168 F.Supp.3d 1082
United States District Court,
N.D. Illinois, Eastern Division.

United States of America, Plaintiff,
v.
Northern Illinois Special Recreation Association, Defendant.

No. 12 C 7613
|
Signed 03/02/2016

Synopsis

Background: United States brought action against community-based park and recreation program for people with disabilities, alleging program discriminated against participant with epilepsy in violation of Title II of Americans with Disabilities Act (ADA) by refusing to administer emergency medication to stop seizures.

[Holding:] Following a bench trial, the District Court, James B. Zagel, J., held that government failed to demonstrate that requiring program to provide medication was a reasonable accommodation under ADA.

Ordered accordingly.

Attorneys and Law Firms

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Gregory Robert James, Jr., David A. Moore, Jennifer Anne Naber, Joseph Michael Gagliardo, Sara Paull Yager, Laner, Mutchin, Dombrow, Becker, Levin, and Tominberg, Ltd., Chicago, IL, for Defendant.

MEMORANDUM OPINION AND ORDER

James B. Zagel, United States District Judge

The United States of America brings this action against Defendant Northern Illinois Special Recreation Association ("NISRA"), alleging that NISRA discriminated against a program participant with epilepsy in violation of Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12131, and its implementing regulation, 28 C.F.R. Part 35, by refusing to allow its staff to administer Diastat AcuDial ("Diastat"), an emergency-rescue medication used to stop prolonged seizures.

The Court held a bench trial on April 27–May 8, with closing arguments on June 5, 2015. Having presided over this action, I am entering the following findings of fact and conclusions of law pursuant to Rule 52(a) of the Federal Rules of Civil Procedure. To the extent that certain factual findings may be deemed to be conclusions of law, they shall also be considered conclusions of law. Similarly, to the extent that matters discussed in the conclusions of law may be deemed findings of fact, they shall be considered findings of fact.

For the reasons set forth below, I conclude that the United States has failed to meet its burden and hereby enter judgment on behalf of NISRA.

STATEMENT OF FACTS

NISRA is an agency that was created through an intergovernmental agreement between 13 local park districts and municipalities for the purpose of providing community-based park and recreation programs for people with disabilities of any age. NISRA's Executive Director, James Wiseman, testified at trial and provided most of the information that follows concerning the operations and organization of NISRA as well as NISRA's specific seizure policies. Wiseman has been NISRA's Executive Director since February 2008.

NISRA provides year-round recreational activities for children and adults with disabilities in northern Illinois. NISRA releases three unique seasonal brochures, one for fall, one for winter and spring, and one for the summer. NISRA does not employ medical personnel, but instead employs a staff experienced in working with people with disabilities. Typically, one counselor is responsible for the supervision of two to four participants, but at times, NISRA provides one-on-one service for its participants.

NISRA is funded through various sources: about 72 percent of its revenues come from its 13 members in the form of annual dues, which come from tax dollars the park districts and municipalities collect; 18 percent comes from the fees charged to program and camp participants; 8 percent from contributions, fundraising and grants; and the small remainder from special interests and miscellaneous things. Regarding the tax-funded portion, the property tax levy rate determines how much money NISRA members pay to NISRA and, because property values have slumped with the recession over the last few years, NISRA's revenues have declined fairly dramatically in the past 5 years.

***1085** *NISRA Participants*

NISRA is currently serving between 1550–1600 individuals, which includes children and adults in both its seasonal programs and summer camps. Although NISRA participants range from three-year-old to people in their 80s, the majority of participants that NISRA serves are comprised of late teens and young adults. NISRA participants have a wide range of disabilities, including developmental disabilities; sensory impairments, such as visual or hearing impairments; autism spectrum disorders; learning disabilities; physical disabilities; behavioral disorders; and multiple handicaps.

NISRA also serves a small number of participants who do not have traditional disabilities, such as "at risk youth," including participants who are first-time offenders, are in the foster system, or are at risk of gang affiliation.

NISRA Programs

NISRA is currently providing around 950 programs, which includes seasonal programs that run six to eight weeks long, special events, and overnight trips. Summer camps typically run 28 days long—four days per week over six to eight weeks—and feature arts and crafts, music and games, singing, theater, swimming, and other camp activities. They take place at many different locations, including Barrington, Cary, Elgin, Algonquin, Huntley, Crystal Lake and Woodstock, and they use facilities at park districts and schools. Some summer camps also have weekly (or more frequent) field trips, in which participants go to bowling alleys, movie theaters, water parks, baseball games, petting zoos, and other public locations. Most summer camps have a swimming component, which can occur at public pools and beaches. NISRA typically operates over 120 weekly programs during the summer, plus 40 special events and overnight trips.

NISRA's weekly programs typically last one to three hours. They take place in 50–70 physical locations, not just at NISRA's main administrative building, and include public locations, like bowling alleys, Pizza Huts, Bulls games, Bears training camp, and casinos. At any time, NISRA uses 10 full-time staff and anywhere between 75 and 100 or more part-time staff and volunteers to run its seasonal programs.

NISRA Staff

NISRA hires and supervises approximately over 100 part-time summer camp staff from mid-May to mid-August every year. For summer camps, NISRA has part-time staff that includes the following positions: Site Coordinators, Site Directors, and Camp Counselors. Site Coordinators are assigned to oversee and supervise four or five camps in a summer and may only spend an hour at each camp per day. For a typical summer program, NISRA hires around four Site Coordinators.

Site Directors are in charge of making sure that the camp runs smoothly, so they do lesson planning, make sure staff feel comfortable with staffing ratios, provide additional training, inventory supplies, and communicate with parents. NISRA typically assigns one Site Director for each camp location. Camp Counselors are assigned a small group of campers and provide the facilitation of the recreation activities; they supervise participant campers and make sure they are safe, having fun, and socializing with each other.

Camp Counselors are typically in their late teens or early twenties. It is often the case that NISRA is their first job. Camp Counselors are not required to have experience with disabled individuals to be hired by NISRA, and most Camp Counselors have not worked with disabled individuals prior to working at NISRA.

***1086** All three of these types of NISRA employees can sometimes also serve as Program Leaders. Program Leaders are responsible for planning and leading programs, which includes giving instructions to the other staff. They can be full-time or part-time, but the majority of Program Leaders are part-time NISRA staff. Additionally, non-NISRA employees (like a coach, dance instructor, yoga instructor, or swim instructor) sometimes also serve as Program Leaders.

NISRA staff members routinely maintain custodial supervision over all participants attending NISRA programs. Their tasks include, among other things, toileting assistance (including the use of a urinal bottle); changing diapers for both adults and children; showering participants and changing their clothes; lifting participants with physical disabilities; monitoring glucose-sugar levels with blood testing; feeding and medicating

participants through gastro-feeding tubes; administering maintenance medications (such as Ritalin and Ativan); and recognizing and responding to a wide range of medical emergencies using first aid.

NISRA's full-time recreation staff, Site Coordinators, Site Directors, and Program Leaders are required to be certified in basic first aid and CPR. As part of their emergency rescue training, NISRA employees also learn how to administer epinephrine auto-injector ("Epi-pen") shots and dispense asthma medication. NISRA's part-time staffers, which include Camp Counselors and Program Assistants, are not required to be certified in basic first aid or CPR.

NISRA employees also receive training in responding to seizures, but it is important to understand seizures and Diastat in general before NISRA's previous and current seizure management policies can be discussed.

Seizures and Epilepsy

A seizure is an electrical storm on the surface of the brain. Epilepsy is a condition in which a person has recurrent unprovoked seizures. A seizure that lasts five to 30 minutes is called a prolonged seizure. A seizure that lasts 30 minutes or longer, referred to as "status epilepticus," is a life-threatening condition.

There are many different types of seizures. The terms tonic-clonic, convulsive, and grand mal seizures can be used synonymously, and all refer to a seizure that involves violent jerking, stiffness of muscles, and loss of consciousness. During a grand mal seizure, individuals can have a bowel movement, urinate, vomit and/or choke. They can also experience difficulty breathing.

Although other types of seizures can be difficult to recognize, grand mal seizures are typically easier to recognize because of the violent jerking and shaking that differentiates them from other types of seizures. Recognizing grand mal seizures is not always easy, however, because a seizure can start as one type, but then morph into another during the same episode.

Diastat

Diastat is the only FDA-approved medication for out-of-hospital treatment of emergency seizures. Diastat, which is also called rectal diazepam, is administered rectally. It is pre-filled with a single dose prescribed by the participant's treating physician and packaged in a

plastic applicator. Diastat is generally prescribed for convulsive seizures that have lasted five minutes or more (*i.e.,* a "prolonged seizure") and for cluster seizures. Roughly 30 current NISRA participants list Diastat as a current medication they are taking.

Diastat works most effectively if administered within five minutes of the onset of a convulsive seizure. If given at the five- ***1087** minute mark, Diastat works only about 80 percent of the time to stop a prolonged seizure; it fails the other 20 percent, even if given correctly. After the five-minute mark, the sooner Diastat is administered, the more effective it will be. Although Diastat does not always work, the risk of adverse reactions from the rectal administration of the medication is extremely low.

The manufacturer's instructions for Diastat are mandated by the FDA to be included as an accompaniment to the drug. These instructions state, in part, that:

> **WARNINGS**
>
> General
>
> Diazepam rectal gel should only be administered by caregivers who in the opinion of the prescribing physician 1) are able to distinguish the different clusters of seizures (and/or the events presumed to herald their onset) from the patient's ordinary seizure activity, 2) have been instructed and judged to be competent to administer treatment rectally, 3) understand explicitly which seizure manifestations may or may not be treated with Diazepam Rectal Gel, and 4) are able to monitor the clinical response and recognize when that response is such that immediate medical evaluation is required.
>
> [...]
>
> The successful and safe use of Diazepam rectal gel depends in large measure on the competence and performance of the caregiver.
>
> [...]
>
> Please do not give Diastat until:
>
> 1. You have thoroughly read these instructions
>
> 2. Reviewed administration steps with the doctor
>
> 3. Understand the directions
>
> [...]

Please do not administer DIASTAT until you feel comfortable with how to use DIASTAT. The doctor will tell you exactly when to use DIASTAT. When you use DIASTAT correctly and safely you will help bring seizures under control. Be sure to discuss every aspect of your role with the doctor. If you are not comfortable discuss your role with the doctor again.

To help the person with seizures:

- You must be able to tell the difference between cluster and ordinary seizures.
- You must be comfortable and satisfied that you are able to give DIASTAT.
- You need to agree with the doctor on the exact conditions when to treat with DIASTAT.
- You must know how and for how long you should check the person after giving DIASTAT.

To know what responses to expect:

- You need to know how soon seizures should stop or decrease in frequency after giving DIASTAT.
- You need to know what you should do if the seizures do not stop or there is a change in the person's breathing, behavior or condition that alarms you.

[...]

DOSAGE AND ADMINISTRATION

A decision to prescribe Diazepam Rectal Gel involves more than the diagnosis and the selection of the correct dosage for the patient. First, the prescriber must be convinced from historical reports and/or personal observations that the patient exhibits the characteristic ***1088** identifiable seizure cluster that can be distinguished from the patient's usual seizure activity by the caregiver who will be administering Diazepam Rectal Gel.

[...]

Third, because a non-health professional will be obliged to identify episodes suitable for treatment, make the decision to administer treatment upon the identification, administer the drug, monitor the patient, and assess the adequacy of the response

> to treatment, a major component of the prescribing process involves the necessary instruction of this individual.
>
> Fourth, the prescriber and caregiver must have a common understanding of what is and is not an episode of seizures that is appropriate for treatment, the timing of administration in relation to the onset of the episode, the mechanics of administering the drug for treatment, how and what to observe following the administration, and what would constitute an outcome requiring immediate and direct medical attention.

A large portion of the trial was spent discussing how to administer Diastat. During the first five minutes of a seizure, the caregiver should first stabilize the person having the seizure, address any head bleeding, and make sure the patient is settled. To administer Diastat, the caregiver then must find the Diastat, pull the cap off, check it and lubricate it. After partially disrobing the individual while the person is convulsing, the caregiver must then insert the syringe into the person's rectum for a count of three, hold it inside while administering for a count of three, and withdraw it for a count of three.

If possible, the caregiver should put on gloves before administering Diastat because the caregiver may be exposed to feces or urine. During trial, several witnesses discussed what can go wrong with the administration of Diastat. In a larger person, it may be difficult to get the syringe into the rectum and, depending on the physical location of the individual, it may be difficult to position the individual to insert the syringe. Improper lubrication can cause damage to the seizing individual's rectum. There is also a danger of the medication leaking out of the rectum. If Diastat does leak, it is difficult to tell how much of it leaked out of the bottle. Lastly, Diastat can be accidentally administered into the vaginas of female patients.

NISRA's Seizure Policy

NISRA's current policy regarding medication is that it administers oral and topical medications only. Most medications NISRA agrees to administer are maintenance medications (*i.e.,* dispensing on planned schedules), such as behavioral control medication. Between 2001–2007, NISRA allowed its staff to administer Diastat in certain situations. After its 2008 summer-camp session, however, NISRA changed its policy to no longer allow its staff to administer Diastat under any circumstance. This policy applies to all NISRA participants.

A "seizure plan" is a pre-determined or pre-specified approach to what a family member or caregiver is going to do if an individual has a seizure. Under NISRA's current seizure policy, NISRA participants with a history of seizures submit a seizure plan in which their doctor

describes the type of seizures they experience, the medications they currently take, and the protocol to follow in the case of a seizure.

If a convulsive seizure occurs, NISRA's current policy requires the nearest staff member to follow basic first aid protocol and move the other participants away from the area to preserve the person's privacy. ***1089** The staff member is trained to ease the person onto the ground, turn the person onto his or her side, and monitor the person's breathing. Additionally, the staff member is directed to follow the person's seizure plan to the best of his ability and call 911 as directed.

Some participants' seizure plans call for assistance with a Vagus Nerve Stimulation ("VNS") device to abort an ongoing seizure. A VNS device is a pacemaker-like device designed to prevent seizures by sending regular impulses of electrical energy to the brain via the vagus nerve. Holding a special magnet near the implanted device triggers it to deliver another burst of stimulation, outside of programmed intervals. This emergency intervention can be used to stop an ongoing seizure. For participants who request this intervention, NISRA staff is required to identify seizures disclosed in the participant's seizure plan and administer VNS therapy to abort an ongoing seizure, in lieu of following the basic first aid protocol described above. NISRA staff is trained by the participant's family member before using a VNS for emergency intervention.

As part of their training, NISRA employees watch a video on seizures that, among other things, states:

> While there are many things that may cause a seizure to occur, the care provided is always the same. Protect the child during the seizure. Move objects away that she may bump into. Do not restrain the child. Allow the seizure to take its course. Do not put anything in the mouth, including your finger.... If vomiting occurs, roll the child as best you can onto a side and allow the vomit to flow out of the mouth. Activate EMS if the child is injured during the seizure, has no history of seizures or continues to seize for more than ten minutes.... If responsiveness and breathing are absent after a seizure stops, begin CPR and get an AED if one is available.... Provide continual reassurance as the child improves. Continue to monitor until the child returns to normal. Expect the child to be extremely tired following the seizure.

Nowhere in the Medic/First Aid training materials or basic first aid response does the training discuss giving Diastat or any other medication in response to a seizure.

Megan and her Family

Megan Monica is a woman who has attended NISRA seasonal programs and summer camps for over a decade. [1] Megan has Steven's Johnson syndrome. As a result of that syndrome, in the past, when two anti-seizure medications she was taking interacted (neither of which were Diastat), Megan developed third-degree burns all over her body and was in the intensive care unit for six months. Megan is currently prescribed Diastat because of her epilepsy.

At various points in her life, Megan has experienced different types of seizures. At times, Megan has had episodes during which her arm simply falls asleep or she has blurred vision that is actually a seizure itself. These sensory seizures are "subjective," meaning Megan can feel something before anyone can see the symptoms of the seizure. For example, Megan's complex partial seizures can, but do not always, morph into grand mal seizures.

Megan has three sisters: Tara, Rianne, and Carley. Megan's three sisters have ***1090** worked for NISRA at various times. In the past, Tara worked as a Camp Counselor and Program Assistant. Carley worked as a Camp Counselor and Program Assistant. Rianne has worked as a Program Assistant, Camp Counselor, Site Director and Site Coordinator. Rianne is currently a NISRA employee.

Megan's mother, Nancy, worked as an Epilepsy Program Manager for an agency that provides telemedicine for people with epilepsy who do not have convenient access to doctors. Prior to working for this agency, Nancy worked for the Epilepsy Foundation on and off for 15 years.

Dr. Marvin Rossi is Megan's current Epileptologist. Dr. Rossi is the only doctor who writes prescriptions for Diastat for Megan, and has treated Megan since about 2004. He is also the only doctor who currently treats Megan for seizures, other than doctors who might treat Megan when she is admitted to a hospital. According to Dr. Rossi, Diastat is only required to be given to Megan for her generalized tonic-clonic seizures, and should be given "at onset."

NISRA's Policy for Accommodation Requests

NISRA evaluates requests for accommodation on a case-by-case basis. Most NISRA participants need reasonable accommodations of some sort, but if there is a request that goes beyond the scope of the reasonable accommodation that is built into the program or camp or

beyond the scope of simple accommodations, NISRA's Superintendent of Recreation reviews the request using NISRA's Personal Medical Care Protocol.

Under NISRA's Personal Medical Care Protocol, the Superintendent of Recreation looks at multiple factors to determine if NISRA can safely provide the requested accommodation: (1) whether the requested accommodation requires medical judgment; (2) the manufacturer's instructions and medical training required to perform the requested accommodation safely; and (3) the risk of harm of providing the requested accommodation if it were performed improperly. If a request is approved under this Personal Medical Care Protocol, NISRA typically requires at least two of its staff to be trained regarding the accommodation.

Although NISRA no longer does a case-by-case analysis of whether it will permit its staff to administer Diastat, it does do a case-by-case analysis of the other alternative accommodations NISRA would provide to an affected participant. After deciding that it would not allow its employees to administer Diastat, NISRA began offering families other accommodations, including asking if the parent or family could provide a family member or personal aide at the program, who would not be charged program fees. NISRA also offered scholarship assistance (up to 100 percent of the participant's program or camp costs) to offset some of the costs to provide a personal aide.

NISRA has given Megan a 75 percent discount because of her family members having worked there. Although she was offered one, Nancy did not need the scholarship assistance offered to offset the costs of providing a personal aide because she was already receiving the family employee discount. During the course of this litigation, NISRA indicated that it would allow the Epilepsy Foundation to provide volunteers to attend NISRA programs and administer Diastat when needed.

NISRA has also offered to keep participants' Diastat on-site in a locked medication bag carried by the Program Leader (in the case of programs) or the Site Director (in the case of summer camps) so that the paramedics could administer the medication upon arrival. For Megan specifically, because she has sisters employed by NISRA, NISRA has offered to allow ***1091** her sisters to come off the clock and provide Diastat to Megan as a family member, should the need arise. For example, in summer 2013, Nancy and NISRA came to an agreement that Carley could be Megan's one-on-one Camp Counselor and that if Carley needed to administer Diastat to Megan, she would come off the clock and act as a family member to do so. The government was directly involved in the negotiation, drafting, and approval of these written agreements.

PROCEDURAL HISTORY

In its original complaint, the government sought an injunction requiring NISRA to administer Diastat to all participants of NISRA programs "as medically required." When the Court sought clarification from the government regarding the requested relief, the government revised its request to the following two forms of revised injunctive relief: (1) requiring NISRA to administer Diastat to participants who have requested Diastat if the Diastat was prescribed for "convulsive seizures" (defined as grand mal/tonic-clonic seizures and "some types of complex partial/focal/localization related seizures"); and (2) requiring NISRA to conduct a case-by-case analysis for all other participants requesting Diastat.

The DOJ now seeks two further revised forms of injunctive relief: "(1) NISRA will administer Diastat to Megan Monica for convulsive seizures; and (2) NISRA will conduct a case-by-case evaluation for all other requests for Diastat from program participants by considering the requirements of Title II of the ADA and its implementing regulations."

DISCUSSION

I. NISRA's Motion to Bar Expert Testimony of Richard Lazar

Before trial, NISRA moved to bar the expert testimony of Richard Lazar as irrelevant. I am denying this motion because Lazar's testimony is relevant to NISRA's affirmative defense that administering Diastat will increase its liability risk. By making the strategic decision to assert this affirmative defense, NISRA opened the door for the government to introduce evidence on this issue.

II. The Government's ADA Claim

The ADA is a comprehensive civil rights law enacted "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 1201(b)(1). Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132.

[1] **[2]** To bring a claim under Title II of the ADA, a plaintiff must establish that: (1) he or she is a qualified individual who has a disability as defined by the statute; (2) he or she was excluded from a benefit provided by the public entity; and (3) the exclusion was "by reason of" the disability. *Brown v. Dist. 299—Chicago Pub. Schs.*, 762 F.Supp.2d 1076, 1083–

84 (N.D.Ill.2010) (citing *Foley v. City of Lafayette,* 359 F.3d 925, 928 (7th Cir.2004) and 42 U.S.C. § 12132). An individual can show he or she was excluded from a benefit provided by a public entity by showing that the entity refused to provide a reasonable accommodation. *Brown,* 762 F.Supp.2d at 1083–84; *see also Wisc. Community Servs., Inc. v. City of Milwaukee,* 465 F.3d 737, 753 (7th Cir.2006) (accord).

[3] Under Title II, a requested accommodation must be a reasonable one. *Wisc. Community Servs.,* 465 F.3d at 751 ("the regulation [28 C.F.R. § 35.130(b)(7)] ***1092** states, in its plain language, that any accommodation must be a reasonable one."); *McDavid v. Arthur,* 437 F.Supp.2d 425, 428 (D.Md.2006) (accord).

[4] Title II regulations require reasonable modifications in policies when necessary to avoid discrimination on the basis of disability unless doing so would fundamentally alter the nature of the service, *see* 28 C.F.R. § 35.130(b)(7), or would create undue financial and administrative burdens. *See School Bd. of Nassau County v. Arline,* 480 U.S. 273, 287 n. 17, 107 S.Ct. 1123, 94 L.Ed.2d 307 (1987). To prove an undue burden, this Circuit requires Defendant to show "the costs are excessive in relation either to the benefits of the modification or to the [entity's] financial survival or health." *Vande Zande v. Wisc. Dep't of Admin.,* 44 F.3d 538, 548 (7th Cir.1995).

[5] Here, the government has failed to show that providing Diastat is a reasonable accommodation. A decision that forces lay people to administer an emergency rectal medication creates several problems. I did not reach this particular conclusion because the evidence showed that recognizing the need for Diastat is an especially difficult task. To the contrary, the evidence presented at trial suggests that recognizing grand mal seizures is relatively easy. Moreover, there does not seem to be any risk of adverse effects from administering Diastat when a person is undergoing a seizure that would not be helped by the drug. This conclusion is consistent with NISRA's decision to allow its staff to operate VNS devices while forbidding its staff from administering Diastat.

The real risk of Diastat, it seems, does not lie in a failure to recognize and classify a seizure, but in the realities of administering the medicine in a real life emergency situation. The majority of NISRA's summer camp employees are part-time high school and college age students—this must be considered when deciding whether it would be reasonable to require NISRA staff to administer Diastat.

On this point, the government presented evidence about some of the other tasks that NISRA staff currently handle, and then argued that these tasks are similar to the administration of Diastat. NISRA workers toilet and diaper adults and children; they feed and medicate participants through gastro-feeding tubes; they help with glucose blood monitoring and

insulin pumps; they change and shower participants as needed; they administer maintenance medications and monitor for side effects; and they administer certain types of rescue medicines, such as Epi-pens and inhalers.

The government spent a considerable amount of time discussing Epi-pens and gastro-feeding tubes in an effort to argue that the government is required to administer Diastat under the ADA because it already performs these other functions. Although I agree with the government that Epi-pens and gastro-feeding tubes share certain similarities with Diastat, I disagree that either of these devices is similar enough to prove that the administration of Diastat must also be considered a reasonable accommodation.

Gastro-feeding tubes differ from Diastat in a crucial way. When a NISRA staff member is learning how to feed a NISRA participant through a gastro-feeding tube, time is not of the essence. Unlike Diastat, a gastro-feeding tube is not reserved for emergency situations that may only happen once in every five years, if at all. Rather, the training process for a gastro-feeding tube allows a staff member to actually see how the gastro-feeding tube works and if a staff member has a question while he or she is assisting a NISRA participant with a gastro-feeding tube, the staff member has enough time to simply ***1093** ask for help. In many ways, therefore, gastro-feeding tubes are much more straightforward Diastat.

Although Epi-pens share certain qualities with Diastat because they are both required in emergency situations, Epi-pens differ from Diastat in material ways. When someone is having an allergic reaction, time is of the essence, and a caregiver must retain his or her composure. Diastat is used under similar circumstances, but a stark difference between Epi-pens and Diastat lies in administration of the drugs. Epi-pens are administered through a needle that can pierce clothing, even thick blue jeans. The government repeatedly argued that Epi-pens are actually very complicated, but this argument is unconvincing.

To administer Diastat, the caregiver must remove a person's clothing between their waist and knees. Instead of a needle, Diastat is administered through a plastic applicator that must be lubricated and inserted into a person's rectum. Compared to Diastat, the operation of an Epi-pen is a much simpler task.

Furthermore, the government's requested accommodation seems to directly contradict the manufacturer's instructions for Diastat, which are mandated by the FDA to accompany the drug. The manufacturer's instructions state, in relevant part, that the medication:

> ... should only be administered by caregivers who in the opinion of the prescribing physician 1) are able to distinguish the different clusters of seizures (and/or the events presumed to herald their onset) from the patient's ordinary seizure activity, 2) have been instructed and

> judged to be competent to administer treatment rectally, 3) understand explicitly which seizure manifestations may or may not be treated with Diazepam Rectal Gel, and 4) are able to monitor the clinical response and recognize when that response is such that immediate medical evaluation is required.

These instructions contemplate a system in which the caregiver and doctor interact directly and come to agreement regarding the caregiver's role and competence and the "exact conditions" when to treat with Diastat, such as what is and is not an episode appropriate for treatment and the timing of administration in relation to the onset of an episode. They also contemplate the caregiver having an intimate knowledge of an individual patient's condition sufficient to distinguish "ordinary" seizures from the seizures that would require Diastat. The government's request, as it has been explained during trial, would require NISRA to disregard these cautionary instructions. This is not a reasonable request.

I therefore conclude that the government has failed to meet its initial burden of showing that its requests are considered reasonable accommodations under the ADA. The evidence showed that NISRA participants have quick access to 911, and I find that NISRA has gone out of its way to give financial discounts to epileptic participants, such as Megan, and other concessions that make its refusal to administer Diastat easier to bear. My decision might be different if the government had presented statistics on how a Diastat program under similar circumstances has worked and been successful.

Although I am not required to reach a decision on whether NISRA successfully raised any of its affirmative defenses, I will briefly discuss these defenses because NISRA spent a great deal of time arguing that the accommodation requested would fundamentally alter the nature of NISRA's services and subject NISRA to an undue ***1094** amount of liability and administrative costs.

[6] The fundamental alteration defense allows a state to avoid making modifications to accommodate disabled individuals if it can "show that adapting existing institution-based services to a community-based setting would impose unreasonable burdens or fundamentally alter the nature of its programs or services." *Radaszewski ex. rel. Radaszewski v. Maram,* 383 F.3d 599, 611 (7th Cir.2004). NISRA failed to prove this defense because, as the government pointed out many times, NISRA already offers many similar health and emergency services. More importantly, NISRA argued that it would be required to hire additional medical personnel, but failed to present sufficient evidence to show that this would actually be necessary.

[7] NISRA also argued that the accommodation sought by the government would subject NISRA to an undue amount of liability and administrative cost. The fear of a lawsuit,

however, alone is not enough to constitute an undue burden under the ADA, because if it were, the defense would swallow the rule. NISRA's argument concerning administrative costs fails for similar reasons. To prove these defenses, NISRA was required to present specific evidence. NISRA chose not to do so.

As discussed above, however, NISRA was not required to prove any of its affirmative defenses because the government failed to meet its initial burden.

CONCLUSION

I find in favor of Defendant NISRA because the government failed to show that its requested accommodation is a reasonable one. My decision might be different had the government presented statistics on how a Diastat program under similar circumstances has been successful. Perhaps this data does not exist, and this issue may need to be reexamined at some point in the future if and when such data becomes available.

All Citations

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Footnotes

1 Because of the involvement of several members of Megan's family in this litigation, I will refer to members of her family by their first names in order to prevent confusion.