

BEFORE THE  
OFFICE OF ADMINISTRATIVE HEARINGS  
STATE OF CALIFORNIA

In the Matter of:

IAN D.,

Claimant,

vs.

FAR NORTHERN REGIONAL CENTER,

Service Agency.

OAH No. 2013051072

DECISION

This matter was heard before Administrative Law Judge Susan H. Hollingshead, State of California, Office of Administrative Hearings (OAH), in Redding, California, on July 24, 2013.

The Service Agency, Far Northern Regional Center (FNRC), was represented by Linda M. Carpenter, Attorney at Law.

Claimant, who participated telephonically for a portion of the hearing, was represented by Kimberlee Candela, Attorney at Law, Office of Clients' Rights Advocacy, Disability Rights California. His parents, who are also his conservators, were present throughout the hearing.

Oral and documentary evidence was received. At the conclusion of the hearing, the record was closed and the matter was submitted for decision.

## ISSUE

Is FNRC required to continue funding claimant's out-of-home placement through Prader-Willi Homes of Oconomowoc, Wisconsin?

## FACTUAL FINDINGS

1. Claimant is a thirty-seven year old man who is eligible for regional center services based on a diagnosis of mild mental retardation. He is also diagnosed with Prader-Willi syndrome (PWS), which has profoundly affected his ability to live independently. PWS is a rare congenital disorder that results in a number of physical, mental and behavioral challenges. One of the key features of PWS is hyperphagia (insatiable appetite) that is believed to result from a defect in the hypothalamus, the part of the brain that regulates hunger, satiety, and the body's metabolic rate. Persons with PWS experience a biochemical drive to eat that is never satiated no matter how much food is eaten. Metabolism is about half the normal rate; therefore people with PWS will gain a considerable amount of weight on considerably fewer calories than the normal population.

Claimant currently lives at Gatehouse, a facility owned and operated by Prader-Willi Homes (PWH/O) of Oconomowoc, in Wisconsin.

2. By letters dated November 14, 2012, January 14, 2013, and March 15, 2013, FNRC requested approval from the Department of Developmental Services (Department or DDS) "to continue to fund the out-of-state placement of [claimant] at Prader Willi Homes of Oconomowoc in Dousman, Wisconsin."

3. The Department responded by letter dated March 19, 2013, as follows:

Based on the information provided in your correspondence,  
FNRC is authorized to fund this placement at a rate not to  
exceed \$226.72 per day, less any benefit he may receive, e.g.,

Social Security Income/State Supplemental Program, effective July1, 2012, through June 30, 2013.

Pursuant to Welfare and Institutions Code Section 4519 (c), if [claimant] is not expected to return to California by June 30, 2013, and the regional center requests an extension of the Department's approval to fund out-of-state services, the FNRC Director's request for an extension must be submitted 30 days prior to the current expiration date and shall include the following information: a new and complete comprehensive assessment and a report to the Director of the Department summarizing the regional center's efforts to locate, develop, or adapt an appropriate program for [claimant] within California. The report must be reviewed and updated quarterly, identify the services and supports needed and the timeline for identifying or developing those services to transition [claimant] back to California. It is the Department's expectation that FNRC explore all in-state residential options, including accessing the Department's "Statewide Specialized Resource Services" at least quarterly. Please notify the Department upon [claimant's] return to California.

4. Welfare and Institutions Code section 4519 provides as follows:
  - (a) The department shall not expend funds, and a regional center shall not expend funds allocated to it by the department, for the purchase of any service outside the state unless the Director of Developmental Services or the director's designee has received, reviewed, and approved a plan for out-of-

state service in the client's individual program plan developed pursuant to Sections 4646 to 4648, inclusive. Prior to submitting a request for out-of-state services, the regional center shall conduct a comprehensive assessment and convene an individual program plan meeting to determine the services and supports needed for the consumer to receive services in California and shall request assistance from the department's statewide specialized resource service in identifying options to serve the consumer in California. The request shall include details regarding all options considered and an explanation of why these options cannot meet the consumer's needs. The department shall authorize for no more than six months the purchase of out-of-state services when the director determines the proposed service or an appropriate alternative, as determined by the director, is not available from resources and facilities within the state. Any extension beyond six months shall be based on a new and complete comprehensive assessment of the consumer's needs, review of available options, and determination that the consumer's needs cannot be met in California. An extension shall not exceed six months. For the purposes of this section, the department shall be considered a service agency under Chapter 7 (commencing with Section 4700).

- (b) No funds shall be expended for the cost of interstate travel or transportation by regional center staff in connection with the purchase of any service outside the state unless authorized by the director or the director's designee.
- (c) When a regional center places a client out of state pursuant to subdivision (a), it shall prepare a report for inclusion in the client's individual program plan. This report shall summarize the regional center's efforts to locate, develop, or adapt an appropriate program for the client within the state. This report shall be reviewed and updated every three months and a copy sent to the director.

Each comprehensive assessment and report shall include identification of the services and supports needed and the timeline for identifying or developing those services needed to transition the consumer back to California.

- (d) Notwithstanding subdivisions (a), (b), and (c), the State Department of Developmental Services or a regional center may expend funds allocated to it for the purchase of services for residents of this state and administrative costs incurred in providing services in the border areas of a state adjacent to California when the purchase is approved by the regional center director.
- (e) Each regional center shall submit to the department by December 31, 2012, a transition plan for all consumers residing out of state as of June 30, 2012, for whom the regional center is purchasing services.<sup>1</sup>

5. A comprehensive assessment was completed by Lisa Ott, Mains'l Services, Inc., who compiled her findings in a report dated December 11, 2012. The assessment identified services and supports FNRC must develop and are required for claimant's success. FNRC used that information to develop a transition plan establishing "steps for accessing and development of the services needed for a successful transition by [claimant] within a timely manner."

The transition plan included that FNRC will "continue a statewide search for suitable resources that meets [claimant's] needs. Use of the statewide specialized resource service (SSRC) data base will be incorporated into this plan."

The transition plan also required the start of "discussions with a service provider who has experience in residential or Supported Living Services (SLS) and has the ability to provide the services and supports identified in the interdisciplinary assessment completed

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<sup>1</sup> Unless otherwise indicated, all statutory references are to the California Welfare and Institutions Code.

by Mains' I in December 2012. A possible service provider is Mid Valley Services, a provider with years of experience and success in providing meaningful lives for consumers. While Mid Valley Services does not operate a PW facility they have been successful in providing services to individuals with PW and others who have transitioned from Developmental Centers and whom require many of the same services and supports that [claimant] requires."

6. In April 2013, claimant's FNRC Service Coordinator, Cynthia Nordstrom, visited claimant in his home in Wisconsin. After this visit, Ms. Nordstrom informed claimant's parents by letter dated April 22, 2013, "FNRC would like to have our vendor, Mid Valley Providers, come and visit [claimant] as discussed in the transition plan. After their visit, they would assess their ability to meet his needs and develop services and supports for him, either in a small two or three-bed group home, or in a supported living environment. In order to get the transition plan started, please sign the transition plan and the release of information for Mid Valley Providers."

Ms. Nordstrom stated, "I hope you know that FNRC is complying with direction from the California Department of Developmental Services, as we contract with them and they are our funding source. I assure you that we want [claimant's] transition back to California to be successful with the least amount of disruption to [claimant] and you."

7. Claimant's parents/conservators did not sign consent to the transition plan because they believe there is not an appropriate placement for claimant within the state of California.

8. A Notice of Proposed Action (NOPA) was issued on May 6, 2013, informing claimant of the following;

Proposed action: Discontinue funding of out of home placement through Prader-Willi Homes of Oconomowoc, Wisconsin and offer out of home placement in California.

Reason for action: Conservators declined the transition plan dated 4/12/2013, developed to begin the assessment process and development of services and supports in California in order to transition [claimant] back to California.

9. Claimant filed a Fair Hearing Request dated May 17, 2013, stating, "[claimant] needs to stay in his current group facility home because there are no facilities in the state of California that can meet his complex needs." He requested to be "authorized to stay in his current PWS Home. . . "

10. A telephonic informal meeting was held on June 10, 2013, between claimant's parents/conservators and FNRC's Executive Director, Laura Larson.

Claimant's mother "reviewed [his] past, which has been difficult and outlines a pattern of failing in one residential care home after another. Since living in Oconomowoc, [claimant's] behaviors have been managed well; he has developed meaningful relationships, and is involved in the community. She also stated that their staff is very well trained and competent. She believes he has been well cared for because the care is specific to Prader-Willi syndrome only. Because of this laser-like focus, this program has experienced many years of successful management of people who have Prader-Willi syndrome. Every staff member understands the complexity of Prader-Willi syndrome and is fully supportive to the individual."

Ms. Larson explained that she "knew [claimant] was doing well in his placement of 8 years in the Prader-Willi Homes of Oconomowoc, Wisconsin, and that the proposed action was due only because of new regulation created by California's severe budget shortfalls."

FNRC prepared a transition plan pursuant to section 4519. The plan was not signed by the parents/conservators. Ms. Larson concluded that FNRC "does not see, at this time, any possible resolution to the issue at hand at our level. We do not have the authority to

continue to fund [claimant's] placement, and so I must uphold the decision regarding the Notice of Proposed Action."

11. By letter dated June 21, 2013, Ms. Larson informed DDS of claimant's current status. She explained that a transition plan had been developed but cannot be implemented because claimant's parents/conservators declined to sign it and that a Fair Hearing was requested to require FNRC to continue funding placement at PWH in Wisconsin. FNRC continues to fund the current placement and sought DDS approval to continue funding the placement until December 31, 2013. Ms. Larson stated, "if the NOPA is upheld in the Fair Hearing process, FNRC will immediately begin implementation of the transition plan and will require at least 6 months to transition [claimant's] services back to California."

12. DDS responded by letter dated July 16, 2013, informing FNRC as follows:

Based on the information you provided in your correspondence, FNRC is authorized to continue funding this placement at a rate not to exceed \$226.72 per day, less any benefit he may receive, e.g., Social Security Income/State Supplemental Program, effective **July 1, 2012, through September 30, 2013.**

It is the Department's understanding, based upon information provided by FNRC staff, that FNRC has developed a plan to transition [claimant's] services back to California. It is the Department's expectation that FNRC implement the transition plan and continue its search for potential resources within the state, including accessing the Department's "Statewide



Specialized Resource Services” at least quarterly, in order to secure appropriate services for [claimant] within the State.

13. Lisa Graziano, M.A., LMFT, is the Executive Director of the Prader-Willi California Foundation (PWCF). She offered insight into PWS and the needs of individuals with the syndrome. Ms. Graziano testified that PWS causes a multitude of complex and life-threatening symptoms. The most prominent symptoms include hyperphagia, severely slowed metabolic rate causing rapid weight gain, cognitive impairment, and a labile affect which interferes with the individual’s ability to manage their emotions and behavior, and frequently leads to severe and sometimes violent behavior meltdowns.

The first stage of PWS is characterized by low birth weight, and subsequent “failure to thrive”, severe muscle weakness (hypotonia) and delayed developmental milestones. Because of weak, limp muscles, infants are often unable to nurse or suck and may require special feeding techniques.

The next stage “usually begins in toddlerhood when a preoccupation with food and a compulsion to eat begins. Life becomes dominated by a voracious appetite and an unrelenting drive for food. People with PWS do not experience normal satiety, a feeling of fullness after eating, and can eat a tremendous amount of food without feeling ill. Often there is an inability to vomit. In addition to the desire for food, there is a rapid weight gain on relatively few calories. Thus, if not controlled, the individual with PWS will quickly become obese. If a person with PWS gains unrestricted access to food, the result can be deadly (GI perforation or stomach tissue necrosis). Uncontrolled obesity may lead to illnesses such as high blood pressure, respiratory difficulties, heart disease, diabetes, and death.”

14. Ms. Graziano has extensive experience working with individuals with PWS, and the residential providers that serve this population. After reviewing claimant’s records and interviewing family and service providers, she testified that PWS is a unique and

extraordinarily difficult syndrome to manage and “there are some individuals with PWS who require an even higher level of care than can be provided in a California PWS group home. [Claimant] is one of them.”

She documented claimant’s unsuccessful placements within California and opined that while there are some excellent in-state providers “none of the residential facilities in California has been or currently is able to provide the organizational structure and supports that will meet [claimant’s] complex needs.” He was moved from home to home due to behaviors that could not be managed. She suggested that “the only residential facility which has proven it can successfully provide the residential supports that [claimant] needs, is the PWS Homes of Oconomowac” where claimant has resided since 2004. Claimant was evicted from his last California placement, Lee Street I, and placed out-of-state after exhausting other options throughout California.

15. Ms. Graziano testified that Prader-Willi Homes of Oconomowoc (PWHO) is “in a class of its own” unique in meeting the needs of claimant and others with the most complex needs. It is actually a community of ten homes, eight with eight beds, one with fourteen beds and one with sixteen. Claimant resides in the latter.

Claimant requires food to be locked at all times, with scheduled low calories meals provided. Every moment must be structured in his day to prevent oppositional behaviors. He is described as “clever and tenacious” in his ability to obtain food. Claimant has picked and broken locks requiring further security. He will elope if not supervised and has broken into neighboring homes and stolen food. He has determined how to muffle alarm systems, and requires awake staff at night to prevent him from searching for food. He cannot manage money because he will spend it on food.

Claimant, as with many individuals with PWS does not regulate his body temperature or regulate pain properly. He can eat dangerously large amounts of food

without feeling discomfort. He may be unable to vomit and he has had difficulty with impaction and rectal picking, which has led to colon perforation and resulting surgery.

There are several unique characteristics of PWHO that have attributed to claimant's successful placement. It offers a larger, sixteen bed placement that is beneficial for claimant. Ms. Graziano testified that a similar placement would not be possible in California where it would be "considered institutionalization." Claimant enjoys the synergy that this environment offers, much like a college dorm or large family. He enjoys the social relationships and has maintained the same girlfriend for many years. Residents of the homes work together at Pantheon Industries, which provides a variety of work situations, and the surrounding community is educated to PWS. Staff at PWHO own part of the company and are invested in its success. There is consistent training with limited turnover. Staff can physically restrain for elopement. Ms. Graziano testified that in California residential staff is "limited to following an individual, keeping in sight and waiting for the police or psych team to intervene." A provider could "follow him to a dumpster and watch him eat or watch him walk up a freeway onramp and get hit. He would need a locked facility."

16. Ms. Graziano was also concerned that she "knows nothing about Mid Valley Services," the proposed provider. She found that "significant and extremely concerning" in light of her professional affiliations and suggested "they don't know what they don't know." She opined that with the level of severity of claimant's disability, an inappropriate change in placement could not just affect the quality of his life but life itself. Claimant, without proper 24-hour per day supervision is at risk of death from "a choking incident, stomach rupture, or from complications related to morbid obesity."

17. Claimant's parents testified to the extreme difficulty claimant had maintaining placement at various residential facilities in California. He lived with his parents until his desire for food became so intense that his behavior became completely

unmanageable. They gave numerous examples of behaviors including incidents where he would elope and steal food from neighbors that he determined had freezers in their garages. On some instances he would hide the stolen food in a nearby hedge. They were concerned that he would be shot by one of the neighbors in his rural community.

They also spoke to the success of claimant's placement at PWHO and their serious concerns with an inappropriate transition back to California.

18. Claimant testified that he likes living at PWHO and wants to continue living there. He explained that he enjoys "outings, programs, friends, participating in Special Olympics, work during the week at the workshop and Sunday church." He enjoys movies, playing board games and PlayStation 2 with his friends, and sharing time with his girlfriend. He explained that the PWHO staff is "nice, respectful, have humor and joke sometimes, and treat me right." He stated that he would like to live closer to his parents but until there is a placement like PWHO, he would like to stay where he is.

19. Kim Tula is the Clinical Coordinator for PWHO where she has been employed for eighteen years. She testified that her office is in Gatehouse and she has seen claimant almost every day since he arrived. He "seeks her out before and after work, and with issues." She stated that he is on the "intense end" of the PWS spectrum and is aggressive in his desire to obtain food. He attempts to break locks to the kitchen and the dumpster. They originally had single locks which claimant could pick. Then he learned to "jimmy double locks" so they now have deadbolts.

She described his aggressive behaviors: usually hitting, kicking, biting, pulling hair or throwing objects. In an attempt to get to the hospital (presumably to obtain food), he stored urine in his room, which he later threw in a staff member's face.

Ms. Tula explained the structure of the PWHO homes and the extensive training required of employees, which includes a minimum of 30 hours of continuing education each year. Gatehouse is designed for individuals with PWS that have more intense needs.

There is a high staff ratio, averaging seven or eight staff during the first two shifts and a minimum of two during the third shift. The third shift is the night shift and requires awake staff to monitor the hallways in the home and make bedroom checks to assure residents are not wandering or attempting to leave.

20. Ms. Tula also described claimant as being “very happy” at PWHO. She explained that Gatehouse is like an “outside family with fifteen brothers and sisters.” She described the activities he enjoyed noting that he participates in “more activities than you or I do.”

When asked her opinion about a move to California, Ms. Tula “did not see it going well.” She opined that he is “extremely manipulative” and she would be concerned if he was “in a setting with one to three individuals with a provider without much experience.” She believes there would be a deterioration of his social skills without a large peer group and he would “go back into a deep depression.” He needs a large peer group where he feels connected.

21. Diana Anderson is FNRC’s Associate Director for Community Services. She testified to the process for requesting approval from DDS to fund out-of-state placement and the proposed transition plan for returning claimant to California. She stressed FNRC’s desire for claimant to be successful and explained how the process would begin to develop a program that would be appropriate for claimant. She explained that the transition would be slow and methodical and that Mid Valley has been identified as a provider that might be appropriate to provide claimant’s level of service. Ms. Anderson testified that funding for claimant’s placement at PWHO has not been terminated but that FNRC cannot continue funding without following the requirements of section 4519. She testified that FNRC would do everything they could to develop an appropriate placement for claimant.

22. FNRC Executive Director Laura Larson also testified. She recounted claimant's "long journey" with California placements that did not work. She acknowledged his uniqueness and the difficulty replicating the services and supports that he is presently receiving. She understands that he is "safe and thriving" and assured the family that FNRC is doing everything they can to support claimant. She stressed the need to take the time necessary to make the transition, stating "we want him to be successful."

23. Claimant contends that his needs cannot be met in the State of California. Therefore, FNRC must be ordered to continue funding his placement at PWHO. He further contends that FNRC has not "met their burden" to show that it has an appropriate placement available to meet his needs. "It is not the intent of the statutory scheme to put him in jeopardy by bringing him back." Claimant also testified that the cost of services in California would be similar to those in Wisconsin.

24. FNRC responded that it has met its burden by responding to the statutory requirements. They have proposed a transition plan and taken other steps necessary for continued funding. FNRC concurred that the cost-effectiveness of the PWHO placement was not the concern.

## LEGAL CONCLUSIONS

1. Pursuant to the Lanterman Act, Welfare and Institutions Code section 4500, et seq., regional centers accept responsibility for persons with developmental disabilities. Welfare and Institutions Code section 4512 defines developmental disability as follows:

"Developmental disability" means a disability that originates before an individual attains age 18 years, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual....[T]his term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall

also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation [commonly known as the "fifth category"], but shall not include other handicapping conditions that are solely physical in nature.

2. The Lanterman Act sets forth the regional centers' responsibility for providing services to persons with development disabilities. An "array of services and supports should be established...to meet the needs and choices of each person with developmental disabilities... to support their integration into the mainstream life of the community...and to enable persons with disabilities to approximate the pattern of everyday living available to people without disabilities of the same age." (§ 4501.) The Lanterman Act requires regional centers to develop and implement an IPP for each individual who is eligible for regional center services. (§ 4646.) The IPP includes the consumer's goals and objectives as well as required services and supports. (§§4646.5 & 4648.)

3. Welfare and Institutions Code section 4646, subdivision (a), provides:

It is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and preferences of the individual and family, where appropriate, as well as promoting community integration, independent, productive, and normal lives, and stable and healthy environments. It 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.

4. The evidence at hearing was overwhelming and undisputed that claimant has unique and extensive treatment needs that were not successfully addressed previously within the state of California. There was no compelling evidence that repeating a failed service model would be effective. In fact, evidence was persuasive that attempting to do so could put claimant at substantial risk.

It was also clear that claimant's placement at PWHO has provided a stable and healthy environment where, to the extent possible, he is able to lead an independent, productive and normal life. Claimant and his parents/conservators prefer this placement, and the parties concur that cost-effectiveness is not at issue.

5. Section 4519, as amended in 2012, clearly limits a regional centers ability to purchase services outside of the state of California. FNRC has taken all necessary action to conform to the requirements of section 4519. An assessment and a transition plan have been completed, and DDS has currently approved the out-of-state services. FNRC is taking action to locate, develop, or adapt an appropriate program within the state. There was considerable evidence that this may take time. It is not the intent of the statute to put claimant in jeopardy by returning him to the state. FNRC has acknowledged this by stating it will take the time necessary for transition because it "wants him to be successful."

The Legislature did not address any exceptions in section 4519. FNRC's authority is limited accordingly.

FNRC must meet the statutory requirements of section 4519, which includes providing DDS with a transition plan. Claimant declined the April 12, 2013, transition plan developed to begin the required process of identifying or developing services and



supports necessary to transition claimant back to California. FNRC may not expend funds for the purchase of any service outside the state, except as directed in section 4519.

## ORDER

Claimant's appeal from the Far Northern Regional Center's determination that it is required to discontinue funding of his out-of-state placement at PWHO, unless claimant agrees to a transition plan, is denied and the regional center's action is upheld.

DATED: August 6, 2013

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SUSAN H. HOLLINGSHEAD

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. (Welf. & Inst. Code, § 4712.5, subd. (a).)**