

BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of:

CLAIMANT,

vs.

FRANK D. LANTERMAN REGIONAL
CENTER,

Service Agency.

OAH No. 2015120652

DECISION

This matter was heard by Julie Cabos-Owen, Administrative Law Judge with the Office of Administrative Hearings, on May 25, 2016, in Los Angeles, California. Claimant was represented by his mother and authorized representative, with the assistance of a certified Spanish language interpreter.¹ Frank D. Lanterman Regional Center (Service Agency or FDLRC) was represented

¹ Claimant's name is omitted throughout this Decision to protect his privacy.

by Path Huth, Attorney at Law.²

Oral and documentary evidence was received, and argument was heard. The record was closed, and the matter was submitted for decision on May 25, 2016.

ISSUE

Should FDLRC make a recommendation to DDS to fund Claimant's participation in the Son-Rise program?

This issue involves the resolution of two sub-issues: (1) whether there are available in-state alternatives to meet Claimant's needs; and (2) whether Son-Rise is an evidence-based program to meet statutory requirements for funding?

EVIDENCE

Documentary: Service Agency exhibits A - U; Claimant's exhibits 1 - 7.

Testimonial: Adriana Aguirre-Robertson; Bill Crosson; Enrique Roman; Jean Johnson; Claimant's mother.

FACTUAL FINDINGS

1. Claimant is a six-year old male consumer diagnosed with autism spectrum disorder.
2. Claimant lives with his parents in their family home. He attends

² Louise Burda Gilbert, Senior Staff Counsel for the Department of Developmental Services (DDS) was present and observed the hearing. However, Ms. Gilbert did not make an appearance on the record. Given the facts of this case to date, DDS was not joined as a necessary party under the provisions of Welfare and Institutions Code section 4519, subdivision (a).

school in his school district. Claimant suffers from language deficits and behavioral issues which include banging objects, yelling, and hitting himself.

3. Claimant's Individual Program Plan (IPP) goals include his ability to "participate independently in typical activities of family life, such as at meal times, getting ready for school and at bedtime," and to "engage in a variety of activities and outings with others." (Exhibit E.)

4. In May 2016, Claimant began social skills training funded by FDLRC.

5. Claimant received Applied Behavioral Analysis (ABA) therapy funded by FDLRC for three years, and those services were terminated in July 2015.

6. According to Claimant's mother, although the ABA provider worked with Claimant on communication, after three years of ABA services Claimant was not able to consistently verbally express his wants with phrases like "give me." Claimant's mother observed that the structured setting of the ABA services caused Claimant frustration.

7. Because she did not feel that Claimant was achieving "real results" through the ABA therapy, Claimant's mother began investigating alternative therapies for autism treatment and found the Son-Rise program, which is located in Massachusetts. She liked that the Son-Rise program was centered around parents working with their children and not having to depend on an "external" therapist. Claimant's mother traveled to Massachusetts to attend the first phase of the Son-Rise program, which she funded through a "Go Fund Me" campaign.

8. Claimant's mother returned home and implemented her Son-Rise training. In five days, she was able to reduce Claimant's yelling and hitting himself, which had been unaltered by the ABA therapy. Claimant's mother observed that Claimant is "completely different" now and is able to play with

others and express himself.

9. In September 2015, Claimant's mother spoke to Claimant's Service Coordinator, reported her concerns about the ineffectiveness of the ABA program, and requested that FDLRC provide funding for the intensive, five-day Son-Rise summer program. The program costs \$18,400, but Claimant's mother obtained a scholarship through Son-Rise (\$7,000), so she sought regional center funding for the remainder of the program cost (\$11,400).

10. Since Son-Rise is an out-of-state program, funding can be obtained only if the regional center requests and obtains DDS authorization to fund the program. (See Legal Conclusion 9.) However, FDLRC did not seek DDS authorization for funding the Son-Rise program because FDLRC determined that Son-Rise was not an evidence-based program and that in-state alternatives were available for Claimant. (See Legal Conclusions 6 through 9.)

11(a). In a Notice of Proposed Action (NOPA) dated December 1, 2015, FDLRC informed Claimant's mother that her request for funding Son-Rise was denied, pursuant to Welfare and Institutions Code sections 4686.2, subdivision (a), and 4519, subdivision (a). The stated bases for the denial were that "appropriate resources to serve [Claimant] exist in the state of California," and FDLRC "determined that Son-Rise does not meet the requirements to be considered an evidence-based program." (Exhibit A.)

11(b). Claimant's mother filed a Fair Hearing Request on Claimant's behalf.

12. At the fair hearing, Claimant's mother testified credibly and presented a video recording of Claimant illustrating his improved ability to communicate and interact with his parents after application of the Son-Rise approach. Claimant's mother observed that the Son-Rise techniques allowed her to communicate with Claimant for the first time, which was a result other

therapies were unable to achieve. Given the improvements Claimant achieved with only the basic Son-Rise program, Claimant's mother believes that he could accomplish a great deal more with the intensive program.

13. The evidence at the fair hearing, including the credible testimonies of FDLRC's witnesses (Adriana Aguirre-Robertson; Bill Crosson; Enrique Roman; and Jean Johnson) support the following findings:

- (a) The cause of autism remains unknown. However, research has shown that early, effective treatment can make a difference in the child's progress. With increased diagnoses of autism, a proliferation of treatments has been promoted as autism treatment. These proffered treatments include established, scientifically-confirmed effective treatments as well as unestablished, experimental treatments. Since the child's age at intervention influences the effectiveness of the intervention, it is important that early treatment be supported by sound research and treatment protocols so that the intervention will produce the desired results.
- (b) The National Autism Center (NAC) launched a project to sort through published research and studies to determine if any treatments emerged as having a substantial body of empirical rigors to support their effectiveness. The NAC project reviewed hundreds of studies in published journals and attempted to categorize the different autism treatments on the basis of the strength of the empirical evidence that supports their efficacy. Their findings were published in the NAC's National Standards Report. As set forth in their 2009 report, treatments were placed into four categories:

- (1) "Established" treatments, meaning "Sufficient evidence [i.e., several, well-controlled studies] is available to confidently determine that a treatment produces favorable outcomes for individuals on the autism spectrum. That is, these treatments are established as effective;"
 - (2) "Emerging" treatments, which meant that "Although one or more studies suggests that a treatment produces favorable outcomes [i.e., preliminary research shows some promise] for individuals with autism spectrum disorder [(ASD)], additional high quality studies must consistently show this outcome before we can draw firm conclusion about treatment effectiveness;"
 - (3) "Unestablished" treatments, which meant "There is little or no evidence to allow us to draw firm conclusions about treatment effectiveness with individuals with ASD. Additional research may show the treatment to be effective, ineffective or harmful;" and
 - (4) "Ineffective/Harmful" treatments, which meant that "Sufficient evidence is available to determine that a treatment is ineffective or harmful for individuals on the autism spectrum." (Exhibit I.)
- (c) ABA therapy is categorized as an "Established" treatment. (Exhibit I.) ABA works to reduce problem behaviors and teaches children new socially-acceptable behaviors in order to fully integrate into, and to fully access, their community. This intervention is based on tracked behavioral data and implementation protocol.
- (d) Pivotal Response Treatment (PRT) is an "Established" treatment which "focuses on targeting 'pivotal' behavioral areas – such as motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues, with the development of these areas

having the goal of very widespread and fluently integrated collateral improvements. Key aspects of PRT intervention delivery also focus on parent involvement in the intervention delivery, and on intervention in the natural environment such as homes and schools with the goal of producing naturalized behavioral improvements.” (Exhibit I.)

(e) Developmental Relationship-based Treatment is one of the emerging treatments for which several studies suggest that the intervention may produce favorable outcomes. This treatment involves “a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatments may be delivered in a variety of settings (e.g., home, classroom, community). All of the studies falling into this category met the strict criteria of: {a} targeting the defining symptoms of ASD, {b} having treatment manuals, {c} providing treatment with high degree of intensity, and {d} measuring the overall effectiveness of the program. . . . These treatment programs may also be referred to as the Denver Model, DIR (Developmental, Individual Differences, Relationship-based)/Floortime, Relationship Development Intervention, or Responsive Teaching.” (Exhibit 7, p. 45.)

(f) Son-Rise is an autism therapy facilitated by the Autism Treatment Center of America. Unlike ABA approaches to the treatment of autism, the core principle of Son-Rise is that autism is not a behavioral disorder, but a relational disorder where motivation, rather than repetition, is the child’s key to learning. Son-Rise is considered a more naturalistic and child-centered approach to addressing autism. Instead of using techniques to extinguish perseverative or stimulating

behaviors or idiosyncrasies of a child on the autism spectrum, Son-Rise program facilitators or the child's parents work with the child by participating in and imitating the child's behaviors. In this way, the adult develops a rapport with the child, gains his trust, and enters his world. ABA interventions involve an adult behaviorist who determines a specific activity, engages the child in a series of repetitions using rewards to encourage the desired behavior, and continues the task until the child repeats it successfully. However, in Son-Rise, the child determines the activity and the adult follows suit. The theory behind this approach is that, by giving the child control over his environment, the child will be motivated to seek out the adult for interaction in future sessions thereby developing social interaction. The Son-Rise promotional literature notes:

Instead of forcing a child to conform to a world they do not yet understand, we seek to engage the child in their world first, . . . The Son-Rise program was the first to treat autism spectrum disorder as relational and neurological challenges versus behavioral. This program places parents, not doctors or therapists, as key teachers. Their long-term commitment and deep love encourages and inspires caring relationships with their children. It also focuses on the home, rather than clinics, as the most stable and nurturing environment in which to help a child. The Son-Rise Program implements a very specific method based on a Developmental Model to guide parents step-by-step,

enabling their children to dramatically improve in all areas of learning, social development, communication and skill acquisition. (Exhibit 7.)

- (g) (1). Based on two research studies conducted using its treatment methods, Son-Rise, at best, falls into the category of "emerging" treatments. Son-Rise is not an established, evidence-based treatment and has not been clinically determined or scientifically proven to be effective for the treatment of autism.
- (g)(2). The first study followed 12 children over a 13-day period. Six of the children received intensive Son-Rise interventions for 40 hours over a five-day period, and the other six did not. The study concluded that the children who received the treatment made gains in the frequency of spontaneous gaze toward the adult examiner and in the cumulative length of time spent engaged with the examiner. However, this study involved a small number of subjects with a small clinical effect. Although it may have potential to become an established treatment, a great deal more research is necessary to test the treatment method and to establish that the findings can be replicated across a wider variety and greater number of children.
- (g)(3). The second study examined whether parents could learn the Son-Rise techniques and achieve changes in their children's presentation. Parents implemented either no treatment, low intensity treatment, or high intensity treatment in their homes, and used a rating scale to report changes in their children's communication, sociability, sensory and cognitive awareness, and physical behavior. Greater gains were associated with greater hours of treatment per week. However, the

study can be discounted based on several factors, including: the rating scale was not defined and it was difficult to determine what the ratings meant in terms of the child's progress; the parent-rating scale was not an objective, blind measure since the rater knew the level of treatment provided; the parents, by virtue of being invested in the program, may be more likely to "observe" changes in their children; the study did not control for other variables across the groups such as other activities in which the child was engaged (e.g., school); and the study's authors indicated that it was a preliminary study, noting, "This study represents a first step in examining the effects of home-based Son-Rise Programs for children with autism." (Exhibit 1.)

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(h) FDLRC noted that the Son-Rise program was most comparable to PRT (an established treatment) and the Denver Model (an emerging Developmental Relationship-based treatment). FDLRC determined that both of these treatment programs are available in California and that either could meet Claimant's individual needs.

14. Claimant's mother disagreed that the California alternatives suggested by FDLRC could meet Claimant's needs. She opined that PRT is a therapy that derives from ABA and is a behavioral model working on conduct. She believes that PRT "pushes the child to do things [he does] not want to do." She also opined that the Denver model is recommended for early intervention, is typically applied to much younger children, and is also "based on correct behavior but derails the [stereotypical behavior] where Son-Rise uses it as a [means] to connect with the child." She believes that Son-Rise is unique in its

focus on “join[ing] the child’s behavior instead of going against it.” However, Claimant’s mother has not yet explored using PRT or the Denver Model, and the evidence did not establish that these in-state alternatives would not meet Claimant’s individual needs.

LEGAL CONCLUSIONS

1. Cause does not exist to grant Claimant’s appeal and to order the Service Agency to make a recommendation to DDS to fund Claimant’s participation in the Son-Rise program (Factual Findings 1 through 14, and Legal Conclusions 2 through 10.)

2. An administrative hearing to determine the rights and obligations of the parties, if any, is available under the Lanterman Developmental Disabilities Services Act (Lanterman Act) to appeal a contrary regional center decision. (Welf. & Inst. Code, §§ 4700-4716.) Claimant timely requested a hearing on receipt of the Service Agency’s denial of recommended funding for Claimant’s participation in the Son-Rise program, and therefore, jurisdiction for this appeal was established.

3. The standard of proof in this case is the preponderance of the evidence, because no law or statute (including the Lanterman Act) requires otherwise. (Evid. Code, § 115.)

4. When a party seeks government benefits or services, he bears the burden of proof. (See, e.g., *Lindsay v. San Diego Retirement Bd.* (1964) 231 Cal.App.2d 156, 161 [disability benefits].) In a case where a party is seeking funding not previously provided or approved by a regional center, that party bears the burden of proof. In this case, Claimant made a new request for FDLRC for recommended funding for Claimant’s participation in the Son-Rise program. Claimant therefore bears the burden of proof. He has failed to meet his burden.

5. A service agency is required to secure services and supports that meet the individual needs and preferences of consumers. (See, *e.g.*, Welf. & Inst. Code, §§ 4501 and 4646, subd. (a).)

6. Welfare and Institutions Code section 4648, subdivision (a)(16), provides:

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. For regional center consumers receiving these services as part of their individual program plan (IPP) or individualized family service plan (IFSP) on July 1, 2009, this prohibition shall apply on August 1, 2009.

7. Welfare and Institutions Code section 4686.2 provides, in pertinent part:

(b) Effective July 1, 2009, notwithstanding any other provision of law or regulation to the contrary, regional centers shall: (1) Only purchase ABA services or intensive behavioral intervention services that reflect evidence-based practices, promote positive social behaviors, and

ameliorate behaviors that interfere with learning and social interactions.

8. Welfare and Institutions Code section 4686.2, subdivision (d)(3), defines "evidence-based practice" as:

a decision making process that integrates the best available scientifically rigorous research, clinical expertise, and individual's characteristics. Evidence-based practice is an approach to treatment rather than a specific treatment. Evidence-based practice promotes the collection, interpretation, integration, and continuous evaluation of valid, important, and applicable individual- or family-reported, clinically-observed, and research-supported evidence. The best available evidence, matched to consumer circumstances and preferences, is applied to ensure the quality of clinical judgments and facilitates the most cost-effective care.

9. Welfare and Institutions Code section 4519, subdivision (a), provides:

(a) The department shall not expend funds, and a regional center shall not expend funds allocated to it by the department, for the purchase of any service outside the state unless the Director of Developmental Services or the director's designee has received, reviewed, and approved a plan for out-of-state service in the client's individual program plan developed pursuant to Sections 4646 to 4648, inclusive.

Prior to submitting a request for out-of-state services, the regional center shall conduct a comprehensive assessment and convene an individual program plan meeting to determine the services and supports needed for the consumer to receive services in California and shall request assistance from the department's statewide specialized resource service in identifying options to serve the consumer in California. The request shall include details regarding all options considered and an explanation of why these options cannot meet the consumer's needs. . . .

10(a). Claimant did not meet his burden to prove that the Son-Rise program is an established, evidence-based treatment. It has not been clinically determined or scientifically proven to be effective for the treatment of autism. Although two studies have been conducted, neither was sufficient to scientifically establish the efficacy of the Son-Rise program. Consequently, the Son-Rise program does not currently meet the criteria for a therapeutic service or treatment which may be funded under the Lanterman Act.

10(b). Additionally, FDLRC submitted evidence that comparable in-state services are available to meet Claimant's needs, and Claimant has not proven otherwise.

10(c). Given the foregoing, Claimant has not established that FDLRC must make a recommendation to DDS to fund Claimant's participation in the Son-Rise program.

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ORDER

Frank D. Lanterman Regional Center's denial of recommended funding for Claimant's participation in the Son-Rise program is upheld. Claimant's appeal is denied.

DATED: June 7, 2016

JULIE CABOS-OWEN

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.