BEFORE THE OFFICE OF ADMINISTRATIVE HEARINGS STATE OF CALIFORNIA

In the Matter of the:

CLAIMANT,

VS.

NORTH LOS ANGELES COUNTY REGIONAL CENTER,

Service Agency.

OAH No. 2020120102

DECISION

Glynda B. Gomez, Administrative Law Judge, Office of Administrative Hearings, State of California, heard this matter on April 6 and 8, 2021, by telephone and video conference.

Claimant was represented by her father.¹

Stella Dorian, Contract Officer, represented North Los Angeles County Regional Center (Service Agency or NLACRC).

A Spanish language interpreter translated the proceedings.

SUMMARY

Claimant contends that NLACRC should pay her parents to provide respite and personal assistant care hours for her because her health is fragile and outsiders coming into her home put her at risk. NLACRC contends that it is prohibited from paying parents to provide respite and personal assistant care assistance and that Claimant's medical needs require nursing level care. Claimant appealed NLACRC's denial of her request that her parents be paid to be provide respite and personal assistance. For the reasons set forth herein, Claimant's appeal is denied.

ISSUE

Is NLACRC required to fund respite and/or personal assistant services provided by Claimants parents.

FACTUAL FINDINGS

1. Claimant is a 13-year-old female eligible for regional center services as a consumer diagnosed with Intellectual Disability. She has also been diagnosed with Leukemia and Down's Syndrome. Claimant is partially deaf, mostly non-ambulatory, incontinent and non-verbal. She also has Pica, displays behavior challenges and tantrums. Claimant receives infusions and other medications through a portable catheter (Portacath) in her chest. Claimant lives with her parents and an adult sibling who is also a regional center consumer. Claimant requires assistance with all daily living activities. NLACRC denied her request for her parents to be the paid respite and/or personal care providers. Claimant timely appealed the denial.

2. On March 4, 2020, the Governor of California proclaimed a State of Emergency and on March 12, 2020, issued Executive Order N25-20 related to the Covid-19 Pandemic. Following the Executive Order, on March 30, 2020, the Department of Developmental Services (DDS) issued "Department Directive 01-033020: Additional Participant-Directed Services" (Directive) which provided in relevant part:

To increase access and flexibility in service delivery, the Department hereby modifies any requirements of the Lanterman Act of Title 17 specifying the services that may be participant-directed. In addition to the services currently available through participant direction, consumers may also choose to direct the following services:

Personal assistance

Independent living skills

Supported employment

This temporary modification is necessary because the Director finds that concerns related to exposure to COVID-19 may prevent consumers' ability to access services. The option to access these services through participant direction affords consumers the ability to choose workers (e.g. friends, some family members, etc.) to provide these services.

This directive remains in effect for 30 days unless extended by the Director of the Department.

(Ex. 10.)

- 3. Enclosed with the Directive was a more detailed document entitled "Additional Participant-Directed Services" which provides that the provider of any additional participant-directed services must, among other things "have the ability to perform the work verified by the consumer/family; Must be 18 years or older; and Cannot be the consumer's spouse or parent for personal assistance or independent living skills." (Ex.10.)
- 4. The Directive has been extended each month in 30 day intervals and was in effect at the time of the administrative hearing.
- 5. Claimant was a client of the South Central Los Angeles Regional Center (SCLARC) until June 2020 when she became a NLACRC consumer. A May 5, 2020, SCLARC Individual Program Plan (IPP) addendum provides that SCLARC approved Self Directed Services for Claimant's parent to be Claimant's respite provider for the month of May 2020. The rationale was that the family was caring for two consumers, Claimant has cancer and additional medical problems, and school closures due to the Covid-19 Pandemic require additional assistance. (Ex. 3.)
- 6. Effective June 1, 2020, Claimant's case management was transferred from SCLARC to NLACRC. An IPP meeting was held on August 5, 2020. The IPP was held by telephone at Parents' request. Service Coordinator Raul Gonzalez and Claimant's mother were the participants. Pursuant to the IPP, Claimant has three desired outcomes:

(1) [Claimant] and family will be able to read and understand IPP; (2) Parents will receive a break from her unusual care and supervision and (3) [Claimant] will receive dental and medical services on an annual basis and as needed to maintain optimal health."

(Ex. 4.)

- 7. According to the IPP, Claimant receives Medi-Cal and 283 hours per month of In-Home Support Services (IHSS) with her mother as the provider. Before the Covid-19 Pandemic, Claimant received special education services from her local school district including a special day class, occupational therapy, speech therapy and a one-to-one aide. The IPP also provides for up to 47 hours per month of respite care funded by NLACRC. Claimant also has an assessed need of 8 hours per day, 7 days per week (56 hours per week), for personal assistant (PA) services.
- 8. In October of 2020, DDS published additional guidance entitled "Frequently Asked Questions for Self-Advocates and Families About Participant-Directed Services During the COVID-19 Pandemic" (FAQ). In relevant part, the FAQ provides as follows:

Q4. Who Can I Hire to Provide Participant-Directed Services?

You, and the Financial Management Services (FMS) agency you select to help you hire and pay staff, must verify that the person has the skills to perform the work. You can ask your regional center for information about how to do this.

- The person must be 18 years or older.
- The person must be eligible to work.
- You may hire a family member, friend or another qualified person to provide participant-directed services. A spouse and generally a parent cannot provide respite, day care, personal assistance, or independent living skills.
- The individual you hire does not need to be a regional center vendor.

(Ex. 11.)

- 9. NLACRC's Service Standards (Standards) were adopted by its Board of Trustees on May 9, 2018 and Approved by DDS on November 16, 2018. On Page 22 of the Standards, "Respite Services" are defined as "intermittent or regularly scheduled temporary non-medical care and supervision provided in the consumer's own home when the consumer resides with a family member." (Ex. 13.)
- 10. On Page 23 of the Standards under the Section entitled "Children", the Standards provides:

It is the policy of NLACRC to empower and advocate for consumers and families to access existing personal and community resources, such as Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), whenever possible to meet their family support needs. Thus, to the extent that the law requires, NLACRC will encourage families to use these resources before expending the center's funds.

NLACRC will consider the provision of generic resources in the family support planning process when the authorization

of the service, or some portion thereof, is for the expressed purpose of providing for the care and/or supervision of the child or for the purpose of providing respite to the child's caregiver Additionally, the planning team must give consideration to the ordinary care, support, and supervision that a family must provide to a child of the same age without a disability and to cost-effectiveness.

The regional center may only purchase respite services when the care and supervision needs of a consumer exceed that of an individual of the same age without a developmental disability. As such, regional center-funded services will focus on services required by and resulting from the consumer's developmental disability. NLACRC will seek to provide effective family support services.

(Ex. 13.)

11. With respect to "Personal Assistants" for "Children", the Standards provide:

Personal assistant services are to assist with bathing, grooming, dressing, toileting, meal preparation, feeding, and protective supervision is a typical parental responsibility for minor children. Personal assistant services for minor children will be considered on an exception basis when the needs of the consumer are of such a nature that it requires more than one person to provide the needed care.

There may be exceptional circumstances as a result of the severity and/or intensity of the developmental disability that may impact the family's ability to provide the needed care and supervision while maintaining the child in the family home. Eligibility and/or use of generic services such as In-Home Support Services will be explored and accessed where possible prior to NLACRC funding as an exception.

(Ex. 13.)

- 12. The Standards provide that NLACRC will consider the following facts in determining the need for personal assistant:
 - Length of time the consumer is able to be left unsupervised.
 - Availability of natural supports (family members, friends, neighbors, etc.)
 - Consumer's involvement in a day program.
 - Eligibility and/or use of generic services such as In-Home Support
 Services, college/university special students services, or Department of Rehabilitation.
 - Support based on an assessed need when a consumer's behavioral or medical issues are of such severity that a parent requires assistance in the home in order to adequately care for the consumer.

(Ex. 13.)

- 13. On February 16, 2021, NLACRC denied Claimant's request that her father serve as her respite provider and personal assistant. The stated basis for denial was California Code of Regulations, title 17, (CCR) Section 54355, Welfare and Institutions Code (Code) section 4646.4, 4659.2, and the Directive prohibiting the regional center from funding respite care and personal assistance provided by Claimant's parents.
- 14. On February 18, 2021, Jenice Turner, MBA, Assistant Director of SCLARC, notified NLACRC that although it had previously allowed Claimant's parents to be the respite providers for Claimant through Participant Directed Services, it has since determined based upon the "Frequently Asked Questions" document issued by DDS that the parents "can no longer be the worker and must therefore identify a non-parent." (Ex. 12.) The letter further states that SCLARC has "notified all families where the parent is the respite worker under Participant Directed Services that they can no longer be the worker and must therefore identify a non-parent respite worker." (Ex. 12.)
- 15. In a March 10, 2021 letter, NLACRC supplemented its February 16, 2021 letter advising that after review of Claimant's medical records, Claimant requires "nursing level care" based upon a review by NLACRC Nurse Consultant Joyce McConnell. (Ex. 7.)
- 16. Ms. McConnell, a registered nurse with more than 30 years of experience who serves as a consultant for NLACRC gave credible and knowledgeable testimony at the administrative hearing. Ms. McConnell reviewed Claimant's medical records and opined: "Level of care at this time for [Claimant] while fluids are infusing through the Portocath and while the heparin is needed to maintain patency" is nursing care. (Ex. 9.) Ms. McConnell based her opinion on Claimant's medical needs and her interpretation of the California Nursing Practice Act (Business and Professions Code section 2725, et

seq.) which defines the practice of nursing and requires that only a licensed individual render such services in most instances. (Ex. 26.)

- 17. Early Periodic Screening Diagnostic Treatment (EPSDT) is a program of services provided to ensure that infants, children, and youth receive appropriate preventive services, including screening for medical, dental, vision, hearing and mental health, and for substance use disorders, as well as receiving developmental and specialty services. Medi-Cal covers EPSDT services that are medically necessary including "physician, nurse practitioner and hospital services; physical, speech/language, and occupational therapies; home health services, including medical equipment, supplies, and appliances; treatment for mental health and substance use disorders; and treatment for vision, hearing, and dental diseases and disorders." (Ex. 15.) These services are considered generic services available to consumers as are the IHSS hours Claimant receives.
- 18. Claimant's father gave detailed testimony about Claimant's extensive needs, the toll the care takes on his family and the need for assistance. He also testified that Claimant does not receive medication or Portacath related treatments continuously and her medication can be administered before or after respite care. He also gave credible and heartfelt testimony about his fears for her safety due to the Covid-19 Pandemic and the risks associated with having outsiders in her home.

LEGAL CONCLUSIONS

1. An administrative hearing to determine the rights and obligations of the parties is available under the Lanterman Act to appeal a contrary regional center decision. (Welf. & Inst. Code, §§ 4700-4716.) Claimant timely requested a hearing

following the Service Agency's denial of Claimant's requests, and therefore, jurisdiction for this appeal was established.

- 2. When a party seeks government benefits or services, the party bears the burden of proof. (See, e.g., *Lindsay v. San Diego Retirement Bd.* (1964) 231

 Cal.App.2d 156, 161 [disability benefits].) In a case where a party is seeking funding for services or items not previously approved by a regional center, that party bears the burden of proof. Here, the funding was for a limited time duration (i.e. May 2020). Therefore Claimant bears the burden of proof. The standard of proof in this case is the preponderance of the evidence because no law or statute (including the Lanterman Act) requires otherwise. (See, Evid. Code, § 115.) Claimant bears the burden of proving by a preponderance of the evidence that the NLACRC is required to fund respite and personal care assistance hours provided by her parents. Claimant has failed to meet her burden.
- 3. A service agency is required to secure services and supports that meet the individual needs and preferences of consumers. (See, *e.g.*, Welf. & Inst. Code, §§ 4501 and 4646, subd. (a).)
 - 4. Code section 4512, subdivision (b), provides, in part:

[T]he determination of which services and supports are necessary for each consumer shall be made through the individual program plan process. The determination shall be made on the basis of the needs and preferences of the consumer or, when appropriate, the consumer's family, and shall include consideration of a range of service options proposed by individual program plan participants, the

effectiveness of each option in meeting the goals stated in the individual program plan, and the cost-effectiveness of each option. . . .

5. Code section 4646, subdivision (a), provides, inpertinent part:

[I]t is the further intent of the Legislature to ensure that the provision of services to consumers and their families be effective in meeting the goals stated in the individual program plan, reflect the preferences and choices of the consumer, and reflect the cost-effective use of public resources.

6. Code section 4646.4, subdivision (a) provides:

Regional centers shall ensure, at the time of development, scheduled review, or modification of a consumer's individual program plan developed pursuant to Sections 4646 and 4646.5[....], the establishment of an internal process. This internal process shall ensure adherence with federal and state law and regulation, and when purchasing services and supports, shall ensure all of the following:

- (1) Conformance with the regional center's purchase of service policies.
- (2) Consideration of the family's responsibility for providing similar services and supports for a minor child without disabilities in identifying the consumer's service and

support needs as provided in the least restrictive and most appropriate setting. In this determination, regional centers shall take into account the consumer's need for extraordinary care, services, supports and supervision, and the need for timely access to this care.

- (3) Utilization of other services and sources of funding as contained in Section 4659.
- (4) Consideration of the family's responsibility for providing similar services and supports for a minor child without disabilities in identifying the consumer's service and support needs as provided in the least restrictive and most appropriate setting. In this determination, regional centers shall take into account the consumer's need for extraordinary care, services, supports and supervision, and the need for timely access to this care.
- 7. Code section 4648, subdivision (a)(1), provides:

In order to achieve the stated objectives of a consumer's individual program plan, the regional center shall conduct activities including, but not limited to, all of the following:

- (a) Securing needed services and supports.
- (1) It is the intent of the Legislature that services and supports assist individuals with developmental disabilities in achieving the greatest self-sufficiency possible and in

exercising personal choices. The regional center shall secure services and supports that meet the needs of the consumer, as determined in the consumer's individual program plan, and within the context of the individual program plan, the planning team shall give highest preference to those services and supports which would allow minors with developmental disabilities to live with their families, adult persons with developmental disabilities to live as independently as possible in the community, and that allow all consumers to interact with persons without disabilities in positive, meaningful ways.

- 8. Code section 4648, subdivision (a)(8), provides that the regional center funds shall not be used to supplant the budget of an agency that has a legal responsibility to serve all members of the general public and is receiving public funds for providing those services.
 - 9. Code section 4659 provides:
 - (a) Except as otherwise provided in subdivision (b) or (c), the regional center shall identify and pursue all possible sources of funding for consumers receiving regional center services. These sources shall include, but not limited to, both of the following:
 - (1) Governmental or other entities or programs required to provide or pay the cost of providing services, including Medi-Cal, Medicare, the Civilian Health and Medical

Program for Uniform Services, school districts, and federal supplemental security income and the state supplementary program.

- (2) Private entities, to the maximum extent they are liable for the cost of services, aid, insurance or medical assistance to the consumer.
- (b) Any revenues collected by a regional center pursuant to this section shall be applied against the costs of services prior to the use of regional center funds for those services. This revenue shall not result in a reduction in the regional center's purchase of services budget, except as it relates to federal supplementary program.
- (c) 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 the 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.

- (d)(1) Effective July 1, 2009, notwithstanding any other law or regulation, a regional center shall not purchase medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi-Cal, private insurance, or a health care service plan denial and the regional center determines that an appeal by the consumer or family of the denial does not have merit. If on July 1, 2009, a regional center is purchasing the service as part of a consumer's IPP, this provision shall take effect on August 1, 2009. Regional centers may pay for medical or dental services during the following periods:
- (A) While coverage is being pursued, but before a denial is made.
- (B) Pending a final administrative decision on the administrative appeal if the family has provided to the regional center a verification that an administrative appeal is being pursued.
- (C) Until the commencement of services by Medi-Cal, private insurance, or a health care service plan.

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10. Code section 4690.2, subdivision (a), provides that:

The Director of Developmental Services shall develop program standards and establish, maintain, and revise, as necessary, an equitable process for setting rates of state payment, based upon those standards, for in-home respite services. The Director of Developmental Services may promulgate regulations establishing these standards and the process to be used for setting rates. "In-home respite services" means intermittent or regularly scheduled temporary nonmedical care and supervision provide ins the client's own home, for a regional center client who resides with a family member.

- 11. Code section 4685.7 and CCR Sections 58884, 58886 and 58887, established the Self-Directed Services Program. Self-Directed services are designed to assist the participant to achieve personally defined outcomes in inclusive community settings. Self-directed services include home health aide services, respite services, and skilled nursing.
- 12. CCR Section 54355, subdivision (a), provides in pertinent part that a regional center may offer vouchers to family members or adult consumers to allow the families and consumers to procure their own diaper/nutritional supplements, day care, nursing, respite, and/or transportation services under certain circumstances.
- 13. When making determinations to acquire services and supports for its consumers the service agency must conform to its purchase of service guidelines. (Code § 4646.4, subd. (a)(1).) Pursuant to the Lanterman Act, the California

Department of Developmental Services reviews the guidelines " to ensure compliance with statute and regulation" prior to promulgation of the guidelines. (Welf. & Inst. Code § 4434, subd. (d).) The guidelines are deserving of deference because they reflect the service agency's expertise and knowledge. (See *Yamaha Corp. of America v. State Bd. of Equalization* (1998) 19 Cal.4th 1, 12-15.) Importantly, guidelines the service agency promulgates must account for its consumers' individual needs when making eligibility determinations for particular services and supports. (See *Association for Retarded Citizens v. Department of Developmental Services* (1985) 38 Cal.3d 384, 388.)

14. Here, Claimant seeks funding for respite and/or personal assistant services. NLACRC does not dispute that Claimant needs such services. However, paying Claimant's parents to provide such services is contrary to the purpose for which the services are provided. The services are meant to give Claimant's caregivers a break from care duties and are not intended to be a source of income for them. There is no authority in law or regulations and no support in directives or policy to conclude otherwise. Claimant requires nursing level care, which may be available from generic services such as Medi-Cal, when receiving infusions through her Portacath. The evidence did not establish that Claimant needs continuous treatment through her Portacath, therefore nursing level care is required only when she receives such treatment, but not at all times. Accordingly, NLACRC should provide appropriate respite and/or personal assistant hours when Claimant secures a provider that meets the statutory and regulatory requirements and complies with the Directive. Her parents are prohibited from receiving compensation to serve as either a respite care worker or personal assistant to her.

ORDER

Claimant's Appeal is denied.

DATE: 04/21/2021

GLYNDA B. GOMEZ

Administrative Law Judge

Office of Administrative Hearings

NOTICE

This is the final administrative decision; both parties are bound by this decision. Either party may appeal this decision to a court of competent jurisdiction within 90 days.