BEFORE THE
OFFICE OF ADMINISTRATIVE HEARINGS
STATE OF CALIFORNIA

In the Matter of: CLAIMANT, and INLAND REGIONAL CENTER, Service Agency.	Case No. 2018080618

DECISION

Debra D. Nye-Perkins, Administrative Law Judge, Office of Administrative Hearings, State of California, heard this matter on September 26, 2018, in San Bernardino, California.

Stephanie Zermeño, Consumer Services Representative, represented the Inland Regional Center (IRC).

Claimant's mother represented claimant.

The matter was submitted on September 26, 2018.

ISSUE

Should IRC permanently fund 160 hours of respite per month for claimant with claimant's preferred provider, who is also her cousin?

FACTUAL FINDINGS

JURISDICTIONAL MATTERS

1. Claimant is a 13-year-old consumer of services pursuant to the Lanterman Developmental Disabilities Services Act (Lanterman Act), Welfare and Institutions Code, section 4500, et seq. Claimant is eligible for services based on her diagnosis of moderate intellectual disability. Claimant also suffers from a number of other diagnoses, including Rett Syndrome, a neurological disorder that causes a disruption of brain function responsible for cognitive, sensory, emotional, motor and autonomic function. Claimant is confined to a special wheelchair, is unable to feed herself, has no control of her bladder or bowel, does not use words to communicate, is unable to perform any personal care activities, and requires constant supervision and care. Claimant lives at home with both her parents and a sibling.

2. On October 1, 2017, through December 31, 2017, IRC increased preferred provider respite for claimant from 30 hours per month to 70 hours per month because claimant had spinal surgery that increased the level of care claimant required, and because claimant's mother injured her back and needed a break from the increased level of care. Claimant's preferred provider of respite services is claimant's cousin.

3. In November 2017, claimant's parents requested an increase in respite hours from 70 per month to 160 per month. IRC approved this increase in respite care, effective December 1, 2017, and continuing to March 1, 2018. During this time period IRC advised claimant's parents to apply for Early Periodic Screening Diagnosis and Treatment (EPSDT) nursing hours, which is a medically funded program providing nursing hours to qualifying individuals. IRC advised claimant's parents that they may apply for the EPSDT program through California Department of Health Care Services (Medi-Cal) directly, or they may opt to go through a home health agency. Claimant's parents opted to use a home health agency named Heavenly Home Care, who

submitted the claim through Medi-Cal in January 2018 after conducting a home assessment with the family.

4. In March 2018, IRC extended authorization to provide 160 hours of respite per month with claimant's preferred provider because claimant had not received approval from Medi-Cal for the EPSDT program. IRC approved this extension of the respite hours through April 30, 2018.

5. In April 2018, IRC again extended authorization to provide 160 hours of respite per month with claimant's preferred provider until May 31, 2018, because claimant still had not received approval from Medi-Cal for the EPSDT program.

6. In May 2018, IRC again extended authorization to provide 160 hours of respite per month with claimant's preferred provider until July 31, 2018, because claimant still had not received approval from Medi-Cal for the EPSDT program. In July 2018, IRC once more extended the authorization to September 30, 2018, for the same reasons.

7. At some point IRC learned that Medi-Cal had denied claimant's application for services from the EPSDT program because claimant had an open application for services through the California Children's Services (CCS). Thereafter, Heavenly Home Care sought approval for services from the EPSDT program through CCS. The day before this hearing, on September 25, 2018, IRC first learned from Heavenly Home Care that CCS denied claimant's application for services from the EPSDT program. Accordingly, claimant's application for services from the EPSDT program was sent back to Medi-Cal for approval of funding. As of the date of the hearing, no decision has been made by Medi-Cal on claimant's application for approval of services from the EPSDT program, and the application is still pending.

8. As a result of the pending application for services from the EPSDT program, IRC has agreed to another extension of authorization to provide 160 hours of

respite per month with claimant's preferred provider until December 31, 2018, if claimant's parents agree to that extension. Claimant's parents have not agreed to this extension because of the issues raised in this hearing.

9. On July 11, 2018, claimant's parents requested that IRC provide authorization for 160 respite hours per month with their preferred provider effective August 1, 2018, to continue permanently without the need for any further temporary authorizations. IRC served claimant with a notice of proposed action on August 1, 2018, denying the request to permanently authorize 160 respite hours per month with claimant's preferred provider on the basis that claimant's appeal to Medi-Cal for EPSDT services has merit and must be exhausted before IRC can consider a permanent authorization. IRC is required to ensure that all potential sources of funding are exhausted before providing services.

10. Claimant timely submitted a fair hearing request objecting to IRC's decision, and this appeal followed.

IRC'S EVIDENCE

Testimony of Gabriella Hernandez

11. Gabriella Hernandez is a program manager at IRC whose responsibilities include the oversight of consumer service coordinators to ensure appropriate services are in place for IRC consumers. Ms. Hernandez is the program manager for claimant's consumer service coordinator. Ms. Hernandez testified that until very recently claimant's consumer service coordinator was Diane Hernandez, who had held that position for a number of years. Gabriella Hernandez stated that IRC is currently in the process of assigning a new consumer service coordinator to claimant. Gabriella Hernandez stated that the only services provided to claimant from IRC are the 160 respite hours. However, claimant also receives 283 hours per month of In-Home Support Services (IHSS) funded

by the County of San Bernardino, which is the maximum number of hours allowed by the county. IHSS is a program that pays for in-home care providers. Claimant's mother is claimant's IHSS care provider.

Gabriella Hernandez explained that respite care is intended to provide a temporary break to the family in the family home for short periods of time for daily activities, but is not intended to provide full nursing care (showering, changing diapers, giving medications, etc.) or for travel outside of the home. She explained that claimant's respite care hours were first increased on October 1, 2017, because claimant's mother injured her back. She further explained that claimant's respite hours were again increased to the current level of 160 hours per month based upon claimant's increased level of care because of claimant's spinal surgery. Ms. Hernandez explained that claimant is likely eligible for EPSDT nursing hours because claimant suffers from seizures, is wheelchair bound, requires diaper changing, and requires 24-hour care. She stated that EPSDT nursing care is a generic resource funded by either Medi-Cal or CCS that claimant must utilize before turning to IRC for nursing needs.

Ms. Hernandez explained that IRC examines various factors when considering the authorization for funding for respite hours, including the individual needs of the consumer as set forth in the Individual Program Plan (IPP), natural resources, and generic resources available to the family. She stated that IRC is the payor of last resort after all other generic resources are exhausted. Ms. Hernandez stated that it has taken almost one year to get clarification from the in-home nursing agency regarding the status of the application for approval from either Medi-Cal or CCS for the EPSDT nursing care, which is longer than the typical time period for this type of approval. Accordingly, IRC has continued to temporarily authorize 160 respite hours during this time of uncertainty regarding the EPSDT program. Regardless, Ms. Hernandez explained that those resources must be the primary resources for the nursing care claimant needs

instead of respite hours, which are not intended to be the equivalent of nursing hours. Ms. Hernandez also explained that once the EPSDT nursing hours are approved from either Medi-Cal or CCS, claimant's family is responsible for coordinating with the in-home nursing agency to fulfill those nursing hours.

12. Ms. Hernandez testified that on the day before the hearing, she first received documentation from the in-home nursing agency that claimant's treatment authorization request to CCS was denied, and as a result the in-home nursing agency must again file the application with Medi-Cal for authorization to fund the EPSDT nursing hours. Ms. Hernandez explained that Medi-Cal initially rejected the application because claimant had an open case with CCS for the payment. Once CCS denied the application, then Medi-Cal would likely approve the application for authorization of EPSDT nursing hours. IRC is waiting for the completion of that process to make any further determinations regarding claimant's respite hours beyond the already authorized temporary approval of 160 hours of respite care. Ms. Hernandez stated that she understands that claimant's current respite provider, claimant's mother's niece, is already providing some of the same care that a nurse would provide. However, claimant's mother's niece is not a licensed nurse and should only be providing respite care, which would not include nursing duties such as showering claimant and changing her diaper. Ms. Hernandez stressed that claimant's current respite provider is giving care that is beyond that which is classified as respite and falls into the category of nursing care. Additionally, she explained that IRC never provides approval for permanent respite care without at least an annual review as required for the IPP review.

CLAIMANT'S EVIDENCE

Testimony of Claimant's Preferred Respite Provider

13. Claimant's cousin (claimant's mother's niece) is claimant's preferred provider of respite care, and she testified at the hearing. She has been providing respite care to claimant in claimant's home for the past eight years. She testified that her duties as the respite provider include feeding, changing diapers, showering, communicating with claimant, and taking care of all her daily living needs. Claimant's cousin stated that she watches movies and "does fun things" with claimant and has learned claimant's method of communication using grunts and other non-verbal cues only after observing claimant over a long period of time. She stated that claimant's surgery has caused claimant pain and resulted in an inability to sit for long periods of time. She also described claimant's sleeping habits as unusual, and sometimes she will not sleep through the night causing difficulty for caregivers. She has a bond with claimant, loves her very much, and enjoys taking care of claimant.

Testimony of Claimant's Father

14. Claimant's father testified at the hearing in support of claimant's request to receive permanent authorization from IRC for 160 hours per month of respite care. He stated he is very concerned about his wife and her health as a result of taking care of claimant all the time. He stated that he supports the family as a long-haul truck driver and is frequently gone from the home during the week and only home on the weekends. As a result, he is not able to assist his wife with claimant's care. He knows that his wife needs assistance to care for claimant, and he believes that claimant's current respite provider is the best person to help take care of claimant because she is family and he trusts her. He stated he is comfortable having claimant's current respite provider in their home and, when she is taking care of claimant, his wife can sleep. In contrast, he

would be very uncomfortable having "a stranger" in his home in the form of a nurse from the in-home nursing agency because he does not trust them. He said he would not feel comfortable or secure having an outsider in his home taking care of claimant. He explained that claimant can't speak, use her hands, or tell them if someone is touching her inappropriately. Accordingly, he does not want to risk having a stranger in their home who could potentially abuse claimant, and he does not leave claimant alone with strangers. He provided an example of when claimant attended elementary school, and he refused to send her to school alone. As a result, his wife attended school every day with claimant. He stated his fears were confirmed when claimant's teacher was accused of abusing his students. Claimant's father stated that he does not believe a nurse from the in-home nursing agency would be any benefit to claimant or his family because having a stranger in their home would only add additional stress. He believes that it is in claimant's best interest to keep claimant's cousin as her caregiver.

Testimony of Claimant's Mother

15. Claimant's mother testified that she believes it is in the best interest of claimant to keep claimant's cousin as her caregiver in their home, rather than bringing in nurses from the in-home nursing agency. She stated she wants to "put aside policies" and "do what is in the best interest of" claimant. Claimant's mother does not trust health care professionals. When claimant was in the hospital for her recent surgery, claimant's mother stated they followed the instructions of a physician to remove bandages on the scar too soon and, as a result, claimant got a serious infection resulting in the need for a second surgery and, ultimately, her lung collapsing. Claimant's mother stated this is an example of why she lacks trust in health care professionals. Additionally, claimant's mother testified she does not trust the in-home nursing agency based upon her interactions with them. Specifically, the agency informed her that they screen the nurses, but "there are always people who slip through the cracks." Also, when she expressed her

concerns to the agency and her desire to keep her niece as a caregiver for claimant, she stated the agency was willing to "break the law" and put claimant's mother's niece "on paper as a licensed vocational nurse," when in reality she is not. As a result of these interactions, claimant's mother does not trust the in-home nurse agency or any nurses they would send to her home.

Claimant's mother believes that keeping their current respite worker for 160 hours per month is better for claimant than bringing in a nurse, who is a stranger. She stated claimant has had "fear instilled in her" from the hospital experience and her mother does not want that to happen again. Claimant's mother stated she "does not want anything inappropriate" to happen to her daughter. Claimant's mother is requesting that IRC's current temporary authorization for 160 hours per month of respite care with claimant's preferred provider be converted into a permanent authorization for an indefinite term.

LEGAL CONCLUSIONS

THE BURDEN AND STANDARD OF PROOF

1. Each party asserting a claim or defense has the burden of proof for establishing the facts essential to that specific claim or defense. (Evid. Code, §§ 110, 500.) In this case, claimant bears the burden to demonstrate that she is entitled to receive permanent authorization for 160 hours in respite care per month with her preferred provider.

2. The standard by which each party must prove those matters is the "preponderance of the evidence" standard. (Evid. Code, § 115.)

3. A preponderance of the evidence means that the evidence on one side outweighs or is more than the evidence on the other side, not necessarily in number of

witnesses or quantity, but in its persuasive effect on those to whom it is addressed. (*People ex rel. Brown v. Tri-Union Seafoods, LLC* (2009) 171 Cal.App.4th 1549, 1567.)

THE LANTERMAN ACT

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

5. When an individual is found to have a developmental disability under the Act, the State of California, through a regional center, accepts responsibility for providing services to that person to support his or her integration into the mainstream life in the community. (Welf. & Inst. Code, § 4501.) The Act acknowledges the "complexities" of providing services and supports to people with developmental disabilities "to ensure that no gaps occur in . . . [the] provision of services and supports." (Welf. & Inst. Code, § 4501.) To that end, section 4501 states: "An array of services and supports should be established which is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of
life. . . ."

6. "Services and supports" are defined in Welfare and Institutions Code section 4512, subdivision (b):

> "Services and supports for persons with developmental disabilities" means specialized services and supports or special adaptations of generic services and supports directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with a developmental disability, or toward the achievement and maintenance of independent, productive, and normal lives. . . . Services and supports listed in the individual program plan may include, but are not limited to, . . . personal care, day care, special living arrangements, . . .protective and other social and sociolegal services, information and referral services, . . . [and] supported living arrangements, ...

7. The Department of Developmental Services (DDS) is the public agency in California responsible for carrying out the laws related to the care, custody and treatment of individuals with developmental disabilities under the Lanterman Act. (Welf. & Inst. Code, § 4416.) A regional center's responsibilities to its consumers are set forth in Welfare and Institutions Code sections 4640-4659. In order to comply with its statutory mandate, DDS contracts with private non-profit community agencies, known as "regional centers," to provide the developmentally disabled with "access to the services and supports best suited to them throughout their lifetime." (Welf. & Inst. Code, § 4620.)

8. In order to be authorized, a service or support must be included in the consumer's individual program plan (IPP). (Welf. & Inst. Code, § 4512, subd. (b).) In implementing an IPP, regional centers must first consider services and supports in the natural community and home. (Welf. & Inst. Code, § 4648, subd. (a)(2).)

9. "Natural Supports" is defined in the Lanterman Act as "personal associations and relationships typically developed in the family and community that enhance or maintain the quality and security of life for people." (Welf. & Inst. Code, § 4512, subd. (e).)

10. Pursuant to Welfare and Institutions Code section 4646, subdivision (a), the planning process is to take into account the needs and preferences of the consumer and his or her family, "where appropriate." Services and supports are to assist disabled consumers in achieving the greatest amount of self-sufficiency possible. (Welf. & Inst. Code, § 4648, subd. (a)(1).) The regional center is also required to consider generic resources and the family's responsibility for providing services and supports when considering the purchase of regional center supports and services for its consumers. (Welf. & Inst. Code, § 4646.4.)

11. Services provided must be cost effective (Welf. & Inst. Code, § 4512, subd. (b)), and the Lanterman Act requires the regional centers to control costs as far as possible and to otherwise conserve resources that must be shared by many consumers. (See, *e.g.*, Welf. & Inst. Code, §§ 4640.7, subd. (b); 4651, subd. (a); 4659; and 4697.)

12. "In-home respite services" are defined in the Lanterman Act as "intermittent or regularly scheduled temporary nonmedical care and supervision provided in a client's own home, for a regional center client who resides with a family member." (Welf. & Inst. Code, § 4690.2, subd. (a).) Welfare and Institutions Code section 4690.2, subdivision (a), states that respite services are designed to "do all of the following:"

> (1) Assist family members in maintaining the client at home.

(2) Provide appropriate care and supervision in maintaining the client at home.

(3) Relieve family members from the constantly demanding responsibility of caring for the clients.

(4) Attend to the client's basic self-help needs and other activities of daily living including interaction, socialization, and continuation of usual daily routines which would ordinarily be performed by family members.

13. Welfare and Institutions Code section 4659, subdivision (c), prohibits IRC from purchasing services available from generic resources, including the EPSDT program. If the family is eligible for EPSDT program, but has chosen not to pursue it, IRC cannot fund the requested services. Welfare and Institutions Code section 4659, subdivision (c), states as follows:

> Effective July 1, 2009, notwithstanding any other law or regulation, regional centers shall not purchase any service that would otherwise be available from Medi-Cal, Medicare, the Civilian Health and Medical Program for Uniform Services, In-Home Support Services, California Children's Services, private insurance, or a health care service plan when a consumer or a family meets the criteria of this coverage but chooses not to pursue that coverage. If, on July 1, 2009, a regional center is purchasing that service as part of a consumer's individual program plan (IPP), the prohibition shall take effect on October 1, 2009.

EVALUATION

14. The Lanterman Act and the applicable regulations set forth criteria that a claimant must meet in order to qualify for regional center services. Claimant had the burden of demonstrating the need for permanent authorization for 160 hours per month of respite care with claimant's preferred provider, and claimant did not meet that burden. The evidence established that claimant requires 24-hour care, including assistance with showering, changing diapers, and other services which are not respite care services. Instead, those services require a nursing professional. Currently, claimant's cousin is providing those services despite the fact she is not a nurse, and claimant's parents prefer to keep claimant's cousin performing those services because they are more comfortable with her in their home than an unknown nurse. However, those services are more appropriately provided through the generic resource of the EPSDT program; claimant's application for these services is still pending. Accordingly, pursuant to Welfare and Institutions Code section 4649, subdivision (c), IRC is forbidden by law from purchasing those services which would otherwise be available from the EPSDT program. While claimant's mother asks to "set aside policy" because she believes that is best for her child, the applicable law forbids such an action.

Claimant's parents are concerned for their daughter and don't want a stranger in their home because they fear something "inappropriate" will happen as a result. Claimant's parent's fears are legitimate and understandable. It is very clear they only seek to protect their daughter and have her best interests in mind. However, applicable laws dictate under what circumstances IRC may fund services, including respite care. IRC is also required to periodically reassess claimant's requirements for services pursuant to her IPP and any "permanent" authorization for services would not be appropriate because all services provided must be pursuant to claimant's IPP. Accordingly, claimant's

request for permanent authorization for 160 hours per month of respite care with her preferred provider must be denied.

ORDER

Claimant's appeal is denied.

October 4, 2018

_____

DEBRA D. NYE-PERKINS
Administrative Law Judge
Office of Administrative Hearings

NOTICE

This is the final administrative decision in this matter. Each party is bound by this decision. An appeal from the decision must be made to a court of competent jurisdiction within 90 days of receipt of the decision.