

BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of:

M. S.,

Claimant,

vs.

Central Valley Regional Center,

Service Agency.

OAH No. 2012120844

DECISION

This matter convened for hearing before Marilyn A. Woollard, Administrative Law Judge (ALJ), Office of Administrative Hearings (OAH), State of California, on April 25 and July 19, 2013, in Fresno, California.

Claimant's mother and grandfather (sometimes referred to as claimant's family) appeared on behalf of claimant.¹

Shelley Celaya, Client Appeals Specialist, appeared on behalf of the service agency, Central Valley Regional Center (CVRC).

Oral and documentary evidence was presented. After the conclusion of the evidentiary hearing on July 19, 2013, the record remained open for the submission of written closing arguments. On July 29, 2013, the parties filed their closing briefs, which were marked for identification, respectively, as Claimant's Exhibit 33 and CVRC's Exhibit

¹ To protect claimant's privacy, the names of her mother and grandfather are withheld.

48. On August 5, 2013, the parties filed their closing briefs, which were marked for identification, respectively, as Claimant's Exhibit 34 and CVRC's Exhibit 49.

The record was closed and the matter was submitted for decision on August 5, 2013.

ISSUE

Under the Lanterman Act, Welfare and Institutions Code section 4500 et seq.,² is CVRC required to fund co-payments for intensive applied behavioral analysis (ABA) therapy services authorized in claimant's Individual Program Plan (IPP), after funding responsibility for those services was shifted from CVRC to her family's Kaiser medical insurance?

FACTUAL FINDINGS

1. Claimant is a 13-year-old girl who was originally determined to be eligible for regional center services in 2003 based on a diagnosis of Pervasive Developmental Disorder (PDD). In 2004, this diagnosis was changed to Autistic Disorder. On January 24, 2006, claimant had a genetic consultation at Kaiser. Her DNA study demonstrated that she had Rett or Rett's Syndrome (also known as Rett or Rett's Disorder), a neurodevelopmental disorder caused by a genetic mutation in the MECP2 gene. The syndrome is characterized by normal early growth and development, followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements (compulsive wringing and washing), slowed brain and head growth, problems with walking, seizures, and intellectual disability. Apraxia (the inability to

² Unless otherwise indicated, all undesignated statutory references are to the California Welfare and Institutions Code.

perform motor functions) is a severely disabling feature of this syndrome that interferes with every body movement, including eye gaze and speech.

Claimant's qualifying condition for regional center eligibility was changed after this diagnosis to Rett Syndrome associated with seizure disorder (March 2006), and to severe mental retardation secondary to Rett Syndrome (September 2010). Her current qualifying condition is profound intellectual disability due to Rett Syndrome (November 2012). Claimant has consistently had substantial handicaps in all major areas of functioning except for mobility, and her complex medical conditions include seizure disorder.

Claimant lives at home with her parents and sibling. Based upon her multiple disabilities and orthopedic impairment, claimant participates in a special education program pursuant to an Individualized Education Program (IEP). Claimant is ambulatory, but she uses a wheelchair for some community outings. She requires physical assistance with all of her self-care skills. Claimant wears diaper pull-ups, and she has been working in incremental steps toward toilet training for many years. As reflected in her July 2012 IPP, claimant's long range goals are to maintain her current physical abilities, to avoid physical deterioration, and to increase her communication skills.

2. Since January 2006, claimant has received intensive ABA therapy services through CVRC.³ From January 2006 through August 2008, these services were provided

³ "Applied behavioral analysis" (ABA) is "the design, implementation, and evaluation of systematic instructional and environmental modifications to promote positive social behaviors and reduce or ameliorate behaviors which interfere with learning and social interaction." "Intensive behavioral intervention" is any form of ABA that is "comprehensive, designed to address all domains of functioning, and provided in multiple settings for no more than 40 hours per week, across all settings, depending on

by the vendor Learning Arts. The Center for Autism and Related Disorders (CARD) became claimant's ABA vendor in September 2008. At the time of the facts giving rise to this hearing, claimant's IPP provided that she would receive 15 hours a week of direct one-to-one (1:1) ABA services from CARD, funded by CVRC, with additional hours for clinic and supervision. These services were provided in the home. In addition, as outlined in her 2012-2013 IEP, claimant received six hours of intensive individualized services five days a week at school.

3. *SB 946:* On January 1, 2012, SB 946 was enacted and codified at Health and Safety Code section 1374.73. Pursuant to this legislation, "every health care service plan contract that provides hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism no later than July 1, 2012." (Health & Saf. Code, 1374.73, subd. (a).)

4. *Current IPP:* On July 9, 2012, claimant's family and her CVRC service coordinator Jacqui Molinet met as an IPP team. They agreed upon services to be included in claimant's IPP, which they determined would remain in effect until July 2013.⁴ At the time of the proposed action that resulted in this hearing, claimant's IPP provided that ABA/Intensive Behavioral Intervention was one of the supports and services "necessary to successfully support [claimant] at home." The IPP's "daily living needs" goal indicated that "CVRC will continue to fund her behavioral intervention program (CARD), and this will be reviewed quarterly."

the individual's needs and progress," delivered in a one-to-one ratio or small group format. ..." (Health & Saf. Code, §§4686.2, subds. (d)(1) and (d)(2).)

⁴ IPPs are reviewed no less often than once every three years. On July 19, 2013, the parties reported that claimant had an IPP meeting scheduled for July 22, 2013.

The IPP's "behavioral health" goal indicated that claimant has "tantrums/outbursts" when she experiences physical discomfort; exhibits stereotypical touching and repetitive vocalizations; can be non-compliant and spit at the television to communicate; and will "run off" in public and not wait for her family when in the community. The "desired outcome" for this goal was that claimant "will minimize her episodes of yelling, crying, and hitting her legs"; "will stop pulling away from whoever is responsible for supervising her in public"; and "will also learn to be patient when out in the community..."

The IPP outlined the following plans to implement claimant's behavioral health goal:

1. ABA/Intensive Behavioral Intervention services to be provided by CARD.
2. ABA services are authorized for 15 1:1 direct therapy/tutor hours weekly, 12 hours per month for Clinic Attendance and 8 hours per month of supervision starting July 2012.
3. Parents will participate in the intervention plan, implement intervention strategies, collect data and participate in clinical meetings as required by CARD.
4. Central Valley Regional Center will fund ABA services.
5. Parents will verify receipt of Behavioral Services provided to their child.
6. CVRC currently funds CARD. As of 8/31/2012 families that receive services and have private insurance, their private insurance should be providing and funding ABA services (SB 946). [Claimant] has Kaiser medical insurance and Medi-Cal as her secondary insurance. Family has already been in contact with Kaiser and they are working on getting ABA services switched over to one of Kaiser's behavior management vendors.

5. On July 10, 2012, the day after the IPP meeting, claimant's mother called Ms. Molinet to ask "if CVRC will be covering the Autism behavior copays." Ms. Molinet advised that this issue would be worked out, once insurance began to pay for the services. Sometime after the IPP meeting, the formal IPP document was written and it was signed by Ms. Molinet on August 9, 2012, and by her supervisor on August 20, 2012.

On September 17, 2012, mother informed Ms. Molinet that the family's co-pay for each ABA service visit would be \$15.

On September 28, 2012, Ms. Molinet extended CVRC's purchase of service (POS) for CARD/ABA services for three months, through December 31, 2012.

6. *Kaiser Authorization:* On October 12, 2012, Kaiser issued an Authorization for Medical Care to claimant for ABA services from CARD through May 12, 2013. The authorization letter specifically instructed claimant not to pay bills from the provider, except for "co-payments, deductibles and non-covered services." Kaiser is currently providing claimant with 25 hours per week of intensive ABA services.

7. CVRC's POS for claimant's ABA services ended October 13, 2012.

8. Claimant's family is currently charged a co-payment for ABA service of \$75 per week (\$15 for each session, five days a week). Claimant's mother, who became disabled and was recently retired for disability, has not paid any of the co-payments. The maximum annual co-payment for which claimant's mother is responsible under her insurance policy is \$1,500.

9. *Notice of Proposed Action Denying Funding for Co-payments:* On November 7, 2012, CVRC convened a Behavior Services Insurance Review to address claimant's request that it pay the co-payments assessed for her insurance-funded ABA services. This review involved several meetings and discussions among regional center

staff. An IPP meeting was never convened to discuss regional center funding for co-payments.

On November 27, 2012, CVRC issued a Notice of Proposed Action (NOPA) to claimant, proposing to deny "funding the co-pays for intensive ABA therapy" effective November 26, 2012. CVRC explained the reason for its proposed action as follows:

Early intensive ABA therapy would not be considered an effective or appropriate means for meeting [claimant's] needs. CVRC has provided 6 years 8 months of intensive ABA therapy. Intensive ABA services were expected to terminate.

As authority for its action, CVRC cited portions of sections 4512, subdivision (b), and 4646, subdivision (a), which address the "effectiveness" and "cost-effectiveness" of services and supports provided to consumers.

10. On December 18, 2012, claimant filed a Fair Hearing Request, challenging CVRC's refusal to fund the co-pays charged for her ABA services. To resolve the issue, claimant requested that the regional center agree to cover co-pays for ABA services.

11. A hearing was originally set for February 1, 2013, but continued at claimant's request and time waiver to April 25, 2013. The evidentiary hearing took place on April 25 and July 19, 2013.

At the hearing, CVRC called the following witnesses: Rebeka Kawashima, M.D.; Carol Sharp, Ph.D.; Emily Branscum, Ph.D.; and Thomas Keenen. Claimant called the following witnesses: Ashley Langeliers; Mary Jones, M.D.; and claimant's mother.

12. At the hearing on April 25, 2013, CVRC stipulated that it would pay claimant's co-payments for ABA services, if it believed that these were appropriate services for her.

I. CVRC'S POLICY FOR REVIEWING REQUESTS TO FUND CO-PAYMENTS

13. Thomas Keenan is CVRC's Director of Clinical Services. His duties include reviewing consumer requests to fund co-payments for ABA services. In his testimony, Mr. Keenan described CVRC's internal process for reviewing co-payment requests. Additional insight into CVRC's process was provided by staff psychologist Carol Sharp, Ph.D., and by behavioral analyst Emily Branscum, Ph.D., who has worked directly with claimant and her family for many years. Based on their testimony, CVRC's policy and process for reviewing co-payment requests is as follows:

14. CVRC considers a request for co-payment as a request for a new regional center service. Before a co-payment request can be decided, CVRC needs an assessment from the vendor and an authorization from the insurer that it will provide the service.

15. After documentation is gathered, Mr. Keenan reviews these requests with input from clinical staff to determine appropriateness and service levels. The service is then discussed using the same decision-making process for clinical relevance and appropriateness of service that CVRC would use when it considers a request to fully fund a new service. In this case, Dr. Sharp and Dr. Branscum were present during meetings where funding claimant's co-payments were discussed. They provided historical clinical data about claimant's level of cognitive and adaptive functioning and her progress toward meeting the goals worked on by CARD.

16. CVRC does not feel bound by the determination of an insurance company that a particular service is medically appropriate for a particular consumer, and it does not consider itself obligated to fund co-payments for all insurance funded services. There is no legislation that mandates a regional center to fund co-payments simply because insurance covers the service. CVRC would not fund co-payments for services it would not purchase. Since the passage of SB 946, however, CVRC has worked with all families to transition their ABA services to their insurers. CVRC has decided to fund co-

payments for such ABA services when it agrees with the efficacy of the services and that their provision is “evidence-based.” In some instances, CVRC has funded additional ABA services for consumers when it determined that the level of insurer-provided services was inadequate. CVRC would pay claimant’s ABA co-pays, if it believed that these were appropriate services for her.

17. In this case, Mr. Keenen testified that claimant has received intensive ABA services for six years and eight months, at a cost of over \$283,000 in CVRC funding. Cost is only one of the factors that were considered in denying her co-payment request. Other considerations were claimant’s history of receiving services for over half of her life, and the facts that she made little or no progress despite these services and was also receiving 30 hours of 1:1 services at school. Mr. Keenen opined that Kaiser may not have had access to all the data CVRC has regarding the effectiveness of claimant’s intensive ABA services. He also opined that Kaiser may have authorized these services based upon an erroneous autism diagnosis.

18. According to Mr. Keenen, CVRC did not believe that an IPP meeting was required to deny the co-payment request, because this was a request for a “new service” from claimant’s family. A NOPA was provided to the family, giving them an opportunity to disagree with the decision and challenge it in a fair hearing. CVRC intended to terminate the ABA services outlined in claimant’s IPP in any event, so the issue of the appropriateness of continuing such services is one that needs to be addressed.

Dr. Branscum agreed that the IPP process takes precedence over the issue and that co-payments would be funded for a consumer if the IPP team agreed to do so. Dr. Branscum clarified that she believed the quarterly review process, attended by claimant’s family, was part of the IPP process or was an informal IPP.

II. EFFECTIVENESS OF INTENSIVE ABA SERVICES FOR CLAIMANT

19. *Contentions:* CVRC contends that it has discretion under the Lanterman Act, to fund ABA co-payments, if it clinically determines that these are appropriate services for claimant. In CVRC's view, it appropriately declined to assume responsibility for claimant's ABA co-payments, based on its review of her long history of receiving intense ABA services, the limited progress she has made, and the absence of "evidence-based" research demonstrating that such services are effective for individuals with Rett Syndrome.

Claimant contends that the Lanterman Act requires CVRC to pay co-payments charged for ABA services included in her IPP which are now funded by her insurance as required by SB 946. In claimant's view, once Kaiser authorized and agreed to fund her ABA services, CVRC relinquished control over them and it can no longer challenge their appropriateness for her. Claimant also contends that ABA services have enabled her to make progress on her goals by breaking them down into very small steps, even though this is not reflected in the standard scores from assessments used to measure progress.

A. Cvrc's Evidence

20. *Testimony of Rebeka Kawashima, M.D.:* Dr. Kawashima is a board-certified pediatrician who works at Kaiser and has been a consultant to CVRC for the past nine years. Dr. Kawashima treated claimant once at Kaiser in the past. She has worked with many medically-complex children, but was not sure how many children with Rett Syndrome she has treated. Dr. Kawashima's testimony, paraphrased below, was based on her review of claimant's medical records at CVRC.

Claimant's genetic testing confirmed that she has Rett Syndrome, a degenerative disorder found in girls. The syndrome has three stages: initial normal development, rapid regression between ages one and four; and a plateau period where cognitive level

does not decline but remains between one to three years old. During the regression phase, there is a loss of movement, a loss of hand and oral skills, and dyspraxia. Individuals with this syndrome have an average life span of 50 years. Dr. Kawashima noted that Rett Syndrome is a distinct diagnosis from Autistic Disorder. At the time the Diagnostic and Statistical Manual, Fourth Edition – Technical Revision (DSM-IV-TR) was published, Rett Syndrome was not established as genetic in origin. The 2013 DSM-V recognizes that children with Rett Syndrome often regain social interests at later stages in life.⁵

Dr. Kawashima opined that claimant is in the plateau stage of Rett Syndrome. The medical records demonstrate that claimant has a poor prognosis for increase in her functional ability, consistent with what is known about this stage. There is no cure for this condition. Treatment involves medical management designed to address complications and issues such as nutrition, oral-motor dysfunction, gastric dysmotility and seizure control. In her opinion, claimant's lack of improvement in functioning is the result of her medical conditions, rather than any behavioral issues. Dr. Kawashima could not find any support in the peer-reviewed medical literature to show that ABA therapy is the standard of care for treating those with Rett Syndrome.

21. *Testimony of Carol Sharp, Ph.D.:* Dr. Sharp has a doctoral degree in clinical psychology specializing in children. She has worked as a staff psychologist for CVRC for the past 10 years. Dr. Sharp's testimony, paraphrased below, was based on her review of claimant's medical and treatment records at CVRC.

⁵ The DSM-IV-TR noted that "[p]reliminary data suggest that a genetic mutation is the cause of some cases of Rett's Disorder." Rett Syndrome has since been determined to be a genetic disorder. (DSM-V at p. 33.)

The diagnostic criteria for Autistic Disorder specifically excludes those individuals whose condition is better accounted for by Rett Syndrome. Claimant's cognitive ability, originally reported as in the severe range of mental retardation, is now in the profound range, as reflected in Kaiser's October 20, 2011 Multidisciplinary Evaluation Summary prepared by the Autism Spectrum Disorders Center. This is the lowest measurable range of intelligence quotient (I.Q.). In reaching her conclusions about claimant's cognitive and adaptive progress over time, Dr. Sharp prepared a summary of assessment scores on various testing instruments. (Ex. 27) These included the Vineland Adaptive Behavior Scales (Vineland), the Stanford-Binet, the Developmental Assessment of Young Children (DAYC), the Bayley Scales of Infant Development (Bayley), the Adaptive Behavior Assessment System II (ABAS-II), and the Leiter.

Dr. Sharp reviewed CARD's Program Design (Design). Under "anticipated consumer outcomes" for ABA services, the Design provides that "[i]t is not anticipated that consumers who present with profound or severe mental retardation or older consumers with autism would significantly benefit from this program." The Design also indicates that CARD administers the Vineland, both at initiation of treatment and annually, to the consumer "so that the effectiveness of the intervention can be consistently monitored."

The Vineland measures a consumer's adaptive functioning with progression of skills, using the reports of individuals who are familiar with the consumer, such as a parent or teacher. Scores under 70 on the Vineland indicate a significant deficiency. Claimant's Vineland scores in the areas of communication, daily living skills, socialization, and motor have generally decreased from a range predominantly in the 50s in 2003, when she was two years, nine months old, to the 40s in 2011, when she was ten years, eight months old. The ABAS-II also measures adaptive functioning. In the 2011 Kaiser assessment, claimant's global ABAS-II score was the lowest possible score.

Claimant has demonstrated gains in the social arena, which have slightly increased her composite. Claimant's 2011 Bayley estimated her mental age as less than 18 months.

Claimant has received intense ABA services since 2006. Based on these scores, Dr. Sharp concluded that claimant did not appear to have made progress. Claimant's apraxia would not impact the results on the Vineland or ABAS-II, which are derived from reliable reporters and not the consumer. Apraxia may affect a timed test, but claimant was assessed with the Leiter, a non-verbal standardized test which is not timed. Claimant's profound range of intellectual disability is not based on her inability to speak.

Dr. Sharp agreed that there is a fine line between severe and profound retardation. Those in the profound range function under the level of a two-year-old child and generally cannot talk, toilet, dress or care for themselves. Dr. Sharp was not sure where claimant was in her toilet training or ability to dress herself. She has never met or assessed claimant. She acknowledged that Rett Syndrome is a rare disorder and that she has worked with fewer than 10 such cases, determining initial or continuing eligibility for services. Dr. Sharp agreed that it would be helpful if claimant could go to the bathroom independently.

22. *Testimony of Emily Branscum, Ph.D.:* Dr. Branscum has a doctorate in developmental psychology and is a board-certified behavior analyst (B.C.B.A.). She was recently hired by CVRC as a behavior analyst. For approximately nine years before this, Dr. Branscum worked with CVRC as an independent contractor. She is responsible for reviewing the programming of CVRC consumers receiving behavior services. From 2006 until the transition of these services to Kaiser, Dr. Branscum has participated in regular quarterly reviews of claimant's behavior services with the vendor, claimant's case manager and her family. Dr. Branscum's testimony, paraphrased below, was based on her ongoing involvement with claimant's behavior program, as well as her review of claimant's medical and treatment records at CVRC.

ABA services are generally provided in one of two categories: (1) early intensive behavior services (also known as e.i.b.s., intensive or comprehensive ABA) which are typically provided by a one-to-one tutor, or (2) behavior intervention services (also known as b.i.s. or focused ABA), which are often provided by consultation with a B.C.B.A. rather than individual tutoring. Intensive ABA services are designed to prepare a consumer for academic services. This is one reason why they are typically considered "early intervention" and should be completed prior to entry into kindergarten or first grade. The California ABA Task Force (CalABA) indicates that intensive ABA services should be for consumers between the ages of three and eight with a diagnosis of Autism Spectrum Disorder. The goal of early intensive ABA services is to help the consumer to catch up to typically developing children. This has never been a realistic expectation for claimant.

Dr. Branscum acknowledged that claimant has made "some really important progress over treatment." However, her progress is "minimal given the level of service" provided and the expectation for the intervention. For example, after receiving early intensive ABA services from both Learning Arts and CARD, as of 2011, claimant still had not mastered many IPP goals established in 2006, some of which were also worked on as part of her special education IEP goals. In Dr. Branscum's opinion, for intensive ABA treatment to be considered effective, a consumer should demonstrate a rate of acquisition that is more than expected with typical maturation – i.e., there is an expectation of more than a year's growth for one year of services provided. Based on the Vineland, claimant's overall functioning in areas of major focus has not improved during her years of early intensive ABA treatment. CARD's own charts in Quarter 15, through August 2012, indicate that claimant has experienced an increase in some maladaptive behavior (i.e., noncompliance). At the same time, the "good news" is that claimant's tantrums have become a "nonissue."

Dr. Branscum has been concerned about the appropriateness of providing claimant early intensive ABA services for many years. For example, in her March 17, 2006 report to CVRC about claimant's program, Dr. Branscum concluded:

This child is over 5 years old. A cautionary note should be made regarding the likelihood of success of intensive programming. This caution is exacerbated by the Rett's Syndrome diagnosis.⁶ I would prefer this child to receive consultation service and not tutoring.

Dr. Branscum explained that she continued to agree to provide claimant with intensive ABA services because CVRC was trying to work closely with claimant's family. Claimant's family has known her position for years that intensive ABA services are not effective for claimant and that claimant deserved the "right to be a little girl" and not to be "programmed."

In 2012, Dr. Branscum asked CARD to develop "terminal goals" for claimant's intensive ABA services. These goals were designed to "signify when the end of programming was to occur," and specifically, to reach a point where claimant's family would feel comfortable in removing intensive ABA services. Eight terminal goals were developed for claimant in July 2012, and included achieving independence in her toileting routine.⁷ Dr. Branscum was never able to discuss these goals with the family

⁶ At the time, claimant had a dual diagnosis of Autism and Rett Syndrome.

⁷ The terminal goals involved claimant's: (1) using appropriate functional communication to request preferred items/activities or cessation of those activities by selecting an icon from a field and traveling to the appropriate communication partner; (2) responding to generalized compliance instructions in home and community settings;

because the insurance process began and claimant switched to Kaiser. As of July 2012, CVRC was trying to end claimant's intensive ABA services. If the co-payment issue had not arisen, CVRC would be terminating these services.

Dr. Branscum conducted a literature search on Rett Syndrome and treatment over the past five years. She obtained and reviewed 49 articles, the vast majority of which focused on gene or drug therapies. She concluded that, over this period, the peer-reviewed literature did not contain articles showing that ABA is an effective, evidence-based treatment for Rett Syndrome. Given claimant's diagnosis and progress since 2006, Dr. Branscum's current recommendation would be for the IPP team to withdraw intensive ABA services. Instead, claimant's family should be provided with "focused" ABA services, for one quarter, with regularly scheduled consultation with a B.C.B.A. of approximately 20 to 25 hours a month. In this way, one or two skills could be targeted at a time to see if claimant makes progress. Thereafter, based upon the parents' level of comfort, the service might change to parent-initiated consultation for new issues or regression.

B. Claimant's Evidence

23. *Testimony of Ashley Langeliers:* Ms. Langeliers holds a master's degree in clinical psychology and anticipates completion of her doctoral degree in this area in 2013. She is a B.C.B.A. who has worked with developmentally delayed consumers

(3) independently completing toileting routine; (4) independently dressing, undressing and putting clothes away when given verbal instruction; (5) independently manipulating fork and spoon and appropriately holding, biting, chewing and swallowing food; (6) appropriately engaging in independent toy and/or electronic play; (7) appropriately and independently initiating play or social activity; and (8) completing daily routines (shower, change clothes, brush hair and teeth, put on lotion).

through CARD since 2008. Ms. Langeliers was claimant's behavioral therapist for approximately six months beginning in 2008. Last year, Ms. Langeliers became CARD's clinical manager in the Fresno area and supervised claimant's behavioral therapist. In June 2013, she became claimant's assigned behavior analyst and is familiar with her ABA goals, treatment and progress. Ms. Langeliers' testimony, paraphrased below, was based on her direct and supervisory involvement with claimant's ABA behavioral program through CARD.

Based on her review of CARD's quarterly reports to CVRC regarding claimant, Ms. Langeliers opined that claimant has made consistent progress on her goals and that, every time a goal has been met, a new goal has been introduced. Claimant has mastered over 500 skills and has shown she has the capacity to learn. Due to her heavy ABA maintenance schedule, claimant has not had significant skill regression. Claimant's biggest success in ABA therapy has been on her toileting goals, which involves independent toileting on a timed schedule. This is an important adaptive skill for claimant to remain independent and in the home. Over several years, this goal has been broken down for claimant into extremely small steps, which include selecting and giving an icon to communicate, going into the bathroom, turning on the light, using her hands/thumbs to pull her pants down and up after voiding, turning the water on, rubbing her hands together to wash them, and turning the water and light off. Many of these incremental steps have been required due to claimant's apraxia and inability to use her hands easily. During this time, claimant has significantly decreased her number of accidents; she has increased the amount of time between required toileting routines from once every 15 minutes to once every 35 minutes; and she has achieved 80 percent mastery of this goal. Claimant's progress has spanned environments to both home and school.

In Ms. Langeliers' opinion, ABA therapy is important and has been an effective treatment for claimant even though there is and will remain a huge discrepancy between her chronological and her mental age. Because claimant has severe delays, standard scores on the Vineland and other instruments do not accurately assess claimant's progress or ability to learn. If there is no increase in standard scores, CARD's policy is to contact the consumer's behavioral supervisor to determine if there have been specific areas of improvement based on raw scores. Increases in claimant's raw scores have indicated progress, as also reported by the parent. For claimant, these increases in raw scores have not translated into increases in standard scores which are normed on the typically-developing population. Many individuals who receive ABA services receive significant benefit, even though they will never reach the skill level of typically-developing children. The appropriateness of the services is based on a review of the child's data to see if they are mastering skills and creating meaningful change.

Even though CARD reported that claimant mastered no skills during the year encompassing the quarters Q12 through Q15, claimant mastered very small skills that can ultimately lead to a bigger goal. Examples include being able to use her thumbs to grasp her underwear and pull down her pants; taking an icon and exchanging it with a communication partner; tapping rather than spitting for attention; and transitioning from one play station to another. In this latter regard, Ms. Langeliers commented that claimant does not know what to do with unstructured time. Other examples include claimant's initial difficulty visually scanning a field to track and pick out a relevant object, and difficulty grasping certain icons from a board, which ultimately had to be modified to enable her grasp. After working on these micro-skills, claimant is now able to work with an icon book and a choice board for communication. Although CARD reported an increase in noncompliance in Q15, it is not unusual to have some regression and, more importantly, CARD also reported that claimant's tantrums and aggression were down.

In response to CVRC's request at the July 2012 quarterly meeting, CARD prepared "terminal goals" for claimant. As reflected in its September 2012 progress report to CVRC, these were goals that claimant would need to meet before discontinuation of ABA services would be requested. CVRC did not mention "fading" services, and CARD continued to recommend 15 hours a week of 1:1 direct therapy, with supervision and clinic attendance. Because no timeline was established, CARD's terminal goals were not a recommendation for the termination of claimant's ABA services.

24. *Testimony of Mary D. Jones, M.D., MPH:* Dr. Jones is the Medical Director of Katie's Clinic for Rett Syndrome at Children's Hospital in Oakland, California. She has held this position since 2008. Dr. Jones is a board-certified pediatrician. She also holds a Masters of Public Health in maternal-child health and a Bachelor of Science in nursing. She is a member of the International Rett Syndrome Foundation and has given academic presentations on and written about Rett Syndrome. Since 2010, Dr. Jones has been a principal investigator for the National Institute of Health's (NIH) Natural History Study of Rett Syndrome (NIH Study). In addition to her testimony, Dr. Jones submitted two "to whom it may concern" letters she authored, dated January 2, 2010 and July 18, 2013. Her testimony, paraphrased below, is based upon her knowledge of claimant and her expertise in Rett Syndrome.

Rett Syndrome is not a degenerative condition. It is a genetic disorder characterized by the loss of purposeful speech, loss of hand use, and difficulty with mobility. Apraxia is the inability to efficiently carry out cognitive intent (motor planning). Claimant also has neurosensory regulation disorder and problems with proprioception (perception of stimuli relating to position, posture, equilibrium, or internal condition). Claimant is able to learn and benefit from therapies such as occupational therapy for hand use, physical therapy for proprioception and mobility, and ABA therapy for

neurosensory regulation. Dr. Jones has worked with hundreds of girls with Rett Syndrome; the oldest is 70 years old. Claimant is expected to live 50 years or more.

The NIH Study is headed by lead investigator Alan Percy, M.D., a neurologist and international authority on Rett Syndrome. Dr. Jones and Steven Skinner, M.D., a senior geneticist at the Greenwood Genetics Center, are principal investigators at different centers for the NIH Study. In her January 2, 2010 letter, Dr. Jones reported that she had reviewed the existing literature addressing cognitive evaluations for girls with Rett Syndrome and had discussed this issue with Drs. Percy and Skinner. She wrote: "we conclude that at the present time no appropriate method exists for assessing the cognitive abilities of individuals with Rett Syndrome." She urged that educational placements not be based upon the results of instruments like the Vineland and Bayley.

In Dr. Jones's experience, and based on reports from psychologists at Katie's Clinic, the Vineland is not an appropriate test for the Rett Syndrome population. While it may be appropriate to use the Vineland initially as a baseline, it cannot be used to measure progress. The Vineland is too insensitive to capture claimant's progress. Each task she learns involves multiple motor movements, which take thousands of repetitions of coordinated muscle movements to function. These deficits make her progress slow and difficult to quantify by Vineland reporters. It would be "a big mistake" to use progress on the Vineland to terminate ABA services. According to Dr. Jones, not only is claimant not regressing, she has made significant progress on her independent toileting goal. After working on it for three years, claimant has mastered 90 percent of the components of this goal. This is a significant accomplishment.

ABA services are very valuable for individuals with Rett Syndrome and for claimant in particular. Dr. Jones has met with claimant at the clinic and she has observed her on at least an annual basis for the NIH Study. Claimant's behavior therapy over the years has helped her with movement, communication, management of position in space

and with the ability to handle the challenges of her environment. The NIH study has shown that Rett Syndrome girls benefit from treatment. Genetic treatments are now in clinical trials and it is also important to keep therapies up "so we don't waste their potential." Dr. Jones acknowledged that, while there are anecdotal results, there are no clinical studies that prove the effectiveness of ABA services for consumers with Rett Syndrome. In Dr. Jones's opinion, it would be a mistake to terminate claimant's ABA services, which not only enrich her, but assist in her functioning abilities.

25. *Dr. Skinner's May 3, 2013 Letter:* Dr. Skinner is Board certified, both as a clinical geneticist and as a pediatrician. He is the Director of the Greenwood Genetic Center in South Carolina. He has followed claimant as part of the NIH Study since October 1, 2006. In his May 3, 2013 letter regarding claimant, Dr. Skinner noted that, since its inception in 2006, the NIH Study has collectively followed and analyzed data on over 1,200 individuals with Rett Syndrome.

Describing the trajectory of this condition, Dr. Skinner clarified that Rett Syndrome is not a degenerative disorder. After the initial period of regression and loss of skills, "girls frequently show stabilization and improvement in the overall function with sometimes showing development of new skills." He also noted that there is a wide spectrum of the degree of severity in Rett Syndrome, that the degree of severity cannot be predicted by the mutation type, that there is "a long lifespan into the 50s and beyond," and that "many of these patients continue to be ambulatory and maintain a stable medical course throughout their lives."

Discussing the efficacy of ABA therapy, Dr. Skinner wrote:

There is not good published data regarding the benefit of ABA therapy in Rett syndrome. Anecdotally, we know of many individuals that have had very positive responses to ABA therapy with improvements in behavior and

socialization. It has been our experience and impression that individuals with Rett syndrome who have intensive therapy using a variety of modalities have a much improved medical, behavioral, and social outcome than patients who do not receive these therapies. At this time, there is not a specific therapeutic program that is specific for Rett Syndrome. Each of the individuals with Rett syndrome is unique with their own skills and challenges. The therapeutic program should be tailored to the specific strengths and weaknesses of the patient with Rett syndrome.

[¶]...It is clear that Rett syndrome is not a degenerative disorder and that not all individuals show continued regression or progression of problems. In fact, most patients with Rett syndrome show stabilization and slow improvement. Individuals with Rett syndrome do show positive responses to comprehensive and intensive interventions, including ABA therapy...

Dr. Skinner also clarified that autism is a behavioral diagnosis and that "15% to 20% of individuals with autism have a concurrent diagnosis of other genetic conditions such as . . . Rett syndrome. Thus, the diagnosis of Rett syndrome does not exclude the possibility of also meeting criteria for autism."

26. *Testimony of Claimant's Mother:* Claimant's mother explained how claimant's life was different before she received ABA services and how her life has been since receiving these services. For example, before regular ABA services, claimant was totally dependent, had protracted daily "meltdowns" that involved crying and

screaming; throwing herself on the floor; kicking, hitting and scratching herself and others; running off while in public; and “grunting or spitting” to communicate. She was asocial and “wouldn’t let us in.”

After her years of ABA services, claimant can now communicate using the Picture Exchange System (PECs) and this is being transferred over to her I-Pad. Claimant also communicates with a movie board, will “tap us on the arm” to gain attention or turn her back to show she wants her own space. Claimant will not run off while in the community; she can assist in dressing; and she engages in social activities with her family (watching TV together). Claimant’s mother noted that “potty training” is one of claimant’s most important goal acquisitions. She performs many tasks involved in her toileting routine, and the family now has her on a 30-minute schedule which is audibly announced by a timer on her I-Pad. She still needs some assistance pulling her pants back up but does most of the other tasks independently. Claimant’s mother noted that it took four years to accomplish these toileting tasks and that it was a “major accomplishment” for claimant.

Claimant’s mother is hopeful that claimant will be able to independently use the bathroom in the future, “successfully without prompts,” and independently perform other tasks of self-care regarding washing and dressing herself. She wants claimant to continue receiving ABA “to attain independence” and she is concerned that claimant may regress in these hard-won skills if services are not continued.

DISCUSSION

27. Claimant’s request that CVRC fund her ABA co-payment was not a request for a “new service.” The IPP that was in effect at the time the NOPA was issued provided that ABA services were necessary to successfully support claimant at home and that CVRC would fund these services. While the IPP acknowledged that a transfer in primary funding responsibility to Kaiser was in process due to SB 946, it did not terminate funding or ABA services. CVRC was aware that ABA co-payments were an issue at the

time the IPP was being prepared. Claimant's mother raised the co-payment issue with claimant's service coordinator a day after the IPP meeting and before the IPP was finalized. CVRC acknowledged its ongoing responsibility for ABA services when it issued a POS to CARD for such services a month after the anticipated transfer date, which initially extended through the end of the 2012 calendar year.

As described in Dr. Branscum's testimony (Factual Finding 22), CVRC has historically believed that this particular type of "intense" ABA therapy service is not appropriate for claimant. As discussed in Factual Finding 23, intensive ABA services were not expected to terminate because a specific time for "fading" had not been established. Given its long-standing clinical opinion that claimant should no longer receive intense ABA therapy, CVRC should have addressed the termination of this service with claimant's family within the context of the IPP process. The quarterly review meetings were not IPP meetings.

While CVRC essentially asserts there is "no harm, no foul" because it issued a NOPA that enabled claimant's family to request a fair hearing, there is a significant practical effect to its policy of treating claimant's co-payment request as a request for a new service. By denying ongoing funding under the "new service" rubric, CVRC shifts the burden of proof regarding the efficacy of ABA services from itself to the claimant. This is not appropriate. CVRC bears the burden of establishing that it properly denied claimant's co-payment funding request for ABA services contained in her IPP, after the transfer of primary financial responsibility to the family's insurer.

28. Following the transfer mandated by SB 946, CVRC's policy of reviewing the appropriateness of an existing IPP service outside the IPP process to determine whether to fund a co-payment for that service is not consistent with the Lanterman Act. As previously discussed, CVRC and claimant's parents have had very different opinions over the years about the efficacy of intensive ABA services. Despite those differences,

intensive ABA services are included in claimant's IPP and are characterized as being necessary for her success in remaining placed in her home. It is well-established that services in an IPP are an entitlement and that a regional center may not impose a parental co-payment in the absence of express statutory authorization. (*Clemente v. Amundson* (1998) 60 Cal.App. 4th 1094, 1097.) As noted by the Third District Court of Appeal in that case, "remedial statutes such as the Lanterman Act must be liberally construed to effectuate the purposes for which they were enacted." (Id., at 1102.)

29. When it enacted SB 946, the Legislature was aware that consumers who have insurance coverage would be subject to co-payments. Health and Safety Code section 1374.73, subdivision (a), expressly states that the insurance "coverage shall be provided in the same manner and shall be subject to the same requirements as provided in Section 1374.72 [the mental health parity law]." (Health & Saf. Code, § 1374.73, subd. a.) That statute provides that the terms and conditions applied to the required benefits "shall include, but not be limited to ...Copayments. . ." (Health & Saf. Code, § 1374.72, subd. (c)(2).) SB 946 expressly states that its requirement "shall not affect services for which an individual is eligible pursuant to Division 4.5 (commencing with Section 4500 of the Welfare and Institutions Code..." (Health & Saf. Code, § 1374.73, subds. (a)(3).) This reference clearly encompasses services and supports outlined in an IPP. Requiring consumers to pay co-payments after the implementation of SB 946 for IPP services previously fully-funded by CVRC undercuts the IPP process and imposes an additional liability on the parents of those consumers in violation of section 4659, subdivision (e).⁸

⁸ Similarly, despite the requirement to "identify and pursue all possible sources of funding" for consumers receiving services, regional centers cannot "impose any additional liability on the parents of children with developmental disabilities, or to

30. Effective June 27, 2013, section 4659.1 of the Lanterman Act gives regional centers discretion to pay co-payments associated with a service or support provided pursuant to a minor consumer's IPP that are paid for, in whole or in part, by the consumer's parents' health insurance plan or policy, when such payment is "necessary to ensure that the consumer receives the service or support." (§ 4659.1, subd. (a).) Certain conditions must be met before the regional center can exercise this discretion: i.e., the consumer must be covered by her parent's health plan; the family's annual gross income must not exceed 400 percent of the federal poverty level; and there must be no other third party with liability for the costs of such services or supports. (§ 4659.1, subd. (a).) Under certain circumstances, the regional center may pay the copayment where the income of the consumer's family exceeds 400 percent of the federal poverty level. (§ 4659.1, subd. (c).)⁹

restrict eligibility for, or deny services to, any individual who qualifies for regional center services but is unable to pay." (§ 4659, subds. (a) and (e).)

⁹ Section 4659.1 was enacted as an urgent measure effective June 27, 2013, as part of AB 89 (Stats. 2013, c. 25, section 7). In pertinent part, that statute provides:

(a) If a service or support provided pursuant to a consumer's individual program plan under this division . . . is paid for, in whole or in part, by the health care service plan or health insurance policy of the consumer's parent, guardian, or caregiver, the regional center may, when necessary to ensure that the consumer receives the service or support, pay any applicable copayment or coinsurance associated with the service or support for which the parent, guardian, or caregiver is responsible if all of the following conditions are met:

Section 4659.1 does not grant CVRC discretion to determine which IPP services are “appropriate” before it assists consumers whose parents come within the poverty guidelines.

31. Even assuming that CVRC has discretion to determine the appropriateness of a particular IPP service as a precondition of funding co-payments, the evidence in this case does not indicate that it properly exercised that discretion. The evidence demonstrates there are widely divergent opinions about claimant’s abilities and progress in ABA therapy, as well as her overall prognosis. While CVRC clinical staff is highly qualified in certain areas, none of these witnesses had any significant experience with or knowledge of Rett Syndrome, which is an acknowledged rare condition. With the exception of Dr. Branscum, they had little knowledge or experience of claimant’s current functional abilities. There was no evidence that either Dr. Sharp or Dr. Branscum had ever consulted with Dr. Jones, or with any other expert in Rett Syndrome. There was no evidence that CVRC was aware of the NIH Study, that it entailed clinical observation and evaluation over 1,200 individuals with this condition, or that it considered whether the NIH Study provides the best available clinical insight into effective treatments for those so afflicted. CVRC witnesses also suggested that Kaiser funded claimant’s ABA services based upon a misunderstanding that she was on the autism spectrum. There was no persuasive evidence that CVRC ever considered the possibility that claimant may have both autism and Rett Syndrome, with appropriate input from an expert in this field.

-
- (1) The consumer is covered by his or her parent’s, guardian’s, or caregiver’s health care service plan or health insurance policy.
 - (2) The family has an annual gross income that does not exceed 400 percent of the federal poverty level.
 - (3) There is no other third party having liability for the cost of the service or support ...

32. CVRC has worked with claimant's family for many years and has acceded to their desires for intensive ABA therapy, even though those desires have been at odds with the clinical judgment of its professional staff. In this respect, CVRC's responsiveness to the wishes of claimant's family has been more than consistent with the Lanterman Act. Based on the record as a whole, however, CVRC inappropriately denied claimant's request to fund co-payments assessed for her ABA therapy services which are part of the services and supports outlined in her current IPP.

LEGAL CONCLUSIONS

1. *BURDEN OF PROOF:* As set forth in the Factual Findings and Legal Conclusions as a whole and, particularly, in Factual Finding 27, CVRC has the burden of establishing, by a preponderance of evidence, that its denial of claimant's request to fund co-payments for the ABA services in her IPP was appropriate and consistent with the Lanterman Act. (Evid. Code, §§ 115, 500.)

2. As set forth in the Factual Findings and Legal Conclusions as a whole and, particularly, in Factual Findings 28 through 33, CVRC did not meet its burden of proof, and is required to fund co-payments for ABA services contained in claimant's IPP.

ORDER

1. Claimant's appeal is GRANTED.
2. Within ten (10) business days of the date of this Decision, CVRC shall pay claimant's outstanding co-payments for ABA therapy services provided through Kaiser and CARD. In the alternative, within ten (10) business days of the date of this Decision and upon proof of payment, CVRC shall reimburse claimant's mother for any such co-payments she has made.
3. CVRC shall continue to pay co-payments for claimant's ABA therapy services as long as such services are included in the services and supports in her IPP.

4. For co-payments incurred after June 27, 2013, CVRC may require proof of the annual gross income of claimant's family as authorized by Welfare and Institutions Code section 4659.1.

DATED: August 19, 2013

MARILYN A. WOOLLARD

Administrative Law Judge

Office of Administrative Hearings

NOTICE

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