BEFORE THE IOWA DEPARTMENT OF EDUCATION	
(Cite as 29 D.o.E. App. Dec. 160)	

In re <b>main a child</b> :	)	
,	)	Dept. Ed. Docket No. SE-490 DIA Docket No. 19DOESE0009
Complainant,	)	
	)	
V.	) )	
COMMUNITY	)	
SCHOOL DISTRICT AND	)	
AREA EDUCATION AGENCY	)	DECISION
Respondents,	) )	

### SUMMARY OF PROCEEDINGS

On or about November 9, 2018, **Sector** filed a Due Process Complaint on behalf of her daughter, **Sector**, against the **Sector** Community School District and the Area Education Agency (Respondents) pursuant to the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400 et seq., as implemented by 441 Iowa Administrative Code chapter 41. Respondents Answered on December 17, 2018.

Following a December 4, 2018, scheduling conference, a hearing was scheduled to be held on January 17, 2019. However, in a December 18, 2019, email, the Complainant invoked her stay-put rights and a hearing was held on the motion on January 28, 2019. By order entered on February 15, 2019, the request was denied.

The parties and their representatives then participated in another scheduling conference on February 5, 2019. At that scheduling conference, a hearing was scheduled to be held on April 15 and 15, 2019, at the offices of the AEA in AE

Attorney Miriam Van Heukelem was present and represented the Community School District and AEA, while attorney David Roston was present representing the Complainant. Complainant was present along with who provided assitance. Respondents were present through and AEA.

The following people testified at the hearing: **Constant**, Dr. Michael Ciliberto, Dr. Shlomo Shinnar, **Constant**, and **Constan** 

for Respondents. Following a briefing schedule, this matter was considered to be fully submitted and the matter taken under advisement by the undersigned.

Due to the confidential nature of this decision, unless necessary, the parties and some other participants will not be referred to by their proper names. Instead, they will be referred to by their title or position, such as the "child," or the "Complainants," or the "the principal." This will aid in the redaction of this decision for later public disclosure.

## **EVIDENTIARY ISSUES**

Prior to the hearing, Complainant submitted proposed Exhibits A through AS. Respondents stipulated to the admission of Exhibits A through AR, and they were admitted into the record. Respondents submitted proposed Exhibits 1 through 31. Exhibits 7 through 17 and 21 through 31 were admitted into the record by stipulation. Exhibits 18 and 20 were subsequently admitted during the course of the hearing.

At the hearing, Complainants offered Exhibit AS, which consists of excerpts from the testimony of the approximation of a previous hearing on a due process complaint. Respondents objected to the admission of this exhibit on relevance and prejudice grounds. The undersigned reserved ruling at that time, but now overrules the objection and admits Exhibit AS.

In his Reply brief, counsel for Complainants attached nine scholarly articles and a table that appears to be a summary of the findings in each of those studies. These nine studies were referenced in Respondents' Exhibit 31, which was properly offered and admitted into evidence at the hearing. Complainant merely attached these articles and the table, which counsel himself apparently compiled, to the Reply brief and has never sought admission into the record or provided copies of them to opposing counsel prior to the filing of the Reply brief.

Respondents now object to the consideration of this new evidence. This objection has merit, and the articles and table will not be admitted or considered by the undersigned. Respondents have had no meaningful opportunity to review or respond to this evidence. Furthermore, Iowa regulations implementing the IDEA require evidence to be provided to the opposing party at least five business days prior to the hearing. 281 Iowa Administrative Code 41.512(1). This was not done here.

### **FINDINGS OF FACT**

is a second old child who lives in the second Community School District and at the time of hearing was enrolled at the second School, after having attended second the previous year. She suffers from a variety of serious medical issues, including Lennox-Gastaut Syndrome (an intractable form of epilepsy), asthma, impaired mobility, and developmental delays. She is also prone to having absence, cluster, and tonic-clonic (grand mal) seizures. The child has had an

individualized education plan (IEP) since she began attending the District. That plan remained unchanged from May of 2010 through the end of the 2017-2018 school year.

For most people, intervention is generally required when a seizure lasts a certain length. Originally, for the child that time was also five minutes, but due to a decision from her neurologist, medical intervention is only required then her seizures last ten minutes. For that purpose, she has been prescribed a "rescue medication" for years. That medication, known as Diastat, is a prepared form of Diazepam that is delivered rectally in a pre-measured syringe.

In 2013 the child had a vagus nerve stimulator (VNS) device implanted in her upper left chest which can be activated by swiping a magnet across the implant location. The purpose of the device is to prevent or lessen seizure activity. However, according to the child's mother, this device has lost its effectiveness and doctors have recommended that it not be bothered with, although the school continues to utilize it. It is still implanted and activated.

In school year 2014-2015, the child had RD (rectal diastat) administered three times at school by a teacher or paraprofessional; in 2015-2016 she had it administered three times; in 2016-2017 she had it administered three times; in 2017-2018 she had it administered once; and during her short time attending school in the 2018-2019 school year, she had it administered once. On those eleven occasions, the child returned to her class without incident after recovering from her seizure.

Since May of 2010, the child has had an Individual Health Plan (IHP) that, among other things, has provided for a protocol to deal with those epileptic seizures while in school. That IHP has incorporated an Emergency Protocol for Seizures that has provided for the following. At the first sign of a seizure, the health office is to be called, and health staff will be sent to her classroom. Her VNS magnet will then be used to activate her device. This can be repeated every minute for five minutes. However, if the seizure lasts more than five minutes, staff will rectally administer Diastat. If five minutes after Diastat was administered the seizures continue, 911 will be called.

In August of 2018, the child had a corpus calosotomy, in which her two brain hemispheres were surgically separated in an attempt to decrease or stop her seizures. Initially, this proved successful, by decreasing the number and intensity of her seizures. This seemed to work for approximately one year, but by about May of 2018, the seizures began increasing again. Since then, the number and duration of the seizures has increased.

is currently the District's Health Services Facilitator and she was a school nurse for 15 years prior to that. At some point, she learned that the District's various school nurses across the District did not have a consistent response to treating children

who had been administered Diastat. Some nurses required these children to go home after the administration of Diastat, while others did not.

was quite surprised to learn that some children were not being sent home after receiving Diastat. She felt that there should be a consistent District-wide practice so she called an all-nurses meeting to address the differential responses. At that meeting

and the nurses discussed the fact that in some similar circumstances, for example when an Epipen is administered, children are always sent home. Also presented to the nurses certain medical literature, that will discussed later in this decision, which she believed supported the necessity and prudence of sending home students who had received Diastat. After receiving this information, the nurses agreed that as a matter of policy, children would need to leave school after Diastat. Whether this can be termed a policy or a protocol, after this meeting, nurses at all schools were in agreement to send these children home.

In coming to this decision, discussed the matter with other district health facilitators at the Urban Action Network, a group of the top ten most populous school districts in the state. There, she learned that the consistent practice in other districts was to send children home after Diastat has been given. Other nurses were surprised to learn this was not consistently happening in the **districts** District.

According to the decision to require children to leave school Diastat was based on two primary pieces of literature.<sup>1</sup> The first is an article entitled, <u>Evidence-Based</u> <u>Guideline: Treatment of Convulsive Status Epilepticus in Children and Adults: Report of</u> <u>the Guideline Committee of the American Epilepsy Society</u>, In that piece, the authors cite to the following study results:

Respiratory Depression after rectal administration of diazepam in children was reported in five class III trials, ranging from 1.2 percent to 6.4 percent, while two class III trials and two class I trials I acute repetitive seizures reported no incidence of respiratory depression with rectal diazepam in children.

The second was an article from the Epilepsy Foundation indicating that status epilepticus (a tonic-clonic seizure of five minutes or more) requires "emergency treatment by trained medical personnel in a hospital setting." This article also states that "medical treatment needs to be started as soon as possible [and that] oxygen and

<sup>&</sup>lt;sup>1</sup> At the hearing, also claimed the requirement to send students who have been given Diastat was based on the packaging insert for the drug. The instructions on page 14 of Exhibit J in fact advise the caregiver to "stay with the person for 4 hours and made notes on the following: changes in breathing rate, changes in color, . . . [and] possible side effects from treatment." However, this rationale was not provided during discovery.

other support for breathing, intravenous fluids . . . and emergency medication are needed."

was also guided by the maxim that schools are held to a higher standard of care than are parents at home. Also, she believes that a school is not equipped to provide mechanical ventilation. To her, even a 1-to-a para would not be sufficient because respiratory depression is not predictable. She characterized it as a "best practice" to call 911 each time Diastat is administered due to the need for trained medical professionals to monitor these persons. She believes this is an appropriate exercise of the nursing judgment rule.

According to **Mathematical**, the District would have considered alternatives to sending the child home after Diastat if the child's need for Diastat was proven to have increased. However, because the child never returned to school after her removal at the beginning of the 2018-2019 school year, they were unable to determine if this was the case. **Mathematical** never told the child's mother that she could not return to school. In fact, she would have welcomed and she encouraged the child's return to school.

In August of 2018, the child's Emergency Seizure Protocol was amended to require that after Diastat is administered, the parent is to be notified and she must be taken home. If they are unable to reach a parent, 911 must be called and EMS will take over the child's care.

The child has had an IEP since she began attending school in the District. Her most recent IEP is dated April 10, 2018. This document refers to her IHP three times. First, with regard to health needs, it states that it will be "addressed in the Health Plan as a part of the student's health records." Then, following a discussion of the protocol for responding to her seizures, the IEP provides "please refer to the IHP/Emergency Protocol." Finally, in the portion listing her health services, the IEP simply says "see IHP for details."

The IEP that was in effect prior to this change was dated April 10, 2018, which was a result of an IEP meeting on January 4, 2018. That IEP, as noted above, incorporates the child's IHP. The IHP in effect at that time did not require her to be sent home after the administration of IHP. But, in August of 2018 after the new direction from and the nurses, the IHP was amended to include the provision that the child's parent would be notified after Diastat is administered and the parent would take her home when it is safe for her to do so.

Prior to the 2018-2019 school, she had attended to the 2019-2019 year she was to be moved to the 2019 and the new school nurse, the child's first year at the new health plan, she attempted to speak to the mother about the child prior

to the start of school, but was unable to reach her by phone or to leave a message. But, she was then able to speak to the mother at an open house the day before the start of school. During that interaction, they discussed responses to the child's seizures, including Diastat. also notified the mother about the policy change to require students who have received Diastat to be sent home. The mother expressed dissatisfaction with this and indicated that she would not be picking the child up in such a scenario.

Following this conversation, undertook to write the emergency protocol for the child To aid her in doing so, the she contacted the nurse for the child's physician, Dr. Ciliberto. However, she received no response from Dr. Ciliberto until sometime in October.

Mother first saw this new policy when a copy of the child's IHP was sent home in her backpack after school started. Specifically, the IHP stated:

Once Diastat is given, mother will be notified and

- A parent will come and will take the child home when it is safe for her to do so.
- If unable to contact mother, then contact father.
- If unable to contact parents and 911 has been called, EMS will take over care of the child

These procedures were also embodied in an Emergency Protocol for Seizures for the child. When the mother saw this language she was quite concerned and upset and disagreed with many of the changes from the previous IHP. She proceeded to cross out much of the language in the Emergency Protocol and added her handwritten notes and suggestions in many other parts. She gave this document to the school nurse. With regard to the provision that "once she is back to baseline, mother will take her home," the mother wrote "Also it needs to be clear here that you want to ad this after 8 years of not being required." The Protocol also stated that "[the child] must be observed closely for the next 4 hours after receiving Diastat." The mother noted that "this is not protocol, it has nothing to do with her safety." She then refused to sign the document. The mother also talked to the child's teacher, the mother also talked to the child's teacher, the mother also talked to the child's teacher, the mother safet seeing the new language.

On the third day of the school year, August 28, 2018 the child had a seizure at school that lasted long enough to require the administration of Diastat. Pursuant to this new policy, the mother was called and the child was sent home. In response, the mother has kept the child home and out of school ever since this time. She claimed to have not wanted to return the child to school out of a concern that a school nurse would disregard the guidance of her daughter's physician. She feared the nurse might disregard any

other sort of doctor's order and make her daughter unsafe. The mother also claims that the child's seizure activities have increased since her removal and by around August, the child was receiving Diastat a couple times per week.

After receiving this written feedback and hearing the mother's concerns, an IEP team meeting was scheduled for September 10, 2018. The school nurse, the school principal, and the child's special education teacher all attended this meeting, along with the mother. At this meeting, the mother generally explained the child's increasing seizure activity. Encouraged the mother to return the child to school. Nobody at this meeting told the mother that she would have to sign the health plan in order for the child to come to school. Encouraged to re-evaluate the situation and discuss alternative arrangements were it to turn out that the child's need for Diastat at school would increase. This offer was also made by other District personnel as well.

The participants at this meeting were unable to reach any sort of agreement for a different path and the child remained out of school at the sole choice of the mother. Eventually, the mother filed the instant Due Process Complaint as a result of her grievance over the new policy.

On October 16, 2018, the child's physician, Dr. Michael Ciliberto, wrote a letter listing recommendations for how to deal with the child's seizures. Dr. Ciliberto is a child neurologist who is boarded in epilepsy and who is an assistant professor at the University of Iowa Children's Hospital. In that letter, he recommended that Diastat be given only if the seizure lasts longer than ten minutes, and that 911 be called if the seizure then lasts an additional five minutes. He opined that there is no reason for the child to leave school after Diastat has been administered, and that she should otherwise be able to attend school per her usual routine.

Dr. Ciliberto echoed these comments during his testimony at this hearing. In particular, he explained that the child's form of epilepsy is an especially bad form and is pharmacoresistant, meaning that it is resistant to medications. In the case of a seizure, he would first recommend providing first aid, including moving her to her side, getting her to a safe area, and making sure there is nothing in her mouth. He would then recommend giving Diastat after 10 minutes.

He also noted that the child's main side effect from a seizure and Diastat is fatigue. Generally, her seizures stop within 10 minutes and the Diastat allows her to return to her "baseline' more quickly. Once, she returns to that baseline, Dr. Ciliberto believes that the child can resume all normal activities, including her schooling. He would only have someone stay with the child after the administration of Diastat to observe if there are any side effects. He conceives of no medical reason for her to leave school after Diastat because she is medically safe, the Diastat tends not to impact the child for long

periods of time, and it does not impact her ability to participate. But, he would recommend calling 911 if the child's seizures last five minutes after Diastat is given.

According to Dr. Ciliberto, respiratory depression can happen to all epilepsy patients, not just those who have received Diastat. In the past, Diastat has not caused respiratory depression to the child and therefore there is an "exceedingly low" chance she will ever have this issue. She has also never had a second seizure within four hours of Diastat as far as Dr. Ciliberto is aware. In sum, Dr. Ciliberto sees no medical reason that the child should not be in school during the four hours after the administration of Diastat because (1) she tolerates the drug well, (2) she recovers nicely from it, and (3) her historical experience supports it.

Dr. Shlomo Shinnar is a neurologist and pediatrician at the Albert Einstein College of Medicine whose research focuses on childhood seizures and status epilepticus. He is also very familiar with Diastat, which he explained is the only real drug approved for use at home with prolonged seizures, and he in fact testified before the FDA for its approval. He was also made familiar with the child's medical history. He acted in this hearing as an expert witness and he received compensation for his testimony.

According to Dr. Shinnar, Diastat actually reduces the chance of another seizure and it protects the person for quite some time. Although all patients react differently to Diastat, they are actually safer after receiving it than had they not received it. Respiratory depression is one possible side effect, but this happens more frequently from the seizure itself than from the administration of the drug. This shows that it is safer to take Diastat than continuing to seize.

If a person suffers respiratory depression, it would be apparent immediately if it is going to happen at all. It will not simply happen or come about some hours later, according to Dr. Shinnar. And, respiratory depression will not happen after they wake up following Diastat.

Dr. Shinnar reviewed the child's medical history. His medical opinion is that she is not likely to suffer from respiratory depression following the administration of Diastat because she has tolerated it well in the past. In this regard, past performance is a reliable predictor of the future. It may take her a while to "wake up" and to recover after Diastat, however, after her baseline has been reached, Dr. Shinnar sees no chance of respiratory depression in the four-hour time frame after the drug is given. He deems it generally accepted that a child may go back to class after Diastat has been given and the child wakes up. He simply sees no logical meaning to the four-hour exclusion from school, and he would only recommend sending a child to the emergency room if the seizure has not resolved within thirty minutes.

, who taught the child for four years starting at age three and who has also provided her respite care, described her experiences with the child when she experienced a seizure. She recalled her training through the school nurse on the child's seizure protocol. At the time, the child was experiencing frequent seizures and she sometimes administered Diastat every day. On one occasion, she had a seizure that Diastat would not stop and they called the mother and 911. The child, however, came out of the seizure by the time they reached the hospital.

Typically, would see that Diastat resolved the seizure within a minute. After it stopped, the child would be tired, so they let her sleep. However, within thirty minutes she would be up, ready to go, and good for the rest of the day. She never had a second seizure after Diastat and her activities never needed to be limited afterwards. After Diastat, the child exhibited the same behavior as before and she never had respiratory depression.

On February 15, 2019, sent a letter to the parents of all children who had a record of having a seizure diagnosis sharing their "updated district procedure." The letter noted that the Epilepsy Foundation states that status epilepticus (a seizure lasting longer than 5 minutes) requires emergency treatment by trained medical professionals in a hospital setting and that medical research validates that a small percentage of children treated with Diastat may develop respiratory depression. In light of these considerations, whenever Diastat is given that student will be sent home for the remainder of the day.

During the pendency of this Due Process action, the Mother began tracking the child's seizures using an app called Seizuretracker. Between January 28, 2019 and April 17, 2019, the child experienced 136 separate seizures. While these seizures could happen at any time of the day, the morning hours appeared to have more activity. During this timeframe, Diastat was administered 41 times. This is a significant increase in the frequency of Diastat administration when compared to the three previous school years.

As noted previously, according to her mother, Diastat is always effective in stopping the seizure and the child has never had another seizure within four hours of its administration. Her mother has never had to take the child to the hospital due to a seizure and she has never had the need to call for paramedics. But, after Diastat, the child can be tired and might need some rest for up to 20 minutes, but then she will be ready to resume her previous activities. Within 30 minutes, the mother always sees the child as back to her normal self. The child has had no adverse effect related to Diastat and she responds positively to it every time.

## **Due Process Complaint**

On or about November 9, 2018, the mother filed a Due Process Complaint on behalf of the child against the **Community** School District and the **Community** Area Education Agency (Respondents) pursuant to the Individuals with Disabilities Education Act (IDEA), 20 U.S.C. §§ 1400 et seq., as implemented by 441 Iowa Administrative Code chapter 41. In particular, she argued that it is a violation of the IDEA to exclude her daughter from school after she has been administered Diastat. She requested that the District return to the previous protocol, under which the child was allowed to remain in school and return to classes when ready after receiving the drug.

### **Issues Raised**

In post-hearing briefing, Complainant clarified her position from the Complaint by raising two primary issues. First, she argues that nursing services, as embodied in the IHP, are "related services" that are subject to the special education regulations. As such a related service, it was only subject to revision by the IEP team. The failure to seek parental input and follow other procedural protections attendant to changing an IEP amount to a procedural violation, according to Complainant. Second, Complainant argues that the District's decision to exclude the child from school after receiving Diastat "was not individualized to meet her needs [and] is not evidence-based" and there denied her a free appropriate public education.

Respondents counter first that Complainant cannot challenge the District's generally applicable Diastat protocol through the vehicle of a due process complaint. In other words, this case's remedy, if any, should pertain to the protocol as it applies to the child and should have no effect on other students who may receive Diastat. Respondents also believe the Complainant's right to parental participation was not impeded because an IHP may be changed outside the confines of the entire IEP team. Furthermore, Complainants believe this Diastat protocol does not deny the child's right to FAPE because their actions were reasonable based on the information it had at that time.

## **Conclusions of Law**

The IDEA requires that states receiving federal funds for educating children with disabilities "must provide a free appropriate education --- a FAPE, for short --- to all eligible children." *Endrew F. ex rel. Joseph F. v. Douglas County Sch. Dist. RE-1*, 137 S. Ct. 988, 993 (2017). Free appropriate public education, as defined by the IDEA, means special education and related services that:

(A) have been provided at public expense, under public supervision and direction, and without charge;

(B) meet the standards of the State educational agency;

(C) include an appropriate preschool, elementary school, or secondary school education in the State involved; and

(D) are provided in conformity with the individualized education program required under section 1414(d) of this title.

20 U.S.C. § 1401(9). Special education is defined as specially designed instruction to meet the unique needs of a child with a disability across a range of settings, including in the classroom, in the home, in hospitals and institutions, and in other settings. 20 U.S.C. § 1401(28).

The individualized education program, or "IEP," is the "centerpiece of the statute's education delivery system for disabled children." *Honig v. Doe*, 484 U.S. 305, 311 (1988). "The IEP is the means by which special education and related services are tailored to the unique needs of a particular child." *Endrew F.*, 137 S.Ct. at 994 (internal quotations omitted).

When educators and parents disagree about what a child's IEP should contain, the "parents may turn to dispute resolution procedures established by the IDEA." *Id.* Under the IDEA, a parent or public agency may file a due process complaint relating to the identification, evaluation, or educational placement of a child with a disability, or the provision of a FAPE to the child. 34 C.F.R. § 300.507(a); 281 Iowa Administrative Code (IAC) 41.507(1).

The burden of proof in an administrative hearing challenging an IEP is on the party seeking relief. *Sneitzer v. Iowa Dep't of Educ.*, 796 F.3d 942, 948 (2015) (*citing Schaffer ex rel. Schaffer v. Weast*, 546 U.S. 49, 61-62, 126 S.Ct. 528, 163 L.Ed.2d 387 (2005). "At the conclusion of the administrative process, the losing party may seek redress in state or federal court." *Id.* (citing 20 U.S.C. § 1415(i)(2)(A)).

In deciding whether the challenged IEP satisfies the requirements of the IDEA, two issues are relevant: (1) whether the state complied with the procedural requirements of the statute, and (2) whether the challenged IEP was "reasonably calculated to enable the child to receive educational benefits." *Rowley*, 458 U.S. at 206–07, 102 S.Ct. 3034.

"To meet its substantive obligation under the IDEA, a school must offer an IEP reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." *Endrew F.* at 999. The IEP must establish an "educational program [that is] appropriately ambitious in light of [the child's] circumstances," and should give the child "the chance to meet challenging objectives." *Id.* at 1000. In the task to analyze this, the undersigned's "review of an IEP must appreciate that the question is whether the IEP is *reasonable*, not whether the court regards it as ideal." *Endrew F.*, 137 S.Ct. at 999 (emphasis in original). The school is not required to provide an optimal experience for a student with a disability, but instead must simply provide the student with a FAPE consistent with the IEP. *Bd. of Educ. of the Hendrick Hudson Cent. Sch. Dist. v. Rowley*, 458 U.S. 176, 198–200, 102 S.Ct. 3034, 73 L.Ed.2d 690 (1982).

Overall, the IEP "must be responsive to the student's specific disabilities, whether academic or behavioral," *CJN v. Minneapolis Pub. Schs.*, 323 F.3d 630, 642 (8th Cir. 2003). It must be "reasonably calculated to enable" the child to make academic progress. *See Endrew F.* at 997.

# Individual Health Plan as a Related Service under the IDEA

As noted above, Complainant first argues that nursing services, as embodied in the IHP, are "related services" that are subject to the special education regulations. As such a related service, she argues that it was only subject to revision by the IEP team and that the failure to seek parental input and follow other procedural protections attendant to changing an IEP amount to a procedural violation.

Generally, in Iowa, an individual health plan, or IHP, is implemented and evaluated by licensed school health personnel. It is specifically defined as

the confidential, written, preplanned and ongoing special health service in the educational program. It includes assessment, nursing diagnosis, outcomes, planning, interventions, evaluation, student goals, if applicable, and a plan for emergencies to provide direction in managing an individual's health needs.

281 IAC 14.2(1). The plan may be updated as needed and at least annually. *Id*. Licensed health personnel develop this written plan with collaboration from the parent or guardian, individual's health care provider or education team. *Id*. For children who are eligible under the IDEA, the school health services must comply with any additional or differing requirements imposed by the IDEA based on the specific child's needs. 281 IAC 14.2(3). However, the IHP is not a document required by the IDEA. It is a document of general applicability and could be issued for both IDEA-eligible and non-IDEA-eligible students. Prior to the provision of these special health services, the written IHP must be integrated into the IEP if the student has one. 281 IAC 14.2(2)(b)(4).

An IEP must contain, among other things, a statement of the related services and supplementary aids and services that will be provided in order to enable the child to be educated and participate with other disabled and non-disabled students. 281 IAC 41.320(1)(e). Related services are such "supportive services as are required to assist a child with a disability to benefit from special education" and include school health services and nurse services. 281 IAC 41.34(1) School health services and school nurse services are health services that are designed to enable a child with a disability to receive FAPE as described in the child's IEP. 281 IAC 41.34(m).

Complainant couches this argument in terms of a procedural violation. In matters alleging a procedural violation, it may be found that a child was denied FAPE if the procedural inadequacies

(i) Impeded the child's right to a FAPE;

(ii) Significantly impeded the parent's opportunity to participate in the decisionmaking process regarding the provision of a FAPE to the parent's child; or

(iii) Caused a deprivation of educational benefit.

# 34 CFR 300.513.

In particular, Complainant argues nursing services, just as other "related services" provided to a special education eligible student, are subject to the IDEA and special education regulations. As such, because the child's IHP was a part of her April 2018 IEP, it was her IEP team that was required to have determined the content of the IHP. And, when changes were made to her IEP (through the IHP), the IEP team was required to have explained it and offered a prior written notice to the parent. Complainant also argues that as part of the IEP, the IHP can only be revised by the IEP team. Therefore, according to Complainant, it was a violation of the IDEA for the nurse to have revised the IHP without an IEP team meeting and without allowing meaningful involvement by the mother.

First, it is reasonable to conclude that the IHP is incorporated into or effectively made part of the IEP in that the contents of the IHP constitute related services and are uploaded into the Iowa IEP management system. *See* 281 IAC 14.2(2)(b)(4) (requiring "integration" of the IHP into the IEP). However, for something to be incorporated or integrated into something else, as here the IHP into the IEP, that new incorporated thing must have come from someplace else. As here, with the IHP, that "someplace else" must be the regulations that guide the drafting and content of the health plan.

The relevant regulations provide that an IHP is developed by a licensed health personnel in collaboration with the parent or guardian, individual's health care provider or education team. 281 IAC 14.2(1). In contrast, the IEP team generally must include the parents, a general education teacher, a special education teacher, a district representative, someone who can interpret evaluation results, and the child when appropriate. 34 CFR 300.321(a). Thus, a much smaller subset of what comprises the IEP team is authorized to develop the IHP.

Here, nurse drafted drafted will 's IPH and seizure protocol anew at the start of the 2018-2019 school year. Because this was the child's first time in this school and under the care of drafted, this was a new experience and new document for her. Consequently, attempted to contact the mother before the start of the school year, however, she

was unable to make contact. She then met with the mother at the open house before school started. They discussed various aspects of the child's health care, including the new Diastat protocol. The mother was able to express her opinion on this protocol.

then took some time to work on the health plan and provided a copy of the draft IHP, including the emergency protocol, by placing it in the child's backpack like she would normally do for other students. The mother reviewed this document and sent it back with a variety of suggestions, mark-ups, and cross-outs. An IEP team meeting was subsequently called at which many team members, including the mother, discussed the Diastat protocol. Team members were not aggressive with the mother and they listened to her concerns, insisting they could revisit and re-evaluate the protocol if were to return to school and show an increased need for usage of Diasat.

All of this illustrates that the mother was allowed to provide significant input into the contents of the IHP and that the school nurse and school and district personnel provided her many listening opportunities. However, because the child never returned to school after the third day of the school year, there never was opportunity to re-evaluate.

Likewise, the regulations setting forth the IHP requirement do not provide for any further formalized procedure for its development. This lack of formalized procedural requirement is in distinct contrast with the depth of regulation governing the formation of the IEP. These distinctions are significant. And, due to the IHP's own regulatory support and placement, and even though in this case, the IHP was incorporated by reference into **method**'s IEP, it still retains its intrinsic nature and is guided by its own regulations. Those were followed here.

Iowa regulations also provide each board of a public school, in consultation with licensed health professionals, the authority to establish policy and guidelines for special health services. 281 IAC 14.2(2). This prerogative is not subject to the agreement of or consultation with any parent. This is also a recognition of the district or school's ability, in general, to institute policies or protocols of general applicability for special health situations. Here, it was decided that the schools did not have the capability to monitor and treat for potential respiratory depression following the administration of Diastat.

In light of all these considerations, it cannot be said that the Complainant's right to parental participation was impeded, that the child's right to FAPE was denied, or that there was a deprivation of any educational benefit by virtue of the processes undertaken. The school nurse, through a protocol proposed by the District's Health Services Facilitator, drafted the child's IHP in a manner with which the mother disagreed. The nurse sought and received input from the parent about the offending portion of the IHP. Iowa regulations envision and authorize such a change in a student's IHP. There was no

requirement that an IEP team be convened and pass on a modification to an IHP that is later integrated into the IEP. However, after the mother's concerns were heard, an IEP team meeting was promptly held on September 10 to discuss the Diastat protocol. The disagreement remained, and the mother chose to contest the matter through a Due Process complaint, as was her right.

# Did the Diastat Protocol Violate the Child's Right to FAPE?

Complainant next argues the District's decision to exclude the child from school following the administration of Diastat is not individualized to meet her unique needs, is not evidence based, and therefore denies her a free appropriate public education (FAPE). Rather, Complainant believes the child's unique circumstances allow for a return to all school activities after Diastat and return to her baseline. She further argues it violated the child's right to FAPE by predetermining the contents of the IHP, applying a one-size-fits-all policy to her, excluding her from school solely due to her need for a medication, and by reducing her minutes of specially designed instruction by sending her home.

At its heart, this is an argument that the IHP and emergency protocol, as integrated into the child's IEP, violated her right to FAPE. This question should be analyzed under the general standards applicable to the concept of FAPE. As noted above, a school must offer an IEP "reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." *Endrew F*. at 999. And, that IEP must contain, among other things, a statement of the related services and supplementary aids and services that will be provided in order to enable the child to be educated and participate with other disabled and non-disabled students. 281 IAC 41.320(1)(e).

It is first important to note that, to the extent that the **School** District, via the recommendation or decision of **School**, its health services facilitator, adopted a district wide policy or protocol here, then that decision is simply not subject to challenge in this due process action. The general protocol will not be on review here; rather, this review is limited in scope to the impact of the protocol on the child's right to procedural protections and to receive FAPE.

To paraphrase the First Circuit Court of Appeals, the question in this case is not whether the IEP was prescient enough to know that the child's need for Diastat might increase, thus increasing her time away from school, , but whether it was "reasonably calculated" to provide an "appropriate" education as defined in federal and state law. *Roland M. v. Concord School Committee*, 910 F.2d 983, 992 (First Circuit 1990). In other words, what is relevant are the facts and circumstances known and confronted by the school and the district at the time the protocol was integrated into the child's IEP. As the *Roland* court stated:

[The] actions of school systems cannot, as appellants would have it, be judged exclusively in hindsight. An IEP is a snapshot, not a retrospective. In striving for "appropriateness," an IEP must take into account what was, and was not, objectively reasonable when the snapshot was taken, that is, at the time the IEP was promulgated.

## *Roland M.*, 910 F.2d at 992.

Thus, we must judge this IEP and the protocol not in hindsight, but instead based on the information that was reasonably available to the parties at the time of the IEP. See *Baquerizo v. Garden Grove Unified Sch. Dist.*, 826 F.3d 1179, 1187 (9th Cir. 2016); *See also K.E. ex rel K.E. v. Independent School District No. 15*, 647 F.3d 795, 808 ("[Using the snapshot rule] "we do not conclude that K.E.'s IEPs were deficient because they lacked the services and adaptations that she now contends are necessary.").

Given that lens, at the time that **and the nurses agreed on a District-wide protocol** requiring the child to be sent home following the administration of Diastat, the decision that there was an increased need for observation of such children due to the fear of respiratory depression was a reasoned and rational reading of the literature from certain mainstream and credible organizations who deal with epilepsy.

First, the American Epilepsy Society's report did in fact document certain studies that showed some degree of respiratory depression after rectal administration of diazepam in children:

Respiratory depression after rectal administration of diazepam in children was reported in five class III trials, ranging from 1.2 percent to 6.4 percent ....

Additionally, the Epilepsy Foundation literature indicated that status epilepticus, defined as a seizure that lasts longer than five minutes, requires "emergency treatment by trained medical personnel in a hospital setting." This article also states that "medical treatment needs to be started as soon as possible [and that] oxygen and other support for breathing, intravenous fluids . . . and emergency medication are needed." The Diastat packaging instructions also advise the caregiver to "stay with the person for 4 hours and made notes on the following: changes in breathing rate, changes in color, . . . [and] possible side effects from treatment." Finally, even Dr. Shinnar and Dr. Ciliberto conceded at the hearing that respiratory depression is one possible side effect of Diastat.

Respiratory depression is a serious condition for which teachers and nurses in a school setting are simply not equipped to deal with. Most importantly, they cannot provide mechanical ventilation to such children. Teachers and para-educators are not

medically trained and have no expertise or knowledge about treatment for or response to respiratory depression. By requiring a child to leave school after Diastat, then it would allow the parent to seek whatever care or monitoring they believe would best address that possibility, whether that be by the parents themselves or by some other medically trained person. The studies noted in the American Epilepsy Society's report showing some respiratory depression certainly warranted the attention of District nursing personnel as it is their duty to promote and protect the health of the student population and to oversee health policies. This is also the reason the District policy is to always call 911 to get EMS personnel when a seizure lasts five minutes and Diastat is given.

Also, although initially unknown to and the other District nurses, other district health facilitators in the Urban Action Network, a group of the ten most populous school districts in the state all follow the consistent practice of sending children home after Diastat has been given. This protocol is therefore far from the outlier, and it appears to be consistently applied across the state. This was even apparently the practice at some of the second district schools based on decision by the specific school nurses.

Furthermore, at the time the child's new IHP was implemented and integrated into her IEP, it was entirely reasonable and effectively was tailored to her unique situation and needs. In this regard, it is undisputed that from the 2014-2015 school year to the time she stopped attending school, the child had had Diastat administered at school a total of eleven times, or a little over two times per year. She has never had to receive it more than three times in a given year during that span. Thus, had her trend of four-plus years continued—and at the time of the amended IHP there was no reason to believe it would not have continued—then the child stood to have missed only a negligible amount of school. Had this continued, the relatively insubstantial amount of absences from school would have been unlikely to affect the child's learning experience in any substantial way. This was the information which was known to the District at the time it implemented the protocol and effectively made it a part of the child's IEP.

While the mother would later start tracking the child's seizures and Diastat usage, that information was not made available to the District until the Due Process Hearing. There would have been no way for the District to have known the extent to which her Diastat intake would have increased to such a degree without this information. Indeed, the District on several occasions informed the mother that were she to send the child back to school and it turned out that she would have to miss any more time under this new protocol, then its application to her would be reconsidered and perhaps a new plan implemented that would be more responsive and tailored to her situation. However, the mother refused to consider providing this information to the school or to send her back

such that the school itself could have made its own informed determination as to the child's current situation.

Thus, at the time the IHP and emergency protocol were integrated into the IEP, the IEP was objectively reasonable and would have served fully to provide for the child's educational needs and her health needs. This reasoned decision was based on a justifiable reading of medical literature and authoritative guidance from knowledgeable and relevant groups. It was also based on a reasoned reliance on the child's historical need for Diastat while at school in assessing the extent to which she would miss school and educational opportunities.

And, importantly, at that time the district did not have the benefit of Dr. Ciliberto's letter of October 2018 providing recommendations for how to deal with the child's seizures. It did not have the benefit of knowing how substantially the child's need for Diastat might increase during the school year. It also did not have the benefit of Dr. Shinnar's testimony at hearing to the effect that any respiratory depression would be immediately apparent and that it almost certainly will not happen after they wake up following Diastat.

Regardless of this conclusion, the mother was not justified, and acted unreasonably, in refusing to send the child to school after her first in-school seizure that required the administration of Diastat during the 2018 school year. This deprived the District of knowledge of the extent of any increase on the child's need for Diastat and the amount of school time she would miss. It also deprived it of the opportunity to revisit the policy, as applied to the child, based on that new information. In this regard, many persons assured the mother that the District would have considered alternatives to sending the child home after Diastat if her need for Diastat was proven to have increased. All District personnel were likewise encouraging of the child's return to school at all times. Therefore, none of the child's absence from school during the 2018-20198 school year can be attributable to the District or the school.

Moreover, there could have been no safety or health concern because, in fact, the new policy was more conservative and provided for more potential observation of or care for the child than would have been provided under the mother's preferred policy. Any concerns that because of this, the nurses might be disposed to disregard other doctor's orders or other medical issues, is likewise overblown and not justification to refuse schooling. This was a District-wide protocol that was applied in an even-handed fashion to all and that in fact appeared to fit the unique circumstances of this child at the time it was applied.

Certainly, though, as was made clear by the evidence introduced at hearing, the child's circumstances have changed since the time her mother withheld her from school. Based

on the chart of Diastat administration that was compiled on Seizuretracker.com in anticipation of this Due Process hearing, the child actually would have been forced to miss a significant amount of school under the new protocol. In fact, between January 28, 2019 and April 17, 2019, the child received Diastat 41 times. While some of those incidents occurred in the late afternoon or evening hours, a good portion of them would have occurred during a time in which school was in session. Had the child's mother not withheld her from school and only produced this information at the time of the Due Process hearing, this case may have been entirely different.

Likewise, had the District been made aware of the information from Dr. Ciliberto and Dr. Shinnar at the time the protocol was integrated into the IEP, this may have been much different. Specifically, Dr. Shinnar expressed the medical opinion that **second** is not likely to suffer from respiratory depression following the administration of Diastat because she has tolerated it well in the past. In this regard, past performance is a reliable predictor of the future. However, again, this was not information known to the school or its nursing staff.

Given this information from the hearing, the District should convene an IEP meeting as soon as practicable to re-address the protocol and assess whether it should apply as written and without exception to the child. In doing so, it should consider the child's significant increase in the need for Diastat and the resulting school time and educational opportunities she would miss if the protocol is applied in a blanket fashion to her.

The team should also consider the medical opinion of Dr. Ciliberto that there is no medical reason for her to leave school after Diastat because she is medically safe, the Diastat tends not to impact the child for long periods of time, and it does not impact her ability to participate. And, it should consider the similar opinion of Dr. Shinnar that the child is not likely to suffer from respiratory depression following the administration of Diastat because she has tolerated it well in the past, and that there is no reason to withhold her from school. With this information, the IEP team should strive to individualize the policy as applied to the child's unique situation and needs. As the term implies, the IDEA requires that the IEP be *individualized* and tailored to meet the child's unique needs. *Slama ex rel. Slama v. Indep. Sch. Dist. No. 2580*, 259 F.Supp.2d 880, 884 (D. Minn. 2003).

With this determination that the Respondents did not deny the child a FAPE, Complainant is not entitled to any of the remedies sought However, given the information made available at this hearing that was not known at the time the protocol was instituted, the District should reassess the protocol's specific application to this child. To the extent Complainant raised any additional issues that were not otherwise addressed in this decision, they are hereby found to have been deemed without merit.

## Decision

Complainants have not proven that Respondents denied Student a free appropriate public education as alleged in the due process complaint. Complainants' requested relief is therefore denied and the due process complaint is dismissed.

Dated this 13<sup>th</sup> day of September, 2019.

Davil Lige

David Lindgren Administrative Law Judge

cc: Carrie Weber (via email) Cheryl Smith – DOE (via email) Complainant (via First Class Mail and email) David Roston (via email)