# DEFORE THE OFFICE OF ADMINISTRATIVE HEARINGS STATE OF CALIFORNIA

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OAH No. 2013070002

CLAIMANT,

VS.

HARBOR REGIONAL CENTER,

Service Agency.

#### **DECISION**

Howard W. Cohen, Administrative Law Judge (ALJ), Office of Administrative Hearings (OAH), State of California, heard this matter on November 18, 2013, and February 25 and March 3, 2014, in Torrance.

Claimant was not present for the hearing; she was represented by her mother and father.<sup>1</sup>

Gigi Thompson, Manager, Rights Assurance, represented Harbor Regional Center (HRC or Service Agency).

Oral and documentary evidence was received. The record was held open to allow the parties to submit briefs. Claimant submitted a closing brief, which was marked as exhibit C32. The Service Agency submitted a closing brief, which was marked as exhibit S25. The record closed on March 17, 2014, but was reopened on April 1, 2014, by an Order

<sup>&</sup>lt;sup>1</sup> Party and family titles are used to protect the privacy of claimant and his family.

deeming the Service Agency's exhibits moved into evidence and allowing claimant to file objections. Claimant filed no objections.

The record was closed and the matter was submitted for decision on April 11, 2014.

# **ISSUE**

Whether the Service Agency may either (a) fade out funding for a six-hours-perweek direct Applied Behavior Analysis (ABA) services program for claimant through California Unified Service Providers, LLC (CUSP), or (b) require claimant to accept a parenttraining-only ABA program.

# **EVIDENCE RELIED UPON**

*Documents*. Service Agency's exhibits S1-S25; claimant's exhibits C1-C32.

*Testimony*. Brooke Nakagawa; Antoinette Perez; Xeres Orzame; claimant's mother; Carrie Susa.

#### FACTUAL FINDINGS

- 1. Claimant is an 11-year-old boy who is a consumer of HRC based on his qualifying diagnosis of autism.
- 2. Claimant is in sixth grade and will transition to middle school this year. He resides at home with his parents and his 13-year-old typically-developing sister. Claimant's parents are attorneys; they work full-time for the federal government, at different agencies.

# CLAIMANT'S FAIR HEARING REQUEST

3. As reflected in a revised Individual/Family Service Plan (IFSP), bearing

<sup>&</sup>lt;sup>2</sup> For each regional center client, the Lanterman Developmental Disabilities Services

revision dates of October 3 and December 14, 2012, and March 12, 2013, HRC funded direct ABA services for claimant through its vendor, CUSP, beginning in September 2009, and was currently funding those services for six hours per week. HRC was also funding 14 hours per month of respite services, and agreed to "provide information on socialization programs, as needed." (Ex. S7.)

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- 4. By a notice of proposed action (NOPA) letter dated June 14, 2013, Brooke Nakagawa, claimant's counselor at HRC, notified claimant's parents that HRC would either fade out claimant's direct ABA services over the following six months or, if claimant's parents preferred, fund a parent-training program to be provided by CUSP or another provider.
- 5. On June 21, 2013, claimant's mother submitted to HRC a Fair Hearing Request (FHR) on claimant's behalf, appealing HRC's decision to change claimant's services. This hearing ensued.

#### **ABA SERVICES**

6. Claimant was diagnosed with autism in July 2007 by B.J. Freeman, Ph.D.

Act (Lanterman Act) requires an "individual program plan," or "IPP." (Welf. & Inst. Code, § 4646.) HRC, rather than using those Lanterman Act terms, refers to an "Individual/Family Service Plan" or "IFSP," terms derived from the federal Early Intervention Program for Infants and Toddlers with Disabilities, which is known in California as the "Early Start Program" and which applies only to infants and toddlers under the age of three (Cal. Code Regs., tit. 17, § 52100 et seq.). For purposes of this matter, "IFSP" is deemed to be synonymous with "IPP."

Claimant tantrumed frequently for 30 minutes at a time, both at home and in the community. He had poor verbal skills and toileting skills, he could not make sustained eye contact, and he wandered, fixating on garage doors opening and closing.

- 7. When claimant's parents received Dr. Freeman's psychological assessment, claimant's mother reduced her work schedule by 20 percent, and both parents attended a toilet-training, eating, and sleeping workshop at Autism Partnership in Seal Beach, at their own expense. They tried to implement at home what they had learned in the workshop, but it became clear to them that claimant needed direct intervention immediately. Both of claimant's parents then took a week off from work and enrolled with claimant, at their own expense, in a five-day intensive ABA program at Autism Partnership, where claimant made significant progress. Only at that point, in spring 2009, did claimant's school district decide to fund his ABA program.
- 8. Claimant first attended Sunrise, a special needs pre-school in his local school district. He currently receives special education services at an elementary school in the same school district. According to claimant's May 7, 2012, Individualized Education Plan (IEP), the school district provides claimant with adapted physical education, occupational therapy, physical therapy, speech and language therapy, and 30 hours per week of behavior intervention services at school and 75 minutes per week at home, among other services.
- 9. The IEP identifies as areas of need claimant's gross motor skills, fine motor skills, academics, social emotional development, and speech and language. The IEP also states that claimant is social, talks and laughs with friends, and joins in playground games, but his eye contact, though improved, is inconsistent and is "more difficult with peers than with adults even during structured social tasks in the speech room with friends that [claimant] is familiar and comfortable with." (Ex. S8, p. 5.) The IEP team "did not rate

[claimant] in the autism range; however, noted eye contact has to be prompted, and has a delay in processing when listening to auditory directions. [Claimant] continues to meet the criteria for special education eligibility in autistic-like behaviors and speech or language impairment." (*Id.*) After one year of receiving services from CUSP at school, claimant was partly mainstreamed, at least in part due to the success of CUSP's ABA services in addressing claimant's tantrums and toileting behaviors. He was subsequently fully mainstreamed with ABA support for the entire school day. Claimant's mother testified, however, that, even with a one-on-one aide, claimant is not fully integrated into his class. There is no indication that the district intends to change the levels of service.

- 10. HRC did not begin providing services to claimant until fall 2009, two years after his diagnosis. HRC first required claimant's parents to get ABA training. Claimant's parents did so at their own expense; they also paid for ABA training for claimant's afterschool caregivers.
- 11. In January 2011, claimant's mother returned to work full time, and a caregiver provided child care during the afternoons when claimant returned home from school.
- 12. Six months later, claimant's June 14, 2011, IFSP provided for HRC funding for six hours per week of direct ABA intervention. But HRC decided to change claimant's program by fading and ending it. HRC informed claimant's mother that without 100 percent parent participation, services would be discontinued, and that a caregiver could not substitute for a parent in the parent training.<sup>3</sup> In a parent-training-only model,

<sup>&</sup>lt;sup>3</sup> According to Xeres Orzame, BCBA, an HRC behaviorist, some vendors allow for the participation in ABA sessions of a caregiver instead of or in addition to a parent, and HRC has in some cases allowed the parent-training-only model to be used with a caregiver

claimant's parents must actually provide the ABA services to claimant. If they are unable to do so because of the demands of their jobs, then, under the parent-training-only model, CUSP would not be funded to provide services. Antoinette Perez, claimant's program manager at HRC, testified that the CUSP program for claimant had started as a parent-training program, but that it changed at some point to a direct ABA program to address claimant's needs. Perez testified that HRC had told claimant's mother that HRC did not intend the direct ABA program to continue indefinitely.

13. In response to HRC's directive, CUSP modified all of its goals, so that parents/caregivers are responsible for the teaching and implementation of the programs. The program supervisor spoke with [claimant's mother] and informed her that the Regional Center funded program was going to be a full parent-training program. [Claimant's mother] modified her schedule to be home on different days of the week so that she can work with the technicians on the goals outlined in this report. Currently, all home sessions occur with either [claimant's father or claimant's mother] participating, or a caregiver if [claimant's parents] are unavailable during the session.

instead of with a parent. HRC offered no explanation as to why that accommodation was not made in this case. (During the home ABA hours that claimant receives from his school district through CUSP, an adult must be present, but that adult may be a caregiver instead of a parent.)

(Ex. S22, italics added.)

- 14. It took one month for CUSP to reschedule its behavioral workers to be at claimant's home on a day when claimant's mother would be there.
- 15. In addition to training claimant's parents, CUSP asked claimant's mother to collect data for tooth brushing and for showering, to ensure maintenance and continued success. When data collected by the CUSP behaviorist during sessions was consistent with parent narrative reports, the parents were not required to collect additional data.
- 16. A year later, on June 15, 2012, HRC conducted a functional behavioral assessment (FBA) of claimant. In its FBA report, HRC recommended only parent-training goals.<sup>4</sup>
- 17. Claimant's mother disputed the HRC FBA recommendations. In a September 11, 2012, letter to Nakagawa, she wrote that the FBA did not analyze what functions were served by claimant's behaviors and did not address many of claimant's behavioral issues or collect data regarding his social behavior deficits. She wrote that claimant "perseverates, engages in side-gazing (i.e., does not make direct eye contact with others), becomes inappropriately fixated on topics or objects, frequently relies on pedantic communication, physically withdraws from social situations to engage in solitary repetitive tasks, and has difficulty initiating and sustaining social contact." (Ex. C9.) Claimant's mother also wrote that she and claimant's father do participate in claimant's treatment, and asked for citations to peer-reviewed research supporting the efficacy of parent-training only as

<sup>&</sup>lt;sup>4</sup> There had been an IFSP meeting on June 11, 2012; the resulting IFSP, dated October 3, 2012, states that claimant's parents "will learn to become independent in managing [claimant's] behavior." (Ex. C20.) Claimant's parents did not agree to the proposed program.

compared to direct ABA intervention.

- 18. In response to claimant's mother's letter, HRC decided to obtain a new FBA, conducted by Behavior and Education, Inc. (BAE). Beginning in February 2013, with HRC funding, BAE conducted a second FBA of claimant and issued a report dated March 27, 2013.
- 19. BAE administered the Adaptive Behavior Assessment System (ABAS-II), which indicated "severe delays in social awareness, cognition, communication, motivation, and mannerisms. Functional behavior assessment indicated that problematic behaviors occur for the purpose of escaping or avoiding non-preferred tasks or activities, obtaining social attention, and obtaining self-stimulatory input." (Ex. S10.)
- 20. In the BAE FBA's "Recommendations" section, BAE reported that claimant "requires an applied behavior analysis (ABA) intervention program with a strong inclusion in positive behavior support," beginning with understanding behavioral function and teaching replacement behaviors. (Ex. S10.) BAE recommended "active parent and caregiver participation, such that parents and caregivers learn the principles and techniques utilized within [claimant's] behavior intervention plan. Intervention should systematically address goal areas recommended in this report." (*Id.*) None of the recommended goals is for claimant himself; all the goals are for the parents and caregivers, requiring more than just "parent and caregiver participation." Every recommended goal states that, by a certain date, "parents will use" various strategies and techniques in teaching claimant certain skills and behaviors. BAE did not bar caregivers from receiving training to deliver the services to claimant, although, for unstated reasons, HRC has apparently barred it in this case. (Factual Finding 11, fn. 3.)
- 21. Again, claimant's mother disputed the FBA recommendations, though, in a letter to Nakagawa dated June 3, 2013, she agreed with the FBA's conclusion that claimant

has "a significant number of deficits across a wide range of domains (communication, community use, functional pre-academics, home living, health & safety, leisure, self-care, self-direction, and social)." (Ex. 14.)<sup>5</sup> Claimant's mother also wrote of her dismay that, "despite concluding that [claimant] has a low level of behavioral function, a repertoire of problem behaviors, and many areas of identified need the FBA proposed not one single goal targeted to [claimant]." (*Id.*) She reminded Nakagawa of her September 2012 request that HRC provide her with citations to

any peer-reviewed research that supports the conclusion that parent training alone is the preferred treatment for autism. HRC has been unable to do so. In fact, at our April 26 meeting, HRC's behavior analyst admitted that she could find no peer-reviewed research that concluded that parent training alone was a successful or even accepted method of treating autism. And yet, that is precisely the program that the FBA proposes for claimant.

(Id).

22. Perez testified that it is HRC's practice to "empower our parents," and that HRC wants to provide an environment in which claimant's parents feel they have the skills

<sup>&</sup>lt;sup>5</sup> At hearing, Nakagawa first testified that she is not aware of the family's requests that social goals be set for claimant in his behavior program, but then acknowledged that claimant's mother, in the June 2013 letter, complained that, despite her repeated requests, HRC had never approved having claimant's ABA program address his significant social behavior issues.

to help claimant achieve his goals. Claimant's mother told HRC that she was not a behavior analyst and was not as well equipped as CUSP to deal with claimant's deficits. Although claimant's parents may have skills and knowledge equal to some ABA technicians, Perez acknowledged that the BAE behavior analyst herself had difficulty keeping claimant on task during the FBA.

- 23. In June 2013, after reviewing the BAE FBA, CUSP asked HRC to continue to fund direct ABA for two of claimant's existing three goals due to continued deficits, and to approve three new goals targeted at claimant. HRC conceded at the hearing that the CUSP goals addressed the same issues identified in the BAE FBA, but they were rejected because they were not written as parent-focused goals. Nakagawa entered, in the Service Agency's Consumer ID Notes, that she emailed CUSP that "HRC is still not in agreement for implementation as they are not *completely parent training focused*." (Ex. S13, p. 5, italics added.)
- 24. CUSP issued a Progress Report for claimant dated August 15, 2013. The report noted that claimant's current areas of need include safety awareness with strangers, self-help (including eating skills), peer interactions, atypical conversation behavior, and inappropriate attention-seeking means. One of the three goals discussed in the report, to have claimant spit a mouthful of water into the sink, has been a goal for several years. CUSP stopped the spitting goal, however, after collaborating with an occupational therapist and concluding that the problem might be neuromuscular and not susceptible to treatment with ABA. Claimant made some progress on the other two goals. Claimant was reported to have, however, only a 58 percent success rate at meeting his community safety goal of finding a community helper (e.g., a store worker or police officer) when he is lost. Perez testified that the regional center wants to see 90 percent achievement for safety-related goals.

- 25. CUSP's August 2013 progress report reflects that sessions last from two to four hours several days per week, in the home and in the community. The report reflects 47.75 hours of service during the covered time period, of which 16.25 hours were "parent/caregiver observed" and 13.25 hours were "parent/caregiver participation." (*Id.*) Perez testified that parent-observed and parent-participation hours should equal the total hours provided, but they fall short in this report. In a prior CUSP report, dated February 8, 2013, parent participation and observation were higher, at 68.25 per cent; Perez testified that at that time claimant's parents were doing "markedly well" at participation. Perez criticized CUSP for not including in its August report the reason for the decline in parent participation. Perez acknowledged, however, that claimant's mother made a good faith effort to participate, working part-time and taking a 20 percent cut in salary. Nevertheless, she testified, they must shift to a parent-training program because, while CUSP will not always be able to support claimant, claimant's parents will be able to do so.
- September through November 2013, CUSP informed HRC that it would be unable to continue to provide services to claimant until HRC approves new goals for claimant. Carrie Susa, BCBA, the Director of Clinical Programming at CUSP, wrote that claimant had met one of the three existing goals, another could be worked on "in the natural environment when situations arise," and another, spitting, was being discontinued due to continued lack of progress. (Ex. S23.) The progress report reflects parent participation and implementation, but total hours for the quarter had decreased to 23.6. Susa wrote in the report that CUSP had designed new goals but was unable to introduce them or any new goals since August 2012, and that "[c]urrently, we do not have programming enough to fulfill the funded 6 hours per week." (*Id.*) Susa wrote in her letter that,

[o]ver the course of the last year, CUSP has proposed goals in areas of deficit for [claimant]. These areas include self-care, social skills, and independence . . . [as] identified in the Functional Behavior Assessment conducted by BAE this year. The goals that have been repeatedly proposed were not accepted or approved by HRC, and therefore CUSP was unable to work on these goals.

At this time, due to HRC's disapproval of the proposed goals, CUSP is unable to continue providing HRC funded services to [claimant]. CUSP continues to maintain that [claimant] requires behavior analytic services to improve his areas of deficit and to help him become a successful and independent child.

(Id.)

27. Before becoming the Director of Clinical Programming at CUSP, Susa was a senior technician and then a program designer. She has worked at CUSP since October 2005, and is very familiar with claimant's case. When his school district referred claimant to CUSP in 2009, Susa was assigned as claimant's case supervisor; she also provided direct services to him for six months so she could better acquaint herself with his needs. She found that claimant presented deficits in communication, social skills, independent play, stereotypical behavior, tantrums, physical aggression, and academics. She developed goals and designed programming for him, collected data, and made program modifications. After about six months, CUSP also began providing direct ABA services to claimant through HRC's funding, until the program changed to a collaborative model in 2011 at

HRC's request, employing an ABA technician who facilitates the services with parents and claimant.

- 28. At the hearing and in its closing brief, HRC mischaracterizes CUSP's withdrawal from providing further services as the equivalent of "discharging" claimant from CUSP's ABA program. Susa testified that CUSP did not recommend discharge; it withdrew from providing services. The BACB guidelines recommend discharge when there are no longer deficits or when the client has achieved all goals. That is not the case here. Since 2009, CUSP has continually proposed new goals as claimant achieved existing goals or as goals were deemed no longer appropriate. In CUSP's December 2013 letter and progress report, CUSP informed HRC that the remaining approved goals did not justify six hours of ABA services per week. CUSP detailed new goals for claimant and sought HRC approval to begin to implement them. Susa insisted in her testimony that CUSP stands ready to implement the new goals for claimant. CUSP ceased to provide services to claimant due to HRC's failure to approve those goals, not, by any reasonable interpretation of the facts, because CUSP determined that claimant should be discharged. Xeres Orzame, BCBA, a behavior analyst at HRC and liaison to CUSP, acknowledged that the fact that CUSP and HRC cannot agree on how to set goals is not sufficient to constitute a basis for a "discharge" under the BACB guidelines.
- 29. After HRC received the December 2013 CUSP progress report, Orzame asked Susa to meet to discuss programming; they met in February 2014 but could not reach agreement on a program model for claimant. Susa did not reformulate CUSP's proposed goals after HRC rejected them because, she testified, it would violate her ethical guidelines, since the parent-training-only model is not described in the literature as the most efficient and effective method of delivering ABA services. She testified that one should only fade out services when the client no longer presents needs, which is not true of claimant.

- 30. It is undisputed that claimant's program should be designed to use the most effective method to address claimant's current needs, that a failure to timely address claimant's core deficits may result in increased costs later, that ABA has been found to be a cost-effective means of addressing core deficits, and that timely use of ABA reduces overall expenses.
- 31. Orzame urged a shift, however, in claimant's programming, from comprehensive ABA to focused ABA, and from direct ABA to a parent-participation model. She testified that when a comprehensive ABA program addressing multiple needs for 35 to 40 hours per week, such as claimant receives at school and home, is no longer effective, a focused ABA program concentrating on one or two behaviors with parent participation is used. Although she asserted that focused ABA is recommended for children over eight years old, Orzame conceded that research demonstrates that ABA can be effective over the consumer's entire life span and that whether a focused or a comprehensive ABA program is required is not age-dependent. As for the parent-participation model, Orzame testified that it would be more effective than direct ABA services in promoting generalization of claimant's skills and that it is supported by

<sup>&</sup>lt;sup>6</sup> Orzame defined direct services to mean a therapist working one-on-one with a child with no parent participation. She defined parent-training or parent-participation to mean a therapist working with parents and child together. And she defined a parent-training-only program to mean a therapist working only with parents, not the child. HRC's witnesses and some documents conflate these terms, and Orzame testified that HRC would fund a parent-participation program for claimant, but she acknowledged that the NOPA letter (Factual Findings 37 & 38) demands that claimant's parents agree to a parent-training-only model.

published research showing that direct services are most effective for children between the ages of two and eight.<sup>7</sup> Orzame conceded, however, that age is not a disqualifying factor for receiving one-on-one direct ABA treatment, that such treatment can yield positive results even in adults, and that if direct ABA services are working then they should be continued.

- 32. Claimant's FBA identified multiple behavioral targets across various domains, and claimant has made significant progress with comprehensive direct ABA. BACB Guidelines state that a focused ABA program should be offered in the form of direct ABA for consumers with "a limited number of behavioral targets," and that a comprehensive ABA program should be used "where there are multiple targets across all developmental domains" (Ex. S24.)
- 33. Nevertheless, Orzame believes changing to a focused, parent-participation model is justified based on her finding that claimant's mother was "fantastic" at running one ABA session she observed and based on HRC's desire to promote skills generalization and independence. Orzame agreed, though, that the BAE FBA did not assess claimant's parents' ability to implement a family training model as an effective treatment. She admitted that BAE recommended a parent training program without stating any basis for concluding that it would be as effective as direct ABA services. And the Behavior Analyst Certification Board (BACB) guidelines require behavior analysts "to recommend the most

<sup>&</sup>lt;sup>7</sup> Orzame testified that an internet article entitled "Why Add a Parent-Implemented Component to Autism Treatment Programs" (Ex. S19) discusses the effectiveness of the parent-participation model, not the parent-training-only model, at promoting generalization and maintenance of skills. She testified that the article only cites research conducted on toddlers and young children, not children of claimant's age.

effective scientifically supported treatment for each client." (Ex. S24, p. 36.)

- 34. Orzame acknowledged that claimant has the deficits reflected in the BAE FBA, and that the Lanterman Act requires the regional center to address those deficits, but that claimant has not received the services for months. Orzame admitted that, under the parent participation model, claimant's parents, or at least claimant's mother, must be at home during claimant's after-school hours and must take off work to do so, even though BACB guidelines state that parents are not expected to forgo employment in order to implement ABA. She suggested that CUSP could provide the six weekly ABA hours on weekends, when claimant's parents would be available. She acknowledged, however, that this would deprive claimant of family time and his participation in weekend sports leagues, which are important for developing claimant's social skills and community integration.
- 35. Claimant's most recent IFSP meeting at HRC was on June 3, 2013. Claimant was unable to attend, so the revised IFSP resulting from that meeting is based on Nakagawa's observations from October 2012, with claimant's parents' consent. The IFSP states that claimant has difficulty with self-care tasks, requiring hands-on assistance and prompting for such tasks as washing his body and hair, brushing his teeth, dressing, eating with utensils, and, on occasion, toileting. He lacks safety awareness skills; he wanders and is overly trusting of strangers. He enjoys sports and computer games, and he plays with others, but his playing must be facilitated and he has difficulty recognizing social cues. He becomes fixated on identifying and numbering chapters in books and stacking them. The revised IFSP notes that:

<sup>&</sup>lt;sup>8</sup> The BACB guidelines also provide that, in a comprehensive ABA program, "[t]reatment hours do not include time spent with . . . family members specifically trained to extend and amplify the benefits of treatment." (Ex. S24.)

[Claimant] has been receiving Regional Center funding for ABA services through CUSP since September 2009. His current program is addressing spitting (in the context of teeth brushing), identifying community helpers and finding help when lost, and compliance with caregivers by decreasing task avoidant behaviors. An updated Functional Behavioral Assessment (FBA) had been completed by BAE in March 2013. Parent-training goals were recommended in the areas of functional communication, social skills, adaptive behavior, tolerance, health and safety, and behavior.

(Ex. S6, italics added.) Claimant's mother annotated her signature to indicate that she approves "6 hours weekly direct ABA services through CUSP." (Id.)

- 36. Perez testified that HRC will not approve new goals if claimant's parents do not accept a parent training program instead of a direct ABA program. Perez testified that the parent-training model she recommends does not mean that no services will be provided directly to claimant; it merely ensures that claimant's parents will have "100 percent commitment" to the program. As with other HRC witnesses' testimony, this is inconsistent with HRC's stated plan for claimant's services as reflected in the NOPA. (Factual Finding 34.)
- 37. Shortly after the June 3, 2013, IFSP, in her June 14, 2013 NOPA letter (Factual Finding 4), Nakagawa questioned the suitability of CUSP continuing to provide ABA services because CUSP has "not been collaborative in our efforts to empower you to implement skills and techniques independently." (Ex. 3.) Nakagawa wrote that "FBA's have now been completed both by HRC and BAE, both recommending a *parent-training only*

program." (*Id.*, italics added.) Nakagawa offered three options for continued HRC funding for ABA services:

- Switch providers for implementation of a parent-training program as recommended in the FBA's completed by both HRC and BAE;
- Remain with CUSP and transition his program to a parenttraining program as recommended in the FBA's completed by both HRC and BAE;
- Remain with CUSP and complete the remaining goals currently in place, prior to termination of this program. (Ex. S3).
- 38. Under the third option, claimant's hours were to fade over six months and end on December 31, 2013. Nakagawa wrote that "no new goals will be approved for implementation unless it [sic] is designed as a parent-training goal recommended via the FBA." (Id.) She continued,

Should you agree to begin implementing a parent focused program, I wanted you to know that it still does include direct services to [claimant]; however, the program is more focused on empowering you as the parent to implement techniques and strategies more independently. The ultimate goal is to be able to fade-out intensive intervention services

as you would be able to manage any undesirable behaviors as they occur, and could provide intervention as needed.

(Ex. S3, italics added.)<sup>9</sup>

39. A month later, in a July 11, 2013, email to Nakagawa, Susa wrote:

For all goals related to [claimant's] program, we still feel at this time that a combined approach of parent/caregiver and technician implementation is necessary. Though parents have learned skills such as using a task analysis and different types of prompts, we continue to maintain that there is no empirical indication that parent training is more beneficial than intensive one-on-one behavior analytic treatment. . . . If you have come across some research that supports a change in the service delivery format, we would be open to reviewing it.

(Ex. 18.)

40. Susa knows of no research that establishes that a parent-training-only program is more effective than, or as effective as, direct ABA. She testified that the deficits identified in the BAE FBA can be effectively treated through a direct ABA program. Susa has retained supervisory responsibilities for claimant, who, she believes, remains receptive to direct one-on-one ABA services to help him meet new goals. Susa has observed claimant for several hundred hours. Susa testified that she has kept herself abreast of

<sup>&</sup>lt;sup>9</sup> Nakagawa also discussed insurance, addressed below. (Factual Findings 52-58.)

published studies in the field of ABA services, and that the literature supports the finding that ABA is the most effective treatment to address autistic behaviors, that it is effective for autistic people of any age, and that the BACB's guidelines do not recommend age limits for administering ABA. She recently reviewed a sampling of the literature and found that many studies have concluded that ABA is effective for adolescents. Her personal experience of the effectiveness of administering ABA to adolescents is consistent with peer-reviewed literature. Susa currently has seven clients, all over the age of eight; her oldest client is 22 years old.

- 41. Susa also testified that, in every case, it is vital to have parents participate in the program. Claimant's parents have been involved in claimant's school-funded ABA program through the biweekly clinic, through communications with technicians and with Susa, in collaboration with technicians during sessions, and when Susa visits to the home to reinforce the parents' participation. "Participation" in the school-funded program does not require claimant's parents to be physically present in the classroom but, under HRC's strictures, claimant's parents would have to take off work and be present for all six weekly hours of home ABA services. This has been an impediment to CUSP's ability to deliver services to claimant. A caregiver could be present instead of a parent, if HRC would allow it. But HRC requested that goals be rewritten so that the parents, and only the parents, were implementing the program.
- 42. Claimant's mother has been very involved in procuring and implementing services addressing claimant's developmental disability. When claimant was born, she left private practice and began working for a federal government agency that she believed would be family-friendly and allow her time to be involved in claimant's life. She and her husband obtained ABA training through Autism Partnership, at their own expense, and paid to send claimant's caregivers to ABA training. She served as President of the PTA at

Sunrise pre-school. She serves on the community advisory committee to the Southwest Special Education Local Plan Area (SELPA), as well as on other committees, including a new common core standards committee as the special education representative. She attends Legislative Day in Sacramento yearly, in connection with her SELPA activities, to advocate for services for children with special needs. She gave up working full time and arranged to telecommute for a portion of her part-time work schedule in order to participate in claimant's after-school ABA sessions.

- district, every two weeks to review in detail claimant's goals and progress, and frequently talks to and emails Susa about claimant. She has been using all her leave time from work to participate in CUSP's behavioral interventions at home and at the biweekly clinics. She collects data for CUSP on claimant's compliance with showering tasks, and provides that data, along with narratives regarding other behaviors, to CUSP at the biweekly clinics. She and claimant's father and sister engage in role-playing with claimant to implement CUSP's behavior strategies. The entire family, which is very close, engages in numerous weekend activities together, including attending claimant's sports league activities. In her mid-2013 review of claimant's program, Orzame wrote that "[claimant's] parents have fully participated in the program and CUSP has done an exemplary job of providing parent training services . . . ." (Ex. S9.)
- 44. Claimant's mother testified that because of the time she must spend away from work, her involvement in claimant's HRC-funded ABA program has cost her promotions and affects the types of cases she is allowed to work on. She testified that if direct ABA were funded by HRC, she would not have these difficulties at work. She testified, credibly, based on the record of all of her activities with claimant, that she would stay very involved in claimant's program. She has never received from HRC any peer-

reviewed evidence-based support for the proposition that parents alone administering ABA to their child is the most effective way of dealing with the deficits of autistic children.

- 45. Claimant has made great progress due to CUSP's ABA interventions. Claimant's mother testified that CUSP is very systematic, focused, and meticulous about collecting data regularly, interpreting that data, and adjusting to claimant's responses to the program. Perez testified that claimant's goals were being recycled by CUSP over the years, so HRC and BAE decided to refocus on parent training. But this was not established; CUSP sets very precise goals, broken down into small increments, and changes goals when claimant achieves mastery over each increment. Claimant no longer tantrums or engages in self-injurious behaviors, both of which were addressed with direct ABA services. Claimant's mother testified that he is now sweet-tempered; he still elopes, but has made progress correcting that behavior with direct ABA services. Claimant, however, still cannot make direct eye contact and still cannot initiate or sustain conversation on appropriate topics. He is still unable to react appropriately to "stranger danger" in a public setting, being overly trusting and guileless, although he has made progress in home role-playing exercises with his sister and parents designed by CUSP to address that issue. When on several occasions claimant's mother tried to implement the exercise in a store by leaving claimant's sight, claimant became overly anxious. HRC told her that CUSP should be working on ameliorating the adverse effects of the community-therapy-induced anxiety, but she testified persuasively that the adverse effects were not produced by the therapy but by claimant's anxiety in the community when not near his mother. In any event, she has had numerous discussions with CUSP about helping claimant cope with strangers and safety.
  - 46. Claimant's parents have been asking HRC to fund social skills services for

claimant for years, without success. <sup>10</sup> Claimant's mother testified that claimant does not get invited to birthday parties. If he has play dates, they are initiated by claimant and take place at claimant's home. During those play dates, however, claimant cannot sustain social interaction or respond to his friend's attempts to engage in activity together. Instead, claimant stops looking at his guest, walks away, begins engaging in solitary play, and becomes fixated on writing down book chapter numbers. Claimant plays in several special-needs weekend sports leagues—football, basketball, baseball, soccer. All are facilitated play leagues, with volunteers or paid staff; claimant is not in any league with typically-developing children. Claimant has had swimming lessons with a one-on-one instructor since he was a toddler, yet he still cannot lift his arms out of the water to swim; he can dog-paddle, but cannot be left in the water unsupervised. Claimant's mother is concerned that, if claimant does not develop social skills, he will not be able to live a life independent of his parents, functioning at work and in the community. She is also concerned for claimant's safety, because he must know how to discern a threatening situation and, when he needs help, whom to ask for assistance and how to articulate his request.

47. Claimant's mother met with Perez, Orzame, and CUSP in February 2014, between the first and second day of this hearing. Perez for the first time offered HRC funding for a facilitated social skills program for claimant along with the parent-training-only ABA program. Claimant's mother expressed interest in the offer, but not as a substitute for direct ABA services. HRC continued to insist she choose between a parent-training-only program and fading ABA services, and the meeting did not resolve the issue.

<sup>&</sup>lt;sup>10</sup> Nakagawa testified that she believes claimant's deficits are not social behavior deficits but communication deficits, characteristic of autism, that are already targeted through claimant's ABA services.

Claimant's mother does not dispute that parent involvement is an integral part of any ABA program; she disputes that parent-training only, with a fadeout of direct services to the consumer, is appropriate, especially where, as here, direct ABA services have proven effective and there is no support for parent-training-only as an adequate substitute.

- 48. The record does not support the Service Agency's proposed change in services for claimant. The evidence shows that direct ABA has been found to be effective throughout a consumer's lifetime, and HRC has an obligation under the Lanterman Act to meet claimant's service needs throughout his lifetime, even if claimant's parents are no longer alive. HRC's proposal would require more than a significant element of parent training in addition to direct intervention; the program it has offered is one of parent-training only, with a stated goal of shifting responsibility entirely to the parents to reinforce desired behaviors in claimant. HRC did not establish a sufficient scientific or legal basis for this proposed change, nor did it establish why it will not approve a program allowing for the participation of claimant's caregivers during the time each day that claimant's parents are working.
- 49. Claimant's parents presented very credibly, both in their demeanor and in the substance of their testimony, which was substantiated by documentary evidence and the testimony of other witnesses. Their active involvement in claimant's program has been exemplary (see Factual Findings 7, 10, 15, 41, & 42); testimony to the contrary by HRC's witnesses was contradicted by those same witnesses (see, e.g., Factual Findings 25 & 33). The Service Agency's witnesses' credibility was damaged further by inconsistencies and self-contradictions in their testimony and by lack of evidentiary support (see, e.g., Factual Findings 21, fn. 5, 22, 25, 31 & fn. 6, 33, 34, 36, & 45), by the predictably confusing conflation of terms such as "parent participation," "parent training," and "parent training only," when the inescapable conclusion drawn from the evidence as a whole is that the

Service Agency offered to fund a parent-training-only program (see, e.g., Factual Findings 37 & 38), and by the meritless and counterfactual argument that CUSP "discharged" claimant from its ABA program (Factual Finding 28).

- 50. Claimant's parents are willing to have claimant participate in a program that requires significant parent and caregiver training, but are unwilling to have responsibility for intervention with claimant shift to them exclusively. Though they have received training and are very involved in claimant's programs, they are not licensed BCBAs and, while they appear to be competent to implement at least some of claimant's current program, they do not have the expertise to continue to refine and design an appropriate program for claimant. They do not have the experience or the concomitant competence and expertise of behavior technicians, who must deal with numerous consumers presenting with a wide variety of behaviors in a wide variety of settings and who continually interact with their BCBA superiors. The inadequacy of a parent-training-only program is especially true in this case because claimant is transitioning to middle school and his adolescent and teenage years, during which time he may be expected to go through significant developmental changes and present new behaviors and needs that his parents have not been trained to address.
- 51. The fadeout suggested by HRC is supported by testimony that some of CUSP's goals have been recycled since claimant began receiving direct ABA services in 2009, and that claimant's mother does well in parent-training sessions with claimant. Evidence of the continued need for and effectiveness of CUSP's ABA program in ameliorating the effects of claimant's developmental disability is much more convincing. It is premature to build a fade into claimant's ABA program, given that CUSP has identified many goals he has yet to achieve. Based on the evidence at hearing, CUSP's suggested list of goals, which HRC has not approved, are appropriate and likely to effectively assist

claimant and his family. HRC may require periodic assessments of claimant's progress and of the effectiveness of the program, as warranted by law.

# RELATED ISSUE

- 52. Related to the issue to be decided in this matter is claimant's insurance coverage for the services provided by CUSP, a subject on which HRC and claimant's parents offered substantial testimony.
- 53. In 2012, at HRC's request, claimant's parents submitted a claim for claimant's ABA services to their health insurance carrier. The carrier denied the claim on the grounds that federal employees are not covered for those services. In February 2013, after learning that the Affordable Care Act was extended to include federally funded insurance programs, Nakagawa asked claimant's parents to submit another claim. Claimant's mother did so, and informed HRC that their insurance carrier had again denied her coverage request, on the grounds that ABA services are not within the plan's coverage.
- 54. The following month, Nakagawa again asked claimant's parents to submit a claim. She instructed them not to refer to ABA services, but to identify the services provided to claimant as "behavioral health treatment program (BHTP)" services, even though, at the hearing, Nakagawa acknowledged that claimant receives no services from CUSP other than ABA services. Perez testified that insurance companies began using the term "BHTP" to describe ABA services after certain mental health legislation was enacted. She testified that she has found that when families ask for ABA coverage, their carrier denies the request, but if they then ask for BHTP coverage, carriers provide coverage. Claimant's parents refused to resubmit a coverage claim for BHTP services, believing that doing so could mislead the carrier because the services provided to claimant had always been described, both by HRC and by CUSP, as ABA services.

- 55. Nakagawa decided to investigate whether claimant's insurance plan would cover BHTP services, but she was unable to identify claimant's insurance plan type on the carrier's website without an insurance card from claimant's parents that they were unwilling to provide. Knowing that BAE was in the process of gathering information to conduct its FBA of claimant, Nakagawa asked BAE to obtain the insurance card from claimant's parents. BAE did so; claimant's parents did not know that the request for the information was made, not in connection with the FBA, but with HRC's campaign to have them pursue insurance coverage. With the information on the card, Nakagawa was able to identify claimant's plan type. She called the carrier and, without identifying claimant, asked whether that plan type covers BHTP services. She testified that the carrier told her that such services were covered.
- 56. Claimant's mother emailed Nakagawa to express her dissatisfaction with the way Nakagawa obtained the insurance card. She wrote that "she felt that [Nakagawa's] actions betrayed [the] family's trust." (Ex. 13, p. 15.)
- 57. Claimant's mother again submitted a claim for claimant's ABA services; by letter dated September 25, 2013, the carrier again denied the claim, stating that it affords no coverage for ABA. Claimant's mother provided Nakagawa with a copy of the coverage denial letter on October 8, 2013.
- 58. HRC contends that parents are obligated to provide their insurance cards under the Lanterman Act, citing Welfare and Institutions Code section 4643, subdivision (c). That section, however, applies by its terms to information to be provided in connection with an intake assessment performed for the purpose of determining eligibility for regional center services, not for an evaluation of ongoing needs after eligibility has been found. Regardless of whether that section applies here, though, HRC circumvented the IPP process by surreptitiously obtaining claimant's insurance information. HRC's tactics were

not a means prescribed under the Lanterman Act for attempting to resolve a dispute with a consumer's parents. On the other hand, it is reasonable for HRC to require claimant's parents to continue to explore generic sources of funding by submitting another written coverage request to the carrier, in a manner that is not misleading. To that end, in their request claimant's parents may specify that they are inquiring about whether the carrier will cover, under the rubric of BHTP services, the same services for which they previously but unsuccessfully sought coverage under the rubric of ABA services. They may also inform the carrier that, in discussions and in writing, the regional center and the service provider have always referred to the services claimant receives as ABA services.

#### LEGAL CONCLUSIONS

- 1. The Lanterman Act governs this case. (Welf. & Inst. Code, § 4500 et seq. 11) An administrative "fair hearing" to determine the rights and obligations of the parties is available under the Lanterman Act. (§§ 4700-4716.) Claimant requested a fair hearing to appeal the Service Agency's decision to either fade claimant's direct ABA services through CUSP or change to a parent-training-only ABA program. Jurisdiction in this case was thus established. (Factual Findings 1-5.)
- 2. The California Legislature enacted the Lanterman Act "to prevent or minimize the institutionalization of developmentally disabled persons and their dislocation from family and community... and to enable them to approximate the pattern of everyday living of nondisabled persons of the same age and to lead more independent and productive lives in the community." (Association for Retarded Citizens v. Department

<sup>&</sup>lt;sup>11</sup> All further statutory references are to the Welfare and Institutions Code, unless otherwise stated.

of Developmental Services (1985) 38 Cal.3d 384, 388.)

- 3. The Lanterman Act acknowledges the state's responsibility to provide services and supports for developmentally disabled individuals and their families. (§ 4501.) Regional centers must develop and implement IPPs, which shall identify services and supports "on the basis of the needs and preferences of the consumer, or where appropriate, the consumer's family, and shall include consideration of . . . the cost-effectiveness of each option . . . ." (§ 4512, subd. (b); see also §§ 4646, 4646.5, 4647, and 4648.) The Lanterman Act assigns a priority to services that will maximize the consumer's participation in the community. (§§ 4646.5, subd. (a)(2); 4648, subd. (a)(1), (2).) "It is the intent of the Legislature that regional centers provide or secure family support services that . . . promote the inclusion of children with disabilities in all aspects of school and community." (§ 4685, subd. (b)(5).)
- 4. Regional centers must monitor the delivery of services to their clients. (§ 4646.5.) The IPP must include a statement of goals, with objectives stated "in terms that allow measurement of progress or monitoring of service delivery." (4646.5, subd. (a)(2).) Periodic reviews of services enable the service agency to ascertain whether planned services have been provided, whether additional services are needed, and whether the consumer and his or her family are satisfied with the implementation of the IPP. (§ 4646.5, subd. (a)(6).)
- 5. Services and supports under the Lanterman Act may include "behavior training and behavior modification programs . . . [and] training for parents of children with developmental disabilities." (§§ 4512, subd. (b); see also 4685, subd. (c)(1).) With respect to ABA services, the Lanterman Act provides that 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.
- (2) Only purchase ABA or intensive behavioral intervention services when the parent or parents of minor consumers receiving services participate in the intervention plan for the consumers, given the critical nature of parent participation to the success of the intervention plan.

[¶] . . . [¶]

- (4) Discontinue purchasing ABA or intensive behavioral intervention services for a consumer when the consumer's treatment goals and objectives, as described under subdivision (a), are achieved. ABA or intensive behavioral intervention services shall not be discontinued until the goals and objectives are reviewed and updated as required in paragraph (5) and shall be discontinued only if those updated treatment goals and objectives do not require ABA or intensive behavioral intervention services. (§ 4686.2, subd. (b).)
- 6. Cause exists to grant claimant's appeal, as set forth in Factual Findings 1 through 43, and Legal Conclusions 2 through 5. The Service Agency has not met its burden of supporting a fade or change in ABA services to claimant. The direct ABA program claimant has been receiving through CUSP is evidence-based and has been shown to be effective for claimant. By its terms, the Lanterman Act allows funding for parent training and requires parent participation in the delivery of ABA services to consumers; it does not require a parent-training-only ABA model. Claimant's parents have received training at their own expense and are active participants in claimant's ABA program, as are claimant's caregivers. CUSP has identified numerous goals, consonant with those identified in the BAE

FBA, that are designed to address claimant's service needs and that have not yet been

achieved.

7. Cause exists to require claimant's parents to resubmit a claim to their

insurance carrier for coverage for claimant's ABA program to determine whether that

program may be covered as BHTP, and to include all information necessary to ensure that

the reapplication is not likely to mislead the carrier, as set forth in Factual Findings 44

through 50.

ORDER

1. The appeal by claimant is granted. The Service Agency shall continue to fund

claimant's six hours per week of direct ABA services provided by CUSP until such time as a

changed circumstances warrant otherwise, as determined through the IFSP process.

2. Claimant's parents shall reapply for insurance coverage for the HRC-funded

ABA program to determine whether that program may be covered as BHTP. In their

reapplication, they shall include information necessary to ensure that the reapplication is

not likely to mislead the carrier.

**DATED:** April 23, 2014

HOWARD W. COHEN

Administrative Law Judge

Office of Administrative Hearings

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# **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.