



**In the
Missouri Court of Appeals
Western District**

**ANDREA WEISENBORN, A
PARTIALLY INCAPACITATED AND
TOTALLY DISABLED INDIVIDUAL,
BY AND THROUGH DEBBIE
SHOEMAKER AND JIM
SHOEMAKER, HER PARENTS AND
NEXT FRIENDS,**

Respondent,

v.

**MISSOURI DEPARTMENT OF
MENTAL HEALTH, DR. KEITH
SCHAFFER, DIRECTOR, MISSOURI
DEPARTMENT OF MENTAL
HEALTH, SUED IN HIS OFFICIAL
CAPACITY, LINDA BOWERS,
DIRECTOR, FOR KIRKSVILLE
REGIONAL OFFICE, SUED IN HER
OFFICIAL CAPACITY, MR. THAD
TAYLOR, HEARINGS REFEREE,
SUED IN HIS OFFICIAL CAPACITY,
MS. DEBRA WOHLERS, ASST.
DIRECTOR OF HABILITATION,
KIRKSVILLE REGIONAL OFFICE,
SUED IN HER OFFICIAL
CAPACITY,**

Appellants.

WD72126

OPINION FILED: January 25, 2011

Appeal from the Circuit Court of Macon County, Missouri
The Honorable Hadley E. Grimm, Judge

Before Division Three: Cynthia L. Martin, Presiding Judge, James E. Welsh, Judge and
Gary D. Witt, Judge

Andrea Weisenborn appeals¹ the Missouri Department of Mental Health's decision denying her services under the Comprehensive Medicaid Waiver Program. We affirm the judgment of the trial court, which reinstated Weisenborn's Medicaid Waiver benefits, and remand to the trial court for a determination of reasonable reimbursement for attorney's fees and costs expended by Weisenborn at the proceedings below and on appeal pursuant to Section 536.087.

Factual Background

Andrea Weisenborn ("Weisenborn") is a twenty-nine year-old woman who was diagnosed with Prader-Willi Syndrome (PWS) with hyperphagia during her first year of her life. PWS is a genetic condition that affects brain functioning, body composition, metabolism, and cognitive/behavioral functioning. PWS affects brain functioning by causing the individual to be "always ravenously hungry and driven to eat," in that it affects the operation of the hypothalamus which is "responsible for temperature regulation, day/night sleep wake cycles, appetite control, emotional control, and the production of growth and sexual hormones." Body fat/muscle composition ratios are

¹Weisenborn is classified as the Respondent because she appealed the Missouri Department of Mental Health's decision to the Circuit Court of Macon County and the Department's decision was reversed. The Department now appeals the determination by the circuit court. However, because the Court of Appeals reviews the Department's decision, not the circuit court's, the procedural posture in reality is that Weisenborn is appealing the Department's denial of her benefits. *TAP Pharm. Prods. Inc. v. State Bd. of Pharmacy*, 238 S.W.3d 140, 141 (Mo. banc 2007).

reversed as compared to a person without this illness, and metabolism is significantly reduced. Most affected individuals demonstrate cognitive functioning in the mentally retarded range but approximately five percent can test in the normal range of cognitive functioning.

Weisenborn has PWS with hyperphagia. Hyperphagia causes an almost uncontrollable drive to excessively eat, and as a result, Weisenborn is morbidly obese and diabetic. She also has sleep apnea, cellulitis, blood clots in her legs, psoriasis, and scoliosis. According to the Referee:

She is able to use eating utensils, but she does not have self-control over her drive to eat. As a result, she must have a lock on her refrigerator and her blood sugars must be regularly tested, as a screen to determine whether she has been sneaking food. She is able to put on different clothes when instructed, but is not able to dress herself in a manner that will protect her health and hygiene. If she does not receive support, she does not put on her socks and her bra in a way that will avoid rubbing, rashes, and infections, all of which exacerbate her Diabetes and Cellulitis and can be life-threatening if left untreated. . . . [She] is able to get into and out of the shower, but is not physically able to reach around to wash or dry her back, and she is not mentally able to ensure that she adequately cleans and dries all parts of her body, including under the folds of her skin. If her body is not dried properly, she gets yeast infections and exacerbates her Cellulitis. Appellant is not able to trim her fingernails and toenails, due to the danger of injuring the surrounding skin, which causes complications to her Diabetes and Cellulitis.

Weisenborn is part of the small subset of those affected by PWS who do *not* test in the range of mental retardation on a standardized IQ test.² With the help of her mother's tutoring, Weisenborn completed high school receiving A's and B's. Weisenborn then attended Moberly Community College and received an associate's degree, also with

²An IQ score below seventy is the primary tool used to diagnose mental retardation, but an IQ score up to seventy-five can be used if the individual exhibits significant deficits in adaptive behavior. AM. PSYCHIATRIC ASS'N DIAGNOSTIC & STATISTICAL MANUAL OF MENTAL DISORDERS 41-42 (4th ed. 2000).

significant tutoring from her mother. In 1998 at age seventeen, Weisenborn took a WAIS test which measures the IQ of school-aged children and scored a seventy-eight, which is on the border-line of mental retardation (and does not take into account her other significant behavioral deficit) but does not indicate mental retardation. At the age of eighteen, Weisenborn took a WAIS-R psychological test, used to measure IQ for adults, and scored a one-hundred, which is within the normal range of intellectual function.

Weisenborn was married in 2003. Two months later her parents obtained a limited guardianship and conservatorship, at which time they also agreed not to fight her marriage. Weisenborn serves as a self-advocate at the Regional Area Council and works two to three days a week as an in-home aide. To qualify as an in-home aide, Weisenborn had to pass the Medication Administration Examination, which she passed with a score of ninety-six. Weisenborn used to drive an automobile but has not been able to do so for several years because this gave her unsupervised access to food and she could not control her impulses.

Under the Medicaid Waiver program, an administrator from the Missouri Department of Mental Health ("Department") administers a test called the Missouri Critical Adaptive Behaviors Inventory ("MOCABI") for each applicant. To qualify for services, among other requirements, an applicant must show a significant deficit in at least three of the following six areas: (1) self-care; (2) receptive and expressive language; (3) learning; (4) mobility; (5) self-direction; (6) capacity for independent living or economic self-sufficiency.

Weisenborn began receiving Medicaid Waiver services in 2003, at which time she was placed in an Independent Supported Living Placement. Her MOCABI results in both 2004 and 2006 showed she had substantial limitations in the requisite number of three areas. In each evaluation she was found deficient in: self-care, self-direction, and capacity for independent living or economic self-sufficiency. In 2008, Weisenborn was re-evaluated by Department employee Karen Moore and was again found to be deficient in the same three areas and eligible for services. However, Debra Wohlers ("Wohlers"), Assistant Director of Habilitation for the Kirksville Regional Office, reviewed Moore's scoring of Weisenborn's test and found that she had scored it incorrectly. Wohlers has served on a state-wide intake and eligibility work group to make sure assessments are consistent across the state and is experienced in administering the MOCABI. Weisenborn's MOCABI was rescored, and she was found to have substantial limitations in only two areas: self-direction and capacity for independent living or economic self-sufficiency. Weisenborn was thus found not to have substantial functional limitations in the area of self-care. Based on this assessment, Weisenborn was informed that she was no longer eligible for Medicaid Waiver Services. Weisenborn, with the assistance of her parents, appealed the termination decision, and it was agreed that the MOCABI would be re-administered.

On April 29, 2008, Wohlers re-conducted the MOCABI on Weisenborn. As a result of that test, Wohlers found that Weisenborn was no longer eligible for services through the Medicaid Waiver program because she only had a significant deficit in two of

the six areas: self-direction and capacity for independent living or economic self-sufficiency.

Weisenborn appealed the denial of her Medicaid Waiver Services and on September 11, 2008, a hearing was held before Referee Thad Taylor ("Referee"). At the hearing, the Department called witnesses Bowers and Wohlers. Weisenborn's mother, Ms. Shoemaker, testified on her behalf. On October 17, 2008, the Referee issued his initial decision in Weisenborn's favor. In addition to the two uncontested areas of deficiency, the Referee found that Weisenborn had substantial functional limitations in self-care based on the evidence and found: Wohlers noted on her MOCABI that Weisenborn always asks for help to dry her back; Weisenborn once fell when showering; Weisenborn must have locks on her refrigerator; and she is unable to dress herself to protect her health and hygiene.³

On October 29, 2008, the Department filed a Motion to Vacate or Amend Decision. Both parties submitted additional evidence. Weisenborn filed two affidavits, one from her father and the other from Sarah Ford, Weisenborn's personal care attendant. The Department provided the MOCABI tests from 2004 and 2006 and the prior IQ tests taken by Weisenborn.

On January 6, 2009, the hearing officer, after granting the Motion to Vacate and considering the additional evidence, issued an amended decision. The Amended Decision concluded: (1) Weisenborn did not "have a condition that is 'found to be closely

³The Referee noted that these deficiencies could cause other health related issues which, based on her condition, could be life threatening.

related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons"; and (2) Weisenborn did not require an ICF/MR⁴ level of care if not provided the services under the Medicaid Waiver. The decision of the Referee was affirmed on appeal by the Department Director, Dr. Keith Schafer, who determined that, based on all the evidence, Weisenborn was not eligible for Medicaid Waiver services. That decision was appealed by Weisenborn to the Circuit Court of Macon County, and the decision of the Director was reversed by the trial court, which held that Weisenborn was eligible for services.

The Department appealed the decision of the trial court; however, as noted above, in matters of this nature, we review the Department's decision, not the decision of the circuit court. Thus the procedural posture of this case is that Weisenborn is appealing the Department's denial of her benefits.

Standard of Review

In an appeal following judicial review of an agency's administrative action, this Court reviews the decision of the agency, not the circuit court. *Mo. Coalition for the Environment v. Herrmann*, 142 S.W.3d 700, 701 (Mo. banc 2004). Pursuant to section 536.140.2, this Court reviews to determine "whether the agency's findings are supported by competent and substantial evidence on the record as a whole; whether the decision is arbitrary, capricious, unreasonable or involves an abuse of discretion; or whether the decision is unauthorized by law." *Community Bancshares, Inc. v. Secretary of State*, 43 S.W.3d 821, 823 (Mo. banc 2001).

TAP Pharm. Prods. Inc. v. State Bd. of Pharmacy, 238 S.W.3d 140 (Mo. banc 2007).

⁴"ICF/MR" stands for Intermediate Care Facility for Mental Retardation. ("ICF/MR")

"Whether the award is supported by competent and substantial evidence is judged by examining the evidence in the context of the whole record. An award that is contrary to the overwhelming weight of the evidence is, in context, not supported by competent and substantial evidence." *Hampton v. Big Boy Steel Erection*, 121 S.W.3d 220, 223 (Mo. banc 2003).

An administrative agency acts unreasonably and arbitrarily if its decision is not based on substantial evidence. Whether an action is arbitrary focuses on whether an agency had a rational basis for its decision. Capriciousness concerns whether the agency's action was whimsical, impulsive, or unpredictable. To meet basic standards of due process and to avoid being arbitrary, unreasonable, or capricious, an agency's decision must be made using some kind of objective data rather than mere surmise, guesswork, or "gut feeling." An agency must not act in a totally subjective manner without any guidelines or criteria.

Bd. of Educ. v. Mo. State Bd. of Educ., 271 S.W.3d 1, 11 (Mo. banc 2008) (quoting *Mo. Nat'l Educ. Ass'n v. Mo. State Bd. of Educ.*, 34 S.W.3d 266, 281 (Mo. App. W.D. 2000)).

This court will defer to the agency's factual findings, but we will review *de novo* the agency's application of the facts to the law, interpretations, and conclusions of law. *Cnty. Bancshares, Inc. v. Sec'y of State*, 43 S.W.3d 821, 823 (Mo. banc 2001).

Analysis

In her sole Point Relied On, Weisenborn argues the Director erred in upholding the decision of the Department finding Weisenborn ineligible for Comprehensive Medicaid Services in that the decision is not supported by competent and substantial evidence upon the whole record and is arbitrary, capricious, and unreasonable because overwhelming evidence was presented at the hearing that Weisenborn: (1) has substantial functional limitations in three areas of Major Life Activity, and (2) that but for the

Medicaid Waiver services, Weisenborn would require treatment at an ICF/MR level of care.⁵

Medicaid is a "cooperative program under which the federal government reimburses state governments for a portion of the costs of providing medical assistance to low income recipients." *Estate of Shuh*, 248 S.W.3d 82, 84 (Mo. App. E.D. 2008). The Medicaid Waiver program is one through which individuals "receive services funded by the federal program normally available only at an institution." *Hyde v. Dep't of Mental Health*, 200 S.W.3d 73, 74 (Mo. App. W.D. 2006). Eligibility for the program is determined through a combination of federal and Missouri statutes and regulations.

I. Application of 9 CSR 45-2.015(1)(C)

Pursuant to 9 C.S.R. section 45-2.015(1)(C), to qualify for the Comprehensive Medicaid Waiver, one must: (1) be an individual with mental retardation and/or a developmental disability; (2) be Medicaid eligible; and (3) be determined to otherwise require the level of care provided in an ICF/MR.

The Department argues Weisenborn is ineligible for services because she fails to satisfy criteria (1) and (3). First, the Department argues that Weisenborn does not have mental retardation nor a qualifying developmental disability according to federal requirements.

A. Mental Retardation

In Missouri, "mental retardation" is "significantly subaverage general intellectual functioning which: (a) [o]riginates before age eighteen; and (b) [i]s associated with a

⁵The Director adopted the factual findings and the legal conclusions of the Referee.

significant impairment in adaptive behavior." Section 630.005(24).⁶ Under federal regulations, one must show that the mental retardation originated before age twenty-two; the Department does not dispute that for purposes of the Medicaid Waiver Program, the twenty-two year-old age requirement applies.

The evidence as to Weisenborn's level of intelligence was the following: (1) before the age of twenty-two Weisenborn took two IQ tests, neither of which classified her as having mental retardation; (2) Dr. Barbara Whitman ("Dr. Whitman"), an expert on Prader-Willi Syndrome, diagnosed Weisenborn with having Mild Mental Retardation, secondary to PWS and severe behavioral difficulties; (3) Dr. Whitman submitted a letter stating generally that when individuals with PWS test outside the range of Mental Retardation, it is "illusory" because there is an overlay of several significant learning disabilities, so that they "function in the range of mild retardation"; (4) Dr. Whitman conducted a Slosson Intelligence Test-Revised on Weisenborn, who received a Standard Score of 64, placing her in the Mild range of Mental Retardation; (5) Weisenborn went to regular classes throughout high school; (6) Weisenborn obtained an Associate's Degree from community college; (7) for her job as an in-home aide, Weisenborn passed the Medication Administration Examination with a score of ninety-six.

The Department states that it disregarded evidence from Dr. Whitman as to Weisenborn's alleged mental retardation for the following reasons: (1) Dr. Whitman's tests were conducted in 2007 when Weisenborn was twenty-six years old; (2) Dr.

⁶All statutory references are to RSMo 2000 as updated through the 2009 cumulative supplement, unless otherwise indicated.

Whitman's Slosson test is only a screening tool to determine if more testing is necessary and is not used to give a true picture of an IQ; (3) in 2001, Dr. Whitman noted that Weisenborn was among the five percent of people with PWS who do not score within the range of mental retardation.

Considering the evidence as a whole, the Department's conclusion that Weisenborn does not qualify as having mental retardation is supported by substantial evidence. Weisenborn's main witness, Dr. Whitman, initially concluded in 2001 that she is in that five percent group that tests above a mentally retarded range on cognitive testing with the caveat that she has hyperphagia. The additional tests conducted by Dr. Whitman did not satisfy the Department that Weisenborn has mental retardation. Linda Bowers, Director of the Kirkville Regional Office for the Department, and Wohlers testified that the tests used by Dr. Whitman were not used by the Department to evaluate mental retardation in adults. There were multiple IQ tests and substantial evidence that suggest Weisenborn does not have mental retardation, including her accomplishments in education, employment, and community work.⁷

B. Developmental Disability

This does not end our inquiry. Because to qualify for Medicaid Waiver services, Weisenborn must either fall within the regulations as mentally retarded *or* developmentally disabled, the analysis now turns to whether Weisenborn has a "developmental disability" within the meaning of the appropriate regulations. *See* 9

⁷For current purposes it is unnecessary to address the Department's argument that the IQ tests conducted after Weisenborn reached the age of twenty-two are not relevant. We will only point out the peculiarity of this argument in that the relevant statute only says that the mental retardation must *originate* before a certain age irrespective of when it was diagnosed. The parties agree that she was diagnosed with PWS at one year of age.

C.S.R. section 45-2.015(1)(C). Missouri defines a "developmental disability" as a disability:

(a) Which is attributable to:

a. Mental retardation, cerebral palsy, epilepsy, head injury or autism, or a learning disability related to a brain dysfunction; or

b. Any other mental or physical impairment or combination of mental or physical impairments; and

(b) Is manifested before the person attains age twenty-two; and

(c) Is likely to continue indefinitely; and

(d) Results in substantial functional limitations in two or more of the following areas of major life activities:

a. Self-care;

b. Receptive and expressive language development and use;

c. Learning;

d. Self-direction;

e. Capacity for independent living or economic self-sufficiency;

f. Mobility; and

(e) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, habilitation or other services which may be of lifelong or extended duration and are individually planned and coordinated;

Section 630.005(9).

Of import to the case at bar is that instead of requiring only two substantial limitations in a major life activity as set forth in subsection (d) above, the federal regulations require *three substantial limitations* to qualify as having a "developmental disability" that qualifies as a "related condition" to "mental retardation." 42 C.F.R. section 435.1010. Therefore, in order to be eligible for the Medicaid Waiver services, a

person without mental retardation must meet the requirements of having a "developmental disability" pursuant to section 630.005 and must be substantially limited in three of the major life activities listed in subsection (d), as is required by the federal regulations.

The parties agree that Weisenborn has a developmental disability under Missouri law in that she satisfies the definition set forth in section 630.005 because they agree that she is substantially limited in two major life activities: "self direction" and "capacity for independent living or economic self-sufficiency." The issue in dispute is, based upon the evidence, does Weisenborn have substantial functional limitations in the area of "self-care," to satisfy the federal requirements of substantial limitations in three major life activities to qualify for Medicaid Waiver services.

The regulations provide that a comprehensive evaluation is to be conducted to determine whether the applicant is eligible for services from the Department. 9 C.S.R. section 45-2.010(3). The comprehensive evaluation for adults includes, but is not limited to:

an interdisciplinary assessment team's:

- A. Review of the results of the MOCABI;
- B. Review of available vocational, medical and educational information;
- C. Review of additional individualized assessment and interview results to provide evidence of mental or physical impairments likely to continue indefinitely, evidence of substantial functional limitations caused by mental or physical impairments and evidence of a need for sequential and coordinated special services which may be of lifelong or extended duration; and

D. Formulation of conclusions and recommendations;

9 C.S.R. section 45-2.010(2)(D)3. The MOCABI provides for the recording of information for each statement regarding the ability of the applicant to do certain things from three sources: (1) observation by the intake worker; (2) self-report by the applicant; and (3) verbal reports by members of the applicant's family or other reliable individuals. The MOCABI direction manual states that "[d]irect observation by the intake worker is the preferred source of information."

"Self-care" is defined as "[d]aily activities which enable a person to meet basic needs for food, hygiene and appearance; demonstrated ongoing ability to appropriately perform basic activities of daily living with little or no assistance or supervision." 9 C.S.R. section 45-2.010(2)(O)1. The Department argues that the major life activity category of "self-care" only pertains to whether an applicant is *able* to do an activity and not whether the applicant has the capability of properly *choosing* to do an activity. It is the Department's position that "[w]hether Weisenborn chooses to make the decision to follow through on her abilities and knowledge is her choice - and her ability to make appropriate choices is addressed under self-direction and capacity for independent living or economic self-sufficiency, areas in which there is no dispute that Weisenborn is substantially impaired." An evaluation of these alternative categories and the facts of this case refute the Department's conclusion that Weisenborn is not limited in the area of "self-care."

Contrary to the Department's position, "self-care" does in fact contemplate not only knowledge and physical ability to perform various tasks of "self-care" but also the

ability of the applicant to appropriately choose to perform such tasks. Under the "self-care" category, the various ability statements contained within the regulations do not differentiate between the physical ability to do an activity and whether the applicant has the ability to appropriately choose to perform the activity. The instructions for the self-care category require that "[t]he applicant must demonstrate the *ongoing* ability to *appropriately* perform basic activities of daily living with little or no assistance or *supervision*." (Emphasis added.) "Self-care," by definition and as applied in the MOCABI, contemplates not only mental knowledge and physical ability to complete various tasks but also the mental capacity to be able to appropriately choose to perform such tasks.

The Department argues that appropriately choosing to do the activities listed under "self-care" falls under the "self-direction" category. "Self-direction" is defined as "[m]anagement and control over one's social and personal life; ability to make decisions and perform activities affecting and protecting personal interests; demonstrated ongoing ability to take charge of life activities as age-appropriate through an appropriate level of self-responsibility and assertiveness." 9 C.S.R. section 45-2.010(2)(O)5. Ability statements under the "self-direction" category include things such as making and implementing: "essentially independent daily personal decisions regarding a schedule of activities"; "independent major life decisions"; and "independent daily personal decisions regarding diet." Also, that the applicant possesses adequate social skills and can manage personal finances. The "tasks" listed under each category are different, and it is clear that

the "self-direction" category does not contemplate one's ability to appropriately choose to perform the basic tasks of "self-care."

The Department alternatively argues that the ability to appropriately make choices to perform the activities listed under "self-care" comes under the "capacity for independent living or economic self-sufficiency" category. "Capacity for independent living or economic self-sufficiency" is defined as:

[a]ge-appropriate ability to live without extraordinary assistance from other persons or devices, especially to maintain normal societal roles; ability to maintain adequate employment and financial support; ability to earn a living wage, net (determined by the interdisciplinary assessment team for each individual), after payment of extraordinary expenses caused by the disability; demonstrated ability to function on an ongoing basis as an adult independent of extraordinary emotional, physical, medical or financial support systems.

9 C.S.R. section 42-2.010(2)(O)6. Sample activity statements under this category include: that the applicant can carry out regular duties and chores, is aware of community activities, can be left alone for twenty-four hours without being at risk, and is able to demonstrate competence as an employee. This category clearly does not contemplate having the ability to appropriately choose to perform basic tasks of "self-care."

In his original decision, the Referee concluded that substantial evidence had been presented at the hearing that Weisenborn was limited in the category of "self-care." In the Findings of Fact, the Referee found that:

Appellant has a Substantial Functional Limitation in the category of self-care. She is able to use eating utensils, but she does not have self-control over her drive to eat. As a result, she must have a lock on her refrigerator and her blood sugars must be regularly tested, as a screen to determine whether she has been sneaking food. She is able to put on different clothes when instructed, but is not able to dress herself in a manner that will protect

her health and hygiene. If she does not receive support, she does not put on her socks and her bra in a way that will avoid rubbing, rashes, and infections, all of which exacerbate her Diabetes and Cellulitis and can be life-threatening if left untreated. If she does not receive support, she will not regularly change her socks and underwear, which also can lead to hygiene problems. Applicant is able to get into and out of the shower, but is not physically able to reach around to wash or dry her back, and she is not mentally able to ensure that she adequately cleans and dries all parts of her body, including under the folds of her skin. If her body is not dried properly, she gets yeast infections and exacerbates her Cellulitis. Appellant is not able to trim her fingernails and toenails, due to the danger of injuring the surrounding skin, which causes complications to her Diabetes and Cellulitis.

In his Amended Decision, the Referee found Weisenborn ineligible for Medicaid Waiver Services in part because he found persuasive the argument that the previous MOCABI tests conducted on Weisenborn were problematic and that there was a "misunderstanding on how to administer the test. The mistake was discovered after the March 28, 2008 MOCABI, and steps were taken to correct it." Specifically, in the Findings of Fact of the Amended Decision, the Referee found that there had been an error in the scoring of the MOCABI in the area of "self-care," because the worker considered "limitations in the Major Life Activity area of Self-Direction as also being a substantial functional limitation in the area of Self-Care." Comparing the original decision and the amended decision, it is clear that the Referee did not change his original findings of fact as to Weisenborn's limitations but changed his decision based on an erroneous application of the law.⁸ As previously discussed, the area of "self-care" includes both the

⁸A review of the evidence submitted by the parties to the Referee between the original decision and the amended decision shows no factual support for the Referee to abandon or modify his original factual findings regarding Weisenborn's functional limitations.

physical ability and knowledge needed to perform basic life activities and the mental ability to appropriately choose to perform the activities.

Weisenborn's family, her in-home aide, and the MOCABI all provided evidence that while Weisenborn physically may be able to perform some of the tasks identified in the area of "self-care," her illness prevents her from making appropriate choices with respect to such tasks. The testimony provided on behalf of the Department does not refute that Weisenborn has such problems, only that these problems should be classified under "self-direction" rather than "self care." The Department in its brief conceded that "there is no dispute that Weisenborn is substantially impaired" in her ability to make appropriate choices. Accordingly, the Department misapplied the law when it found that Weisenborn was not limited in the area of "self-care." Based on the evidence, Weisenborn has developmental disability and is limited in three major life activities and meets this requirement for eligibility for Medicaid Waiver services.

C. Condition Related to Mental Retardation

Weisenborn qualifies as a person with a related condition to Mental Retardation under the regulations. 42 C.F.R. section 435.1010 defines "persons with related conditions" as "individuals who have a severe, chronic disability that . . . is attributable to [c]erebral palsy or epilepsy; or [a]ny other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons." The condition must manifest itself before the person reaches age 22, be likely to continue

indefinitely, and must result in a substantial functional limitation in three or more areas of major life activity. *Id.* As previously discussed, Weisenborn is substantially limited in three areas of major life activities, so the only remaining question under 42 C.F.R. section 435.1010(a) to analyze is whether the PWS is closely related to mental retardation.

The sole evidence relied on by the Department to deny that Weisenborn's condition is not closely related to mental retardation was the testimony of Wohlers. Wohlers is not an expert in psychology or PWS but rather is the assistant director of habilitation. Her responsibilities include supervising case management, which involves determining eligibility for services. Wohlers has a Bachelors of Arts Degree in Psychology and a Masters Degree in English. Wohlers testified that the services received by Weisenborn assist her in controlling her drive to eat, caused by PWS, and they assist Weisenborn in matters concerning personal hygiene. Wohlers in her testimony stated that she did not believe the effects of PWS (namely hyperphagia) and services related to PWS were traditional with people with mental retardation. To support her position, Wohlers utilized a letter written on behalf of Weisenborn by Dr. Whitman in support of Weisenborn's application for Medicaid. In that letter, Dr. Whitman describes the effects of PWS, including hyperphagia, and continues on to say that:

[t]he impact of this biological driven-ness to eat combined with a lack of medications to manage this drive impacts the affected persons [sic] ability to work in any but the most protected environments, and limits their ability to live independently as there must be a full time "guardian" to protect the person from quite literally "eating themselves to death."

In another letter, Dr. Whitman stated that "[Weisenborn's] cognitive limitations combined with the brain driven hunger leaves [her] severely handicapped. She cannot be left alone

due to the "hyperphagia" or "drive to seek food and eat" and that "even those few individuals who test in a cognitively normal range, function in the range of mild mental retardation." The evidence relied on by Wohlers to support her conclusion refutes her own position. The authority relied on by Wohlers indeed suggests that the services required by a person with PWS are similar to that of a person with mental retardation because they function in the range of mild retardation. Wohlers is not a medical expert and has no expertise in PWS, whereas Dr. Whitman does.

Further, hyperphagia was only one of many symptoms of PWS for which Weisenborn needs care. As found by the Referee, Weisenborn also requires assistance dressing herself to protect her health - assistance in putting on clothing to avoid rubbing, rashes, and infections that exacerbate her Diabetes and Cellulitis, which are both life-threatening if left untreated. Further, Weisenborn needs help in matters of personal hygiene. Wohlers testified to none of this when she determined that she did not believe that the services required by Weisenborn were "traditional" of persons with mental retardation. The Department's decision that Weisenborn was not a person with a "related condition" was contrary to the overwhelming weight of the evidence and, therefore, not supported by substantial and competent evidence. *Hampton v. Big Boy Steel Erection*, 121 S.W.3d 220, 222-23 (Mo. banc 2003).

D. ICF/MR Eligibility

The Department also concluded in its Amended Decision that Weisenborn was ineligible for Medicaid Waiver services because "an individual must be determined to require an ICF/MR level of care if not provided the services under the Medicaid Waiver."

It concluded that "[u]pon subsequent review of the evidence for this Amended Decision, it is clear that Appellant has *never been placed* in an ICF/MR, but rather that she had been placed in an Individualized Supported Living (ISL) arrangement in the community, which does not fulfill the criteria to be found eligible for the Medicaid Waiver." (Emphasis added.) While citing the correct standard, the Department relies solely on the fact that Weisenborn has never been placed in an ICF/MR facility to justify its decision to deny benefits, which is not a requirement under the standard.

The applicable regulations require that the applicant for Medicaid Waiver services have mental retardation or a related condition (42 C.F.R. section 435.1010), have a need for the level of care provided in an ICF/MR (42 C.F.R. section 440.150), and a determination that but for the waiver, the applicant would be institutionalized in such an institution (42 C.F.R. section 441.302). The Medicaid Waiver program, acting as an alternative to institutionalization, does not require prior institutionalization before one is qualified to receive benefits, as conceded by the Department. The Department argues, however, that the Referee in his Amended Decision was merely correcting his original decision, which had found that "[i]f Appellant's Comprehensive Medicaid Waiver-funded services are discontinued [. . .] [it] would require her to *again* be institutionalized at an ICF/MR level of care." (Emphasis added.) Weisenborn had in fact never been institutionalized in an ICF/MR level of care facility but was previously placed in an ISL arrangement. In the Amended Decision, the Referee again concluded that Weisenborn "does not require an ICF/MR level of care."

The problem with this conclusion is that the sole enumerated basis for finding that Weisenborn does not require an ICF/MR level of care was that she had never previously been placed in such an institution. The Amended Decision is bereft of any factual findings that Weisenborn's needs do not in fact rise to such a level. This appears to be due to the fact that no evidence was offered by either party on what the ICF/MR level of care consists of, what services Weisenborn will lose if she is denied Medicaid Waiver services, and what services she will still qualify for subsequent to such a denial. An ICF/MR facility:

- (a) Is primarily for the diagnosis, treatment, or rehabilitation of the mentally retarded or persons with related conditions; and

- (b) Provides, in a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services to help each individual function at his greatest ability.

42 C.F.R. section 435.1010.

However, the evidence is unclear as to whether Weisenborn needs the level of care services provided by an ICF/MR as enumerated in subsection (b). From the evidence it does appear that she needs a protective residential setting that has "ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services." 42 C.F.R. section 435.1010. There is substantial evidence in the record that Weisenborn's PWS requires that she be monitored at all times due to her hyperphagia. Further, the record shows that Weisenborn needs a variety of services with respect to "self-care," which, if not provided, would be severely detrimental to her health and well-being and could result in death. There was substantial evidence that without the services

provided by the Department that Weisenborn does indeed need an inpatient level of care. The Department argues that other services received by Weisenborn from the State of Missouri should be considered when determining whether Weisenborn would be placed in ICF/MR facility without the Medicaid Waiver Services. However, the State did not offer any evidence as to what services Weisenborn would in fact still receive due to her classification as "developmentally disabled" under Missouri law, even if she were denied Medicaid Waiver services.

The burden of producing such evidence at the underlying hearing is set forth in 9 C.S.R. section 45-2.020(3)(C)5, which establishes the appeal procedures within the Department. This section provides that "[t]he head of the facility shall have the burden of proof and the burden of going forward to either establish that either the applicant does not meet the state's statutory criteria for services eligibility or that the client has so improved that s/he no longer would benefit from the level of services which had been previously provided." 9 C.S.R. section 45-2.020(3)(C)5. While inartfully worded, it is clear that the burden was on the Department to produce evidence of whether Weisenborn would require an ICF/MR level of care if she were denied Medicaid Waiver services. Because the Department failed to produce any evidence on this issue at the underlying hearing it has failed to meet its burden.

Conclusion

As was previously addressed, in actions of this nature, we review the agency's decision and not that of the trial court; however, the appellate court acts upon the trial court's judgment. *Bird v. Mo. Bd. of Architects, Prof'l Eng'rs, Prof'l Land Surveyors &*

Landscape Architects, 259 S.W.3d 516, 520 n.7 (Mo. banc 2008) (Citing to Rule 84.14).

Therefore, the judgment of the trial court, which reinstated Weisenborn's Medicaid Waiver benefits is hereby affirmed. Weisenborn made a timely request for fees and costs pursuant to Section 536.087 in the trial court.⁹ The trial court did not address that request due to the appeal filed by the Department. We remand this matter to the circuit court and the circuit court shall award, in the manner provided in section 536.087, what it finds to be Weisenborn's reasonable fees and expenses incurred at the agency, trial and appellate level in this litigation, and enter judgment for the amount thereof, unless the circuit court finds that the position of the state was substantially justified or that special circumstances make such an award unjust.

Gary D. Witt, Judge

All concur

⁹Section 536.087 dictates that a prevailing party in an agency proceeding shall be awarded reasonable attorney's fees and reimbursement for reasonable expenses incurred in the proceeding and also on judicial review.