

BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of:

SAMUEL B.,

Claimant,

vs.

ALTA CALIFORNIA REGIONAL
CENTER,

Service Agency.

OAH No. 2011110083

DECISION

This matter was heard before Administrative Law Judge Susan H. Hollingshead, State of California, Office of Administrative Hearings (OAH), in Sacramento, California, on December 5, 2011.

The Service Agency, Alta California Regional Center (ACRC), was represented by Jason Lindo, Supervising Counselor and Hearing Designee.

Claimant was represented by his father.

Oral and documentary evidence was received. At the conclusion of the hearing, the record was closed and the matter was submitted for decision.

ISSUES

Is ACRC required to fund feeding therapy for claimant?

FACTUAL FINDINGS

1. Claimant is an eleven- year- old boy eligible for ACRC services based on having a disabling condition closely related to mental retardation. He has been diagnosed with Joubert's Syndrome, a rare genetic neurological disorder, which compromises his neurological connections and affects him in numerous ways. He was born with a small, under-developed cerebellum, has very low muscle tone (hypotonia) and is unable to sit or ambulate. Instinctual neurological responses, including breathing, sucking and swallowing, are a constant challenge and, as a result, he has severe dysphagia (difficulty swallowing). He has lost sight in one eye and has minimal sight in the other. Claimant cannot speak but can verbalize sounds and he is prone to self-injurious behaviors. He receives nutrition and hydration through a gastrostomy tube (G-tube), and requires 24-hour care.

Claimant is described as a happy child who loves his family and friends. He resided in the family home with his parents and three brothers until approximately age five. Due to his disabilities and need for required nursing services, he was subsequently placed in a care home. Long-time nurse, Maryann Castaneda, became his foster parent with an agency vendored through ACRC. His family and foster parent are actively involved in his life.

2. Claimant has been receiving services from ACRC pursuant to the Lanterman Developmental Disabilities Services Act (Welfare and Institutions Code Section 4500 et seq.)¹

3. As indicated in his current Individual Program Plan (IPP), dated February 11, 2011, claimant's long range goals are as follows:

1. We want [claimant's] toileting needs to be met.
2. We want [claimant's] communication skills to improve.
3. We want [claimant] to have an appropriate education.
4. We want [claimant] to receive specialized care via a licensed professional.
5. We want [claimant's] health to be maintained at an optimum level.
6. We want a break from [claimant's] consistent care needs.

4. Pursuant to these IPP goals, claimant receives numerous services and supports including funding for his foster family home, respite, and educational services provided through San Juan Unified School District (SJUSD). He receives speech and language services both through SJUSD and private pay.

5. Since approximately May, 2010, speech/feeding therapy for claimant has been at issue. SJUSD provides speech-language services that are educationally based.

¹ Unless otherwise indicated, all statutory references are to the California Welfare and Institutions Code.

6. Claimant received feeding therapy funded by ACRC from approximately August, 2008, to January 31, 2011. Services were discontinued when claimant's appeal of denial of continued funding was dismissed for failure of claimant to appear at a scheduled January 11, 2011 hearing.

7. Claimant made a subsequent request for ACRC funding of speech/feeding therapy which was denied on February 11, 2011. He then submitted a Fair Hearing Request based on this denial. An Informal Fair Hearing was held on April 13, 2011, to discuss the request. At that time, claimant's father explained that his health insurance plan had approved a swallow study that was scheduled for April 21, 2011. He was unsure what the recommendations would be from that study or when they would be made available.

Camelia Houston, ACRC Supervising Counselor, stated that ACRC would be willing to fund feeding therapy for claimant through July 31, 2011, in order to allow sufficient time for the results of the swallow study to be made available and to allow for a funding request through claimant's medical insurance. Should claimant's medical insurance fund the therapy prior to the July 31, 2011 date, it was agreed that ACRC would terminate funding.

The Fair Hearing Request was withdrawn at that time based on the agreement of the parties.

8. On October 18, 2011, ACRC issued a Notice of Proposed Action (NOPA) to claimant, advising that "ACRC is denying your request for continued funding of Feeding Therapy for [claimant]." The NOPA stated the reason for the action:

At this point your private medical insurance has determined that [claimant] "does not meet the qualifying criteria for oral feeding therapy or swallowing therapy." A recent evaluation by Karen Carson [sic], MS CCC-SLP, indicates that [claimant] has a severe oral feeding deficit and that he needs to continue to receive adequate nutrition and hydration via PEG tube feedings. Debra Harms, MA CCC-SLP, ACRC's Speech and Language Pathologist, has reviewed [claimant's] reports [at the request of ACRC's Staff Physician Terry Wardinsky, M.D.] and it is her opinion that [claimant] does not have the potential at this time to make reasonable progress to be an oral feeder for his nutritional needs; therefore, this service is not medically necessary as [claimant's] nutritional needs are met via tube feeding. As such, it is not a cost effective use of public funds for ACRC to continue funding the feeding therapy.

9. Claimant filed a Fair Hearing Request, received by ACRC on October 27, 2011, seeking funding for feeding therapy for claimant.

10. Debra Harms, M.A., CCC-SLP, is ACRC's Speech -Language Pathologist. She has extensive experience in her field, which includes evaluating speech/language and feeding/swallowing skills, and she is on the faculty at California State University, Sacramento.

Ms. Harms offered extensive testimony regarding dysphagia and the four stages of swallowing, beginning with the oral preparatory stage. In November, 2010, she performed a document review for claimant and determined that services then being provided by Speech and Language Therapy Associates were necessary to determine if claimant has the potential to become a safe oral feeder. She defined an oral feeder as one who functions in a safe and adequate manner through all stages of the swallow. She recommended that ACRC purchase services for six months after which "a progress report should be written and the need for continued dysphagia therapy be re-evaluated."

11. On April 21, 2011, a Speech Pathology Oral Feeding Evaluation was conducted by Karen Cason, M.S., CCC-SLP at Sutter Memorial Hospital. In reviewing that evaluation, Ms. Harms concluded:

Results indicated a severe oral feeding deficit and that he needs to continue to receive adequate nutrition and hydration via PEG tube feeding. The goals set for [claimant] were to move towards [claimant] being able to manage his secretions and for oral gratification. His goals do not reflect that he has the potential at this time to be an oral feeder for his nutritional needs. It is my opinion that this service is not medically necessary as his nutritional needs are met via tube feedings.

12. In her report, Ms. Cason opined that claimant "would benefit from continued therapy from a feeding specialist, preferably the specialist he has already become accustomed to and made progress with, to address the following: tongue elevation, lip closure and a complete pharyngeal swallow. Therapy frequency should be determined by the receiving therapist." She also outlined a home program to include the following:

1. Use a cold lemon swab or ice cold cotton tip swab to stimulate the tongue and back of the throat to help elicit a swallow.
2. Chewy Tube-use with and without p.o. [by mouth] tastes. Use tactile stimulations to help elicit a bite.
3. Continue with the facial massage program already in place.
4. NUK Brush- continue with tongue elevation exercises as well as brushing the cheeks, tongue and palate.
5. Use both hot and cold foods as well as food with strong flavors when doing p.o. tastes.

13. Claimant's pediatrician, Richard Loomis, M.D., requested Oral Feeding Therapy through Sutter Medical Group, Sutter Memorial-Pediatric and Infant Services. By letter dated June 6, 2011, Sutter Medical Group informed claimant's parents that this request was being denied because "there is a lack of medical necessity." The denial stated that it "did not consider continued oral feeding therapy involving routine, repetitive and reinforced procedures or services for maintenance programs medically necessary. The clinical information provided by your physician indicates the requested service is for one therapy visit a month with a 'strong focus on home care' which meets the definition as a maintenance program and therefore does not meet criteria."

14. Ms. Harms testified persuasively, that in her professional opinion, claimant does not have the potential at this time to make reasonable progress towards becoming an oral feeder for his nutritional needs. Therefore, she opined that feeding therapy is not medically necessary as claimant's nutritional needs are being met via tube feeding and, as such, it is not a cost-effective use of public funds for ACRC to fund feeding therapy.

In reviewing available records, Ms. Harms explained that the original goal for claimant's therapy was to become an oral feeder. To accomplish this it is necessary to break down the essential steps necessary so he can function in all stages of the swallow to safely and effectively orally feed. It was her opinion that after approximately three and one-half years of receiving this service, "he is no where near" being an oral feeder. He has made no progress in the oral preparatory phase, the initial phase of the swallow. Until he can function in all stages of the swallow, he cannot safely and effectively orally feed. He is unable to accomplish the first stage. She noted that "initially he was making some slow progress which slowed to no measurable progress toward becoming an oral feeder."

Ms. Harms noted that his therapy goals have been "pared down" over time. For example, a previous goal was for claimant to drink from a straw. He was not exhibiting "any kind of suck" so the goal was stepped down to introducing a toothette, with the hope that it would lead to a sucking response. Stronger flavors were also introduced in an attempt to increase claimant's sensory awareness that something was in his mouth. The emphasis shifted from consumption and swallowing to a sensation of taste only.

15. Claimant's father testified that claimant has made some progress in learning to swallow. It is his hope that claimant will one day verbalize words and take foods orally. It is also his hope that his son will be able to one day experience the enjoyment of food. He testified that claimant receives some speech therapy services through the school but these services do not target eating skills. He also receives some speech therapy services that are purchased by his foster parent utilizing his SSI benefits.

Claimant's father would like services to remain in place with the same providers who know claimant well and do a good job providing services. He believes his son needs speech therapy services in addition to those provided by SJUSD to address his oral feeding needs and saliva control. He explained that claimant drools excessively which requires numerous changes

of saturated bibs each day. SJUSD will not provide services in this area as it is not considered an educationally based need.

LEGAL CONCLUSIONS

1. The Lanterman Act sets forth the regional center's responsibility for providing services to persons with development disabilities. An "array of services and supports should be established...to meet the needs and choices of each person with developmental disabilities...to support their integration into the mainstream life of the community...and to prevent dislocation of persons with developmental disabilities from their home communities." (§ 4501.) The Lanterman Act requires regional centers to develop and implement an IPP for each individual who is eligible for regional center services. (§ 4646.) The IPP includes the consumer's goals and objectives as well as required services and supports. (§§4646.5 & 4648.)

2. Section 4646 provides in part:

(a) It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and preferences of the individual and family, where appropriate, as well as promoting community integration, independent, productive, and normal lives, and stable and healthy environments. It is the further intent of the legislature to ensure that the provision of services to consumers and their families be effective in meeting the goals stated in the individual program plan, reflect the preferences and choices of the consumer, and reflect the cost-effective use of public resources."

(b) The individual program plan is developed through a process of individual needs determination. The individual with developmental disabilities...shall have the opportunity to actively participate in the development of the plan.

¶ . . . ¶

(d) 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, where appropriate, the parents, legal guardian, conservator, or authorized representative at the program plan meeting.

3. Section 4646.5, subdivisions (a)(1) and (b), state:

(a) The planning process for the individual program plan described in Section 4646 shall include all of the following:

(1) Gathering information and conducting assessments to determine the life goals, capabilities and strengths, preferences, barriers, and concerns or problems of the person with developmental disabilities. For children with developmental disabilities, this process should include a review of the strengths, preferences, and needs of the child and the family unit as a whole. Assessments shall be conducted by qualified individuals and performed in natural environments whenever possible. Information shall be taken from the consumer, his or her parents and other family members, his or her friends, advocates, providers of services and supports, and other agencies. The assessment process shall reflect awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and the family.

(b) For all active cases, individual program plans shall be reviewed and modified by the planning team, through the process described in Section 4646, as necessary, in response to the person's achievement or changing needs, and no less often than once every three years. If the consumer, or where appropriate, the consumer's parents, legal guardian, or conservator requests an individual program plan review, the individual program shall be reviewed within 30 days after the request is submitted.

4. Section 4648, subdivisions (a)(7), and (8) provide:

In order to achieve the stated objectives of the consumer's individual program plan, the regional center shall conduct activities including, but not limited to, all of the following:

(a) Securing needed services and supports.

(7) No service or support provided by any agency or individual shall be continued unless the consumer or, where appropriate, his or her parents, legal guardian, or conservator, or authorized representative, including those appointed pursuant to section 4590 or subdivision (e) of Section 4705, is satisfied and the regional

center and the consumer or, when appropriate, the person's parents or legal guardian or conservator agree that planned services and supports have been provided, and reasonable progress toward objectives have been made.

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

5. It was demonstrated, by a preponderance of the evidence, that claimant does not presently exhibit the potential to be an oral feeder. Nor has he shown reasonable progress towards attaining that goal to date. His nutrition and hydration needs are being met through tube feedings so he did not show medical necessity. Strategies to address his current goals of learning to manage his secretions and for oral gratification can be implemented in his home program. Additionally, speech and language therapy goals are being addressed by SJUSD. Therefore, it would not be a cost-effective use of public funds for ACRC to provide funding for feeding therapy at this time.

Claimant will continue to receive speech and language services through SJUSD addressing vocalization and increased communication. His family is actively involved and well-trained, his foster parent is also an R.N., and they are able to continue his home program.

It is recommended that the IPP team continue to reevaluate claimant's needs in light of any progress made through the home program.

ORDER

The appeal of claimant Samuel B. is denied.

DATED: December 16, 2011

SUSAN H. HOLLINGSHEAD
Administrative Law Judge
Office of Administrative Hearings

NOTICE

This is the final administrative decision in this matter. Each party is bound by this decision. An appeal from the decision must be made to a court of competent jurisdiction within 90 days of receipt of the decision. (Welf. & Inst. Code, § 4712.5, subd. (a)).