able to meet and interact with other parents of children with Down Syndrome, it was not the sole purpose of the conference. Additionally, unlike some of the other alternative resources suggested by NLACRC, the requested conference also

met need of Claimant's family to minimize the time his mother had to take away from her employment.

13. For the reasons set forth above, NLACRC should have provided funding for the \$150 conference fee, as requested, and as it had in the past. There was no evidence that funding violated any provision of law, or failed to comply with NLARC's purchase of service policy or any regulation.

ORDER

1. Claimant's appeal is granted.
2. North Los Angeles County Regional Center shall reimburse Claimant's mother for the \$150 conference fee associated with her attendance at the "Dear Mom" conference within 90 days.

DATE:

GLYNDA B. GOMEZ
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.