

BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of:

CLAIMANT

vs.

SAN ANDREAS REGIONAL CENTER,
Service Agency.

OAH No. 2016041025

DECISION

This matter was heard before Karen Reichmann, Administrative Law Judge, State of California, Office of Administrative Hearings, on October 13, 2016, in Campbell, California.

James Elliott represented San Andreas Regional Center, the service agency.

Claimant was represented by his parents.

The record closed, and the matter was submitted for decision on October 13, 2016.

ISSUE

Is claimant eligible for regional center services under the "fifth category" because he is substantially disabled from Prader-Willi Syndrome?

FACTUAL FINDINGS

1. Claimant was born on March 4, 2013. Claimant lives in San Jose with his parents and five-year-old sister.

Claimant was diagnosed shortly after birth with Prader-Willi Syndrome (PWS). PWS is a genetic disorder. The most challenging aspect of PWS is hyperphagia, an insatiable desire to eat. Individuals with PWS have an unrelenting desire for food, despite how much they consume. It is believed that their hyperphagia is caused by a defect in the hypothalamus. This inability to feel satiated can result in death from choking, gastric necrosis or rupture, or bowel necrosis or rupture. Without severe restrictions to their access to food, individuals with PWS will become severely obese and are at risk for developing obesity-related illnesses. They will also engage in risky behaviors in an attempt to procure food. Individuals with PWS cannot live independently as their access to food must be strictly monitored. PWS is a permanent, lifelong condition for which there is no cure.

Hypotonia (poor muscle tone) is prevalent in infants with PWS but improves with age. Mild to moderate cognitive impairment is very common in individuals with PWS. Difficulty with speech articulation is typical in children with PWS. Oppositional behavior, high pain threshold, body temperature dysregulation, poor impulse control, and gastrointestinal problems are other common characteristics of individuals with PWS. Many exhibit social deficits akin to those typical of individuals with Autism Spectrum Disorder.

2. By July 2013, Claimant began receiving Early Start services, including speech therapy and physical therapy. As he approached his third birthday, Claimant was assessed to determine whether he would be eligible for San Andreas Regional Center (SARC) services under the Lanterman Act. An Exit Summary Report (ESR) was prepared by a team which included Early Start providers and a SARC Service Coordinator. Claimant was assessed using the Battelle Developmental Inventory, Second Edition (BDI-2), the Hawaii Early Learning Profile (HELP), and Receptive-Expressive Emergent Language Test, Third Edition (REEL-3). Claimant was 34 months old at the time of the

ESR. The team noted the following age equivalencies using the various diagnostic measures:

Gross Motor: 32 months (BDI-2)
27-30 months (HELP)

Fine Motor: 36 months Fine Motor/ 37 months Perceptual Motor (BDI-2)
33 months (HELP)

Adaptive/Self-Help: 31 months Self Care/36 months Personal Responsibility (BDI-2)
26-30 months (HELP)

Cognitive: 34 months Attention and Memory
29 months Reasoning and Academic Skills
23 months Perception and Concepts
(BDI-2)

Receptive
Communication: 32 months (BDI-2)
35 months (REEL-3)

Expressive
Communication: 23 month (BDI-2)
23 months (REEL-3)

Social/Emotional: 34 months Adult Interaction

28 months Peer Interaction

26 months Self-Concept and Social Role

(BDI-2)

3. SARC psychologist Carrie Molho, Ph.D., reviewed the ESR and made the following notation, "significant delays seen in expressive language [and] perceptions/concepts only. No indication of an eligible condition or substantial disability in three or more areas." On April 12, 2016, Claimant's parents were notified that SARC was denying eligibility for services. Parents appealed. Following a May 20, 2016, informal meeting, SARC agreed to arrange for an eligibility redetermination. Claimant's parents were informed that diagnostic assessments were likely to occur as part of the redetermination process.

4. Clinical Psychologist Azelin A. Ellis, Psy.D., was assigned to perform the eligibility redetermination. Dr. Ellis has been working for SARC since January 2015. Dr. Ellis observed Claimant at his preschool class on June 16, 2016, for approximately one hour. Dr. Ellis observed Claimant participating in class activities and following directions. Dr. Ellis interacted with Claimant and observed that he had difficulty with expressive language, but was able to communicate effectively by supplementing his limited speech with gestures. Dr. Ellis interviewed Claimant's teacher, who reported that Claimant displayed behaviors typical of a three-year-old. Dr. Ellis planned to observe Claimant for longer, but she terminated her visit early because of conflict she experienced with Claimant's mother. Dr. Ellis chose not to schedule any other visits with Claimant or administer any diagnostic tests. She made this decision because she did not feel comfortable with Claimant's mother's "aggressive" behavior and also because she did not believe that additional observation or testing was necessary for her to reach a conclusion. Dr. Ellis asked Claimant's parents to provide her with Claimant's Individualized Educational Plan (IEP), but the parents declined to provide it.

5. Dr. Ellis wrote an Eligibility Redetermination Report dated July 11, 2016. She noted that her conclusion was based on her review of the ESR, her interview of Claimant's teacher, and her one hour observation of Claimant at school. In her report, Dr. Ellis noted her impression that Claimant's mother "substantially underestimates [his] true functioning," and for this reason she did not ask her to complete an ABAS-3.¹ Dr. Ellis concluded that Claimant was not eligible for regional center services because he did not demonstrate substantial disability in three or more areas. After receiving a copy of Dr. Ellis's report, Claimant's parents submitted a letter disputing Dr. Ellis's description of events at the school observation and disagreeing with her ultimate conclusion.

6. Dr. Ellis testified at the hearing and explained the rationale for her conclusion. She noted that Claimant's scores as reflected in the ESR did not demonstrate substantial disability in any area except expressive language. She further noted that to be considered substantially disabled in communication, an individual must be substantially disabled in both expressive and receptive language. In her opinion, Claimant is not disabled in receptive communication. Finally, Dr. Ellis stated that a disability in expressive communication that had a physical cause would not be considered to stem from a developmental disability. In her opinion, Claimant's delay in expressive language is caused by oral motor challenges due to PWS-related hypotonia and would not be considered an impairment caused by a developmental disability. Dr. Ellis further explained that she did not think it was necessary to observe Claimant in

¹ The ABAS-3 (Adaptive Behavior Assessment System, Third Edition) is used to assess adaptive skills. Input from those familiar with the individual being assessed, including parents, is a part of this diagnostic tool.

another setting because an individual with a developmental disability will demonstrate impairment across all environments.

Dr. Ellis based her conclusion largely on the ESR, which was drafted by Early Start providers and not by a psychologist. Dr. Ellis did not administer any diagnostic tests herself. She observed Claimant for one hour in a highly structured setting. Her opinion regarding Claimant's functional abilities is rendered less persuasive given the limitations of the information upon which it was based.

7. Claimant attends Donald J. Meyer Elementary School pursuant to an IEP. He attends a highly structured classroom consisting of eight students and three adults. He goes to school four days a week for two hours a day and has attended since March 2016. Claimant's teacher, Monica Zamolo, writes that Claimant has been thriving in her highly structured special education classroom, but that he "struggles with noncompliance and resistance, transitions, social skills, and participation when new or unexpected transitions occur, when significant processing time is not able to be provided, or when a routine has to be changed." Zamolo adds that she does not believe that Claimant's mother underestimates his abilities.

8. Claimant's parents disagree strongly with the ESR and Eligibility Redetermination Report. Claimant's parents described Claimant as oppositional and extremely inflexible. He has tantrums or "shuts downs" in reaction to change. Claimant demonstrates poor problem-solving skills and is easily frustrated and cries. He is not entirely potty-trained and will not reliably report whether he needs to use the bathroom. Claimant does not play cooperately with others and prefers to play by himself. He is inappropriately friendly with adults he does not know. He does not appear to understand the concept of danger. Claimant's parents acknowledge that he has made decent progress in his motor skills as a result of physical and occupational therapy.

Claimant's parents disagree with Dr. Ellis's opinion that Claimant's expressive language delay is physical in nature.

Claimant has begun to demonstrate the food-seeking behaviors that are characteristic of PWS, such as searching for food in garbage cans and trying to eat things he finds on the sidewalk. Claimant needs constant supervision and cannot be left to play without supervision in their fenced-in backyard for fear that he will escape. He has the temperature dysregulation that is typical of PWS and strenuously resists dressing appropriately for weather conditions.

Claimant has received support since birth from a team of specialists, including special education teachers, speech therapists, physical therapists, occupational therapists, geneticist, gastroenterologist, endocrinologist, dietician, and behavior therapist.

Claimant's parents expressed frustration with SARC's handling of the eligibility determination. They were disappointed that Dr. Ellis did not administer any diagnostic tests, did not seek their input when reaching her determination, and did not observe Claimant in any setting other than at school. They explained that Claimant's behavior at school is not typical of his behavior in other settings.

Claimant parents' testimony was credible and compelling. It did not appear that they were intentionally exaggerating Claimant's symptoms or understating his abilities.

9. Lisa Graziano, M.A., M.F.T., Executive Director of the Prader-Willi California Foundation, wrote a letter and testified in support of Claimant. She described the severe functional limitations experienced by those with PWS. They are unable to take public transportation, have access to money, or live independently. They have poor executive functioning skills. Some individuals have been able to maintain employment, but only in a highly structured, sheltered work environment. Graziano is unaware of a single individual with PWS who has managed to have full independence as an adult.

DIAGNOSTIC CRITERIA FOR INTELLECTUAL DISABILITY

10. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, (DSM-5), defines intellectual disability as “a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.” The following criteria must be met for a diagnosis of intellectual disability as follows:

- A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.

- B. Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

- C. Onset of intellectual and adaptive deficits during the developmental period.

LEGAL CONCLUSIONS

1. The State of California accepts responsibility for persons with developmental disabilities under the Lanterman Act. (Welf. & Inst. Code, § 4500 et seq.) The purpose of the Act is to rectify the problem of inadequate treatment and services for the developmentally disabled, and to enable developmentally disabled individuals to lead independent and productive lives in the least restrictive setting possible. (Welf. & Inst. Code, §§ 4501, 4502; *Association for Retarded Citizens v. Department of Developmental Services* (1985) 38 Cal.3d 384.) The Act is a remedial statute; as such it must be interpreted broadly. (*California State Restaurant Association v. Whitlow* (1976) 58 Cal.App.3d 340, 347.) It is claimant's burden to prove that he has a developmental disability, as that term is defined in the Act.

2. A developmental disability is a disability which originates before an individual attains age 18, is likely to continue indefinitely, and constitutes a substantial disability for that individual. (Cal. Code Regs., tit. 17, § 54000, subd. (b).) The term "developmental disability" includes intellectual disability, autism, epilepsy, cerebral palsy, and what is commonly referred to as the "fifth category." (Welf. & Inst. Code, § 4512, subd. (a).) The "fifth category" includes "disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability." (*ibid.*) An individual with an average I.Q. can establish eligibility under the fifth category. (*Samantha C. v. State Department of Developmental Services* (2010) 185 Cal.App.4th 1462, 1494.)

Handicapping conditions that consist solely of psychiatric disorders, learning disabilities or physical conditions do not qualify as developmental disabilities under the Lanterman Act. (Cal. Code Regs., tit. 17, § 54000, subd. (c).) The fifth category was created "to allow some flexibility in determining eligibility so as not to rule out eligibility

of individuals with unanticipated conditions, who might need services." (*Mason v. Office of Admin. Hearings* (2001) 89 Cal.App.4th 1119, 1129.)

3. The evidence established that PWS is a disabling condition that is both closely related to intellectual disability and requires treatment similar to that required for individuals with intellectual disability. Individuals with PWS typically have intellectual deficits, especially in the areas of problem solving and judgment. Many are in fact intellectually disabled. All individuals with PWS have serious deficits in adaptive functioning and require ongoing support in the activities of daily living. Individuals with PWS requires treatment similar to that required by individuals with intellectual disability, such as specialized education, sheltered work environments, supported living environments, assistance managing money, and assistance with transportation and other activities of daily life. (*See Samantha C. v. State Department of Developmental Services, supra*, 185 Cal.App.4th at p.1493.)

4. To qualify for Regional Center services, an individual must be substantially disabled by the qualifying condition. Pursuant to section 4512, subdivision (l), the term "substantial disability" is defined as "the existence of significant functional limitations in three or more of the following areas of major life activity, as determined by a regional center, and as appropriate to the age of the person: (1) Self-care. (2) Receptive and expressive language. (3) Learning. (4) Mobility. (5) Self-direction. (6) Capacity for independent living. (7) Economic self-sufficiency." The last two major life activities are generally not taken into account when assessing very young children such as Claimant.

5. Claimant contends that he is substantially disabled in all of the seven domains. SARC contends that Claimant's condition, as it has manifested thus far, is not substantially disabling, and that he has not demonstrated significant functional limitations in any of the seven domains. SARC acknowledges that at some point in the future, Claimant may qualify as developmentally disabled, as his condition develops.

6. A preponderance of the evidence established that Claimant has significant functional limitations in self-care. Because of the hyperphagia that is the hallmark of PWS, Claimant's eating must be closely supervised so that he does not harm himself by compulsive overeating or ingesting inedible objects. In addition, Claimant has poor temperature regulation and lacks the ability to dress appropriately for weather conditions.

A preponderance of the evidence further established that Claimant has significant functional limitations in self-direction. Claimant must be supervised at all times to prevent dangerous food-seeking behavior. A structured environment with no independent access to food sources must be maintained and Claimant must be safeguarded against attempts to escape supervision.

A preponderance of the evidence established that Claimant has significant functional limitations in expressive language. The evidence was insufficient, however, to demonstrate significant delays in receptive language. Therefore, Claimant did not establish that he has significant functional limitations in the domain of "receptive and expressive language."

Graziano persuasively testified that all individuals with PWS have significant functional limitations in the areas of capacity for independent living and economic self-sufficiency. As noted above, these domains are not considered relevant when assessing a child of Claimant's age because a typically developing three-year-old child would not be expected to demonstrate these skills. Absent a breakthrough treatment for his condition, it is highly likely that Claimant will require lifelong support and will not be able to live independently or achieve economic self-sufficiency. At this point in time, however, it cannot be found that Claimant demonstrates significant functional limitations in these two domains, as appropriate to a child his age.

Similarly, Claimant contends that individuals with PWS have substantial functional limitations in mobility because they cannot drive or use public transportation independently due to their food-seeking compulsion. The evidence did not establish that Claimant is currently significantly limited in mobility, as compared to the typical three-year-old, who would not be expected to use public transportation without supervision.

The evidence was insufficient to establish that Claimant has significant functional limitations in learning.

7. Claimant has met his burden of establishing that he has a disabling condition that is both closely related to intellectual disability and requires treatment similar to that required by individuals with intellectual disability. On this record, Claimant failed to establish that he is substantially disabled by his condition because he failed to establish, by a preponderance of the evidence, that he has significant functional limitations in three of the seven realms of major life activity, as would be appropriate for a three-year-old child.

ORDER

The appeal of claimant is denied. Claimant is not eligible for regional center services.

DATED: October 24, 2016

_____/s/_____

KAREN REICHMANN

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.