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Article

STUDENTS WITH PRADER-WILLI SYNDROME: CASE LAW UNDER THE IDEA

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Abstract: Prader-Willi Syndrome (PWS) is one of the low-incidence physical disabilities that the literature has not addressed in relation to the Individuals with Disabilities Education Act and its case law applications. To help fill the gap, this relatively brief article provides (a) an introduction of PWS from legal sources; (b) an overview of the IDEA, including its primary components and alternate decisional avenues; (c) a synthesis of the case law to date, which amounts to a limited variety of administrative and judicial decisions; and (d) a brief set of conclusions from an impartial legal perspective.

Keywords: *case law; Prader-Willi syndrome*

Introduction

Prader-Willi Syndrome (PWS) is one of the low-incidence physical disabilities that the literature has not addressed in relation to the Individuals with Disabilities Education Act (IDEA, 2015) and its case law applications. To help fill the gap, this relatively brief article provides (a) an introduction of PWS from legal sources; (b) an overview of the IDEA, including its primary components and alternate decisional avenues; (c) a synthesis of the case law to date; and (d) a set of brief conclusions.

PWS

Although subject to individual variations and medical nuances, here is a snapshot of the lifelong genetic disorder of PWS viewed through the lens of a recent court decision (*Zachary G. v. School District No. 1*, 2017):

Typical manifestations of PWS early in life include weak muscle tone, feeding difficulties, and delayed development. Later in childhood, persons with PWS typically develop hyperphagia—persistent extreme hunger and an inability to feel satisfied. They often experience extreme stress and anxiety related to their constant feeling of hunger and obsession with food, to the point that they are unable to focus on anything else. Even seeing or smelling food can cause extreme anxiety and perseveration about how to access the food, even if the event occurred in the past. If an individual with PWS is permitted uncontrolled access to food, there is a risk of overeating to the point of gastric rupture and possible death. (p. *2)

Further complicating the IDEA issues, in some of the cases, the students with PWS also have other related or separate impairing conditions. For example, Zachary, the student in the abovementioned case, also had diagnoses of mood disorder, general anxiety disorder, autism spectrum disorder, and nonverbal learning disability.

The IDEA

As recited in more detail elsewhere (e.g., Yell, 2016), the IDEA, in contrast with pure civil rights laws, such as Section 504 of the Rehabilitation Act of 1973 and its sister statute, the Americans with Disabilities Act of 1990, the IDEA started as a funding act, with the focus being the availability of special education programs. Originally enacted as the Education of Handicapped Children's Act of 1975, the legislation has undergone successive amendments, including the 1986 addition of attorneys' fees for prevailing parents. The most recent IDEA amendments were in 2004, with the applicable regulations issued in 2006.

Decisional Avenues

For individual cases that are not resolved via the partnership-like IDEA process between parents and school districts, including the option for mediation, the two alternative avenues for deciding disputes under the IDEA are (a) adjudicative, and (b) investigative. As detailed elsewhere (e.g., Zirkel, 2016), the IDEA's adjudicative process starts with an administrative proceeding called a

due process hearing, with subsequent right of appeal to the courts. The investigative avenue is an administrative proceeding called the complaint procedures process, which each state education agency must provide under the IDEA and which in most states does not provide the right of appeal to the courts. Although parents prevail more often in complaint procedures cases than in due process hearings, the adjudicative avenue starting is much wider in terms of traffic and attention, in large part due to the precedential effect of court decisions (Zirkel, 2017a).

Basic Components

The successive basic building blocks of the IDEA are (a) eligibility; (b) free appropriate public education (FAPE), (c) least restrictive environment (LRE), and (d) remedies (Zirkel, 2015). In general, FAPE—as documented in the eligible child’s individualized education program (IEP)—is the centerpiece, or hub, among these various legal obligations of school districts. For students with PWS, it is of particularly central significance because their eligibility under the IDEA is typically not at issue.

FAPE, as evolved in the case law has three successive, established dimensions. First, as clearly recognized in the Supreme Court’s landmark decision in *Board of Education v. Rowley* (1982), the IDEA is replete with procedures such that procedural compliance is an initial dimension of FAPE. The *Rowley* Court also identified a second, substantive dimension of FAPE, with the standard being whether the IEP is “reasonably calculated to enable the child to receive educational benefits?” (p. 207).

More recently, Congress and the Supreme Court have respectively refined the procedural and substantive standards for FAPE as applied in the adjudicative avenue. First, the IDEA amendments of 2004 provided a second step for the procedural dimension, specifying that hearing officers and courts may not find a denial of FAPE unless the procedural violation(s), if any, results in a loss to the student in terms of the requisite benefit or a loss to the parents in terms of the opportunity for meaningful participation in the IEP process. Second, the Supreme Court, in its recent decision in *Andrew F. v. Douglas County School District RE-1* (2017), refined the substantive standard to require the IEP to be “reasonably calculated to enable [the] child to make progress appropriate in light of the child’s circumstances” (p. 999).

Finally, the lower courts in various jurisdictions have recognized a third dimension of FAPE based on failure to implement the IEP, referred to herein as “FTI.” Neither this acronym nor the applicable standard has yet evolved to a uniform level, but it is clearly the subject of both the adjudicative and investigative decisional processes under the IDEA (Zirkel, 2017b).

Overlapping with the hub of FAPE, LRE depends on a multi-factored “test,” or standard, and the primary remedies are tuition reimbursement and compensatory education. Miscellaneous other issues include whether the district is obligated to provide an independent educational evaluation at public expense.

Case Law

In light of aforementioned characteristics of PWS and the IDEA, the case law is quite limited under the IDEA, with the majority of the decisions being at the due process hearing, or impartial hearing officer, level of the adjudicative avenue and addressing one or more dimensions of FAPE. The following synthesis organizes the cases chronologically within three successive categories—(a) preliminary, technical issues; (b) FAPE and overlapping issues; and (c) miscellaneous other issues. The case law is limited to the impartial hearing officer, complaint procedures, and court decisions available in the national database, Special Ed Connection®, with supplementation of court decisions in Westlaw. For cases with more than one ruling, the focus is on those of generalizable significance.

Preliminary, Technical Issues

In some cases, the basis of the decision is a prerequisite of the adjudicative or investigative process, such as timely filing, which is referred to as the statute of limitations. For example, in *Aileen v. Department of Education, State of Hawaii* (2011) a federal court vacated an impartial hearing officer's dismissal of a FAPE complaint of the parents of a student with PWS. The impartial hearing officer had ruled that the parents' complaint was not within the IDEA's two-year statute of limitations for due process hearings, but the court concluded that the impartial hearing officer had erroneously interpreted the applicable starting and ending dates for this two-year period. The court sent the case back to the impartial hearing officer for further proceedings, but any subsequent decision for this case is not available in the only national database for IDEA administrative decisions; one likely possibility is a settlement.

FAPE

Most of the PWS cases to date have focused on FAPE. In the first decision (*Anaheim Union High School District*, 2000), the parents of an eighth grader with PWS asserted both procedural and substantive FAPE claims at a due process hearing in California. For the procedural claim, the impartial hearing officer ruled that the failure to specify the related services in the written placement offer amounted, in effect, to harmless error under the applicable two-part test. More specifically, the failure was a procedural violation but, because the parents understood that the related services would be basically the same as in the previous IEP and because they disputed their location, not amount, the violation did not result in the requisite loss to them or the student. On the substantive side, the impartial hearing officer ruled that the proposed placement met the *Rowley* standard of being reasonably calculated to yield benefit. Finally, the impartial hearing officer rejected the parents' prospective claim that the student needed a private school placement, finding that the proposed public school self-contained placement with substantial supports adequately addressed the student's behavioral needs.

In *New Hope-Solebury School District* (2003), the parents of a kindergarten child with PWS, who were dissatisfied with the district's proposed half-day program, unilaterally placed the child in a private full-day program and sought tuition reimbursement. The impartial hearing officer concluded that the district's proposed program, which included physical, occupational, and speech therapy, met the requisite substantive standard for FAPE. The parents appealed to a

review panel, which Pennsylvania had at the time for IDEA cases. The panel affirmed the impartial hearing officer's decision, concluding that the courts have established that the IDEA only requires a reasonably-calculated, not an optimal, program. Thus, despite the acknowledged continuing and extensive efforts of the parents on behalf of their child, they were not entitled to tuition reimbursement.

In *Kern High School District* (2004), the parents of a ninth grader with PWS, who only had mainstreaming for physical education and choir, claimed denial of FAPE for all three of the aforementioned dimensions and also for LRE. For the procedural claim, the parents pointed to the district's failure to have all of the student's special education teachers and the school nurse at the IEP meeting, but the California impartial hearing officer concluded that the parents had not met the first part of the applicable two-part standard. Specifically, the impartial hearing officer found that neither the IDEA nor California law required more than one special education teacher or the school nurse to be members of the IEP team. Thus, there was no procedural violation, and the impartial hearing officer did not have to address the second step, which was whether the violation(s) resulted in the requisite loss to the student or parents. For the substantive claim, the impartial hearing officer ruled that the proposed IEP did not meet the applicable *Rowley* reasonably-calculated standard with regard to the student's individual needs for functional academics, adaptive physical education, and behavior interventions. For the parents' FTI claim, the impartial hearing officer ruled that the district had not implemented the IEP's provision for a behavior intervention plan. Finally, for the LRE claim, the impartial hearing officer ruled that the district violated the applicable multi-factor test, particularly in its failure to provide careful consideration as to whether the student could be mainstreamed beyond the proposed minimal extent with adequate supports and services for his behavioral needs. As the remedies for the substantive FAPE and LRE violations, the impartial hearing officer ordered a limited amount of compensatory education and a new IEP in conformity with the decision's various rulings.

In *Student with a Disability* (2009), the parents of a five-year-old with PWS utilized the complaint procedures process in Indiana, alleging three violations of the state's regulations with regard to procedural requirements for the IEP. The complaint procedures investigator concluded that the IEP team (a) included the required participants, (b) considered the parents' concerns with the team's evaluation, and (c) although it failed to address the student's need for a school bus monitor, this failure was not a violation because the parents withdrew the student and enrolled her in a different district before the IEP team meeting.

In *Broward County School Board* (2010), the parents of a ninth grader with PWS claimed that the last two IEPs were not substantively appropriate, but the Florida impartial hearing officer ruled that they had not met their burden with regard to either IEP. The district's requirement for PWS training for all staff members who might come into contact with the student and its continuous fine-tuning of the behavior intervention and crisis management plans were notable factors in the impartial hearing officer's *Rowley* calculus. However, the impartial hearing officer ruled in the parents' favor for its related FTI claim, concluding that the district failed to sufficiently implement the training requirement, particularly in not assuring the attendance of the substitute behavior specialist and the principal, who were key participants for a separate issue in the case (reported below in the Miscellaneous Other section).

In one of the few cases at the court level, *K.C. v. Nazareth Area School District* (2011), the parents of a 20-year-old student with PWS and other medical complications asserted overlapping substantive FAPE and FTI claims. For the substantive FAPE claim, which was focused on transition services, a federal district court in Pennsylvania concluded that the IEP's provision for transition services, including the related service of travel training, met the requisite IDEA reasonableness, as contrasted with optimality, standard. As an additional, contributing factor, the court upheld the impartial hearing officer's finding that the parents had impeded the district's efforts to further individualize the IEP. For the FTI claim, the court similarly upheld the impartial hearing officer, concluding that the district had sufficiently implemented the IEP's provisions for physical therapy, sensory occupational therapy, and executive functioning therapy. The court avoided determining whether the impartial hearing officer erred by faulting the parents, reasoning that the limited delays, even if attributable to the district, were procedural violations that did not result in the requisite loss to the student or the parents.

Next, in *Green Local School District* (2013), the parents of a 16-year-old with PWS and other medical complications filed a due process hearing in Ohio seeking tuition reimbursement for Latham Center, a residential placement in Massachusetts specializing in PWS. The parents claimed denial of FAPE on both procedural and substantive grounds. For the procedural dimension, the impartial hearing officer's rulings were mixed: (a) the parents failed to meet their burden to prove their allegation that the district members of the IEP team had decided the child's placement prior to the first three of the disputed IEPs, but (b) the parents preponderantly proved that the other team members had engaged in such predetermination for the fourth IEP. Specifically, the district IEP team members had made up their mind against residential placement before the meeting by (a) failing to consider the recommendations for a residential placement from the child's therapeutic, crisis treatment at Children's Institute in Pennsylvania, and (b) refusing to discuss the parentally-provided information about the recommended Massachusetts school at the meeting. For the second step for procedural denial of FAPE, the impartial hearing officer concluded that this predetermination violation resulted in substantial harm to the student. For the substantive side, the impartial hearing officer concluded that the district's four IEPs did not meet the *Rowley* reasonably-calculated standard based on (a) the unwarranted use of restraint and seclusion and (b) the failure to address food security. Next, the impartial hearing officer concluded that the residential placement at Latham Center met the applicable standard for substantive appropriateness, thus warranting the requested tuition reimbursement for the fourth year. However, the impartial hearing officer refused to order reimbursement of the previous three years as compensatory education because the parents failed to show how this requested relief met the applicable standard for this separable remedy.

In *Stoneham Public School District* (2013), the filing party for the due process hearing was the school district, seeking a declaratory ruling that its private placement of a 12-year-old with PWS and autism was appropriate and also an order providing consent for her reevaluation. The parent had failed to attend IEP meetings for two years or otherwise respond to district requests for placement approval or reevaluation consent. The child was nonverbal, engaged in self-injurious behaviors, and presented delayed protective balance reactions. The impartial hearing officer concluded that the proposed placement met the substantive standard with one modification, the addition of a 1:1 aide. As a result, the impartial hearing officer ordered the specified IEP modification, granted substitute consent for the reevaluation, and, by way of recommendation,

urged the parent to work collaboratively with the district for the student's physical safety as well as educational opportunity.

In *South Western School District* (2016), the substantive issue was food security for a first grader with PWS. In response to the parents' requests for rather absolute revisions to the IEP, such as removal of all images or references to food in his instruction, and for compensatory education for the classroom removals for food-related behaviors, the Pennsylvania impartial hearing officer reached a mixed outcome based on what he found to be insufficient information specific to this child. First, he declined to award compensatory education because the parents had failed to prove the amount of time of the student's behavior-based removals from the classroom. Second, he ordered revisions to the IEP that were more tempered than the parents' requests. Third, and rather creatively, he ordered the district to collect data for four weeks to determine the correlation between food images and the student's behavior and to submit the data to a qualified specialist for preparation of a functional behavioral assessment for the IEP team's consideration.

In *Zachary G. v. School District No. 1* (2016), the only other decision at the judicial level, the parents of the aforementioned 17-year-old with PWS and multiple other diagnoses sought tuition reimbursement for their unilateral out-of-state placement of their son at the Latham Center. Although reciting the severe behavioral problems of the student, which resulted in emergency treatment first at a local therapeutic hospital and subsequently at the Children's Center in Pennsylvania, the federal district court in Colorado ruled that the district's proposed placement at its high school met the substantive standard for FAPE. This IEP included a wide array of specialized provisions including (a) extensive training about PWS and this individual student's complicated needs; (b) two specialized and supportive aides; (c) food security provisions for all his settings; (d) a detailed behavior intervention plan, (e) reverse mainstreaming for lunch; (e) a graduated transition to the high school; (f) continuous fine-tuning and parent reporting; and (g) transportation services with behaviorally trained personnel extending from the student's bedroom to the classroom. However, this decision warrants two caveats. First, the court based its ruling on the more-than-de-minimis version of the substantive standard for FAPE that the Supreme Court more recently rejected in *Andrew F.* (2017). Second, the decision was confusing, if not confused, by mixing its substantive FAPE ruling with a separable emerging fourth dimension of FAPE, which concerns capability to implement the IEP. More specifically, the court reasoned:

It may be that if Zachary had enrolled at East High School the District's plan would not have been effective, and that a residential placement would have been proven necessary. We cannot know because the District was denied the opportunity to show its efficacy. The evidence does not support Plaintiffs' assertion that the District was necessarily incapable of providing Zachary by implementing this IEP and its supporting implementation plans. (p. *13)

Miscellaneous Other

In *Anchorage School District* (2005), two issues arose from a disciplinary change in placement for an 11-year-old student with PWS who, in an agitated state upon his third day in a new class placement, rushed at the teacher with scissors extended. First, the Alaska impartial hearing officer ruled that the scissors, based on their non-normal use under the circumstances, constituted

a weapon under the IDEA provision that authorized removal to a 45-day interim alternate educational setting. Second, however, the impartial hearing officer ruled that the specific interim alternate educational setting in this case was not appropriate because its implementation required at least three transitions, whereas the evidence at the due process hearing was that for students with PWS, in general, and for this student, in particular, transition is difficult. As the remedy, the impartial hearing officer ordered that the district provide the child with 21.25 hours per week of specified services pending prompt IEP team development of a new interim alternate educational setting, including a behavior intervention component.

In the aforementioned *Broward County School Board* (2010) case, the school principal similarly placed a student with PWS in an interim alternate educational setting as a result of an incident with scissors, but the circumstances were notably different. The student, who had serious behavioral issues, went into a crisis meltdown in an empty classroom upon being removed from the lunchroom. When he found a pair of scissors in the classroom, a substitute behavioral specialist, who lacked training regarding PWS, asked for them without specifying the manner of conveyance. In response, the student, who was five feet away, threw the scissors to him, resulting in a slight bruise without any cutting. The Florida impartial hearing officer concluded that the scissors did not constitute a weapon under the IDEA discipline provision and, alternatively, even if the interim alternate educational setting had been warranted, it was not appropriate because its behavioral system would have exacerbated the student's medically-based behaviors.

Finally, in *Fairfield Board of Education* (2012), the parents of a 14-year-old with PWS were dissatisfied with the district's reevaluation and requested an independent educational evaluation at public expense. The Connecticut impartial hearing officer ruled that they were not entitled to an independent educational evaluation at public expense because the district reevaluation met the applicable IDEA regulatory standards for comprehensiveness. In response to the parents' two alleged deficiencies of the reevaluation, the impartial hearing officer concluded (a) contrary to the parents' preference of evaluation instruments, the district's selection was entitled to deference in relation to appropriate professional standards and judgment; and (b) an additional medical evaluation was not necessary because the PWS diagnosis had not changed and the district had adequate information on the child's resulting individual needs.

Conclusions

This synthesis suggests three levels of conclusions. First, at the macro level, the limited frequency of reported case law concerning students with PWS is not surprising in light of the relatively low incidence of this condition. Similarly, the outcomes generally align with the approximately 2:1 pattern in favor of districts for IDEA case law more generally, which is at least partly attributable to the skewing effect of settlements for the most parent-favorable cases. At this macro level, the predominance of FAPE rulings also fits with the distribution of IDEA case law more generally (e.g., Karanxha & Zirkel, 2014; Zirkel & Sidmore, 2014).

Second, at a more specialized level, the case law reflects key characteristics associated with PWS, including (a) food security, (b) challenging behaviors, and (c) response to transitions. These issues become significant for FAPE, especially but not exclusively for its substantive dimension.

The resulting IEP features that are often significant are extensive PWS training and effective behavior interventions.

Third, at ultimate IDEA-related level the significant variety among the students in these cases reveals the need for emphasis on individualization. The particular scope and severity of PWS, the addition of other interrelated or independent diagnoses, and the particular features of the home and school environments all contribute to the individualized nature of IDEA cases.

Finally, returning to the overall level, this synthesis serves as a generalized reminder of the IDEA's alternative decisional mechanisms of complaint procedures and due process hearing, the hierarchy and complexity of the adjudicative avenue, and the value of effective communications and early dispute resolution. These lessons of law warn against the over-legalization of the educational process.

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*Note: IHO = Impartial hearing officer

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