

RECTAL SYRINGE PROCEDURE UNREASONABLE ADA ACCOMMODATION

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The Americans with Disabilities Act (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. § 12101(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.

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.

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. Under Title II, a requested accommodation must be a reasonable one.

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. To prove an undue burden, a public entity would be required to show the costs are excessive in relation either to the benefits of the modification or to the entity's financial survival or health.

CAMP SEIZURE MEDICATION

In the case of *United States of America v. Northern Illinois Special Recreation Association*, 2016 U.S. Dist. LEXIS 31565 (N.D. Ill. 3/2/2016), the issue before the federal district court was whether it would be a reasonable accommodation to require employees at a summer camp to administer seizure medication (Diastat) through a rectal syringe in the event of a seizure emergency.

The Northern Illinois Special Recreation Association (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 programs include seasonal programs as well as summer camps that run six to eight weeks long, featuring arts and crafts, music and games, singing, theater, swimming, and other camp activities.

NISRA staff members routinely maintain custodial supervision over all participants attending

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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.

A majority of NISRA summer camp employees are part-time, typically high school and college age students in their late teens or early twenties. Oftentimes employment with NISRA is their first job. NISRA camp counselors are not required to have experience with disabled individuals to be hired by NISRA. Moreover, most camp counselors have not worked with disabled individuals prior to working at NISRA.

For over a decade, Megan Monica had attended seasonal programs and summer camps offered by the Northern Illinois Special Recreation Association (NISRA). Megan was prescribed Diastat because of her epilepsy.

Diastat is the only FDA-approved medication for out-of-hospital treatment of emergency seizures. Diastat is administered rectally in a pre-filled 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. Approximately, thirty current NISRA participants listed Diastat as a current 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 applied to all NISRA participants.

Under NISRA's seizure policy, NISRA participants with a history of seizures submitted a seizure plan in which their doctor described 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 occurred, NISRA's policy required 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. The staff member was 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 members were directed to follow the person's seizure plan to the best of his ability and call 911 as directed.

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

### NISRA ACCOMMODATIONS

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

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

Under NISRA's Personal Medical Care Protocol, the Superintendent of Recreation looked 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 was approved under this Personal Medical Care Protocol, NISRA typically required 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. Since Megan's siblings were NISRA employees, Megan received a 75 percent discount on program fees. In addition, NISRA offered to allow Megan's siblings "to come off the clock and provide Diastat to Megan as a family member should the need arise." During the course of litigation, NISRA indicated it would also allow the Epilepsy Foundation to provide volunteers to attend NISRA programs and administer Diastat when needed.

#### MOTION TO DISMISS ADA COMPLAINT

In the original complaint against NISRA, the federal government, through the Department of Justice (DOJ), petitioned the federal district court to order NISRA to "administer Diastat to Megan Monica for convulsive seizures." In response, NISRA filed a pretrial motion to dismiss, claiming DOJ had not alleged a sufficient set of facts that would support a claim under the ADA. The federal district court rejected NISRA's motion to dismiss and allowed the federal government's ADA claim to proceed to trial, *United States of America v. Northern Illinois Special Recreation Association*, No. 12 C 7613, 2013 U.S. Dist. LEXIS 52100 (N.D. Ill. 4/11/2013).

SEE: [Administration of Emergency Seizure Medication Discontinued](#)

[James C. Kozlowski, Parks & Recreation, Jul. 2013 Vol. 48, Iss. 7](#)

<http://www.parksandrecreation.org/2013/July/Administration-of-Emergency-Seizure-Medication-Discontinued/>

<http://cehdclass.gmu.edu/jkozlows/lawarts/07JUL13.pdf>

Two years later, in 2015, the federal district court conducted a trial on the ADA claim against NISRA, issuing the reported opinion described herein in 2016.

EMERGENCY REALITY

As noted by the federal district court, the ADA would require DOJ to show that NISRA camp staff administering Diastat was a reasonable accommodation under the circumstances. In the opinion of the federal district court, issuing an order that "forces lay people to administer an emergency rectal medication creates several problems." In particular, the court found the "realities of administering the medicine in a real life emergency situation" would have to be taken into account in determining whether it would be reasonable to require NISRA staff to administer Diastat. In so doing, the court noted that NISRA does not employ medical personnel and "[t]he majority of NISRA's summer camp employees are part-time high school and college age students."

DOJ had argued that the administration of Diastat was a reasonable accommodation under the ADA because it was similar to other medical accommodations already provided by NISRA staff. Specifically, DOJ had cited NISRA policy to allow staff to feed a participant through a gastro-feeding tube or administer other rescue medicines, such as an Epi-pen or inhaler. While acknowledging some similarities, the federal district court disagreed that devices like gastro-feeding tubes and Epi-pens were necessarily "similar enough to prove that the administration of Diastat must also be considered a reasonable accommodation."

While a gastro-feeding tube may be part of a daily routine, the court noted Diastat is reserved for emergency situations that may only happen once in every five years, if at all." Moreover, the court found "time is not of the essence" when a NISRA staff is learning to feed a NISRA participant through a gastro-feeding tube. On the contrary, the court noted a staff member with questions would have enough time to ask for help in assisting a NISRA participant with a gastro-feeding tube.

Further, while Epi-pens and Diastat were both required in emergency situations, the court found "a stark difference between Epi-pens and Diastat lies in administration of the drugs." Compared to Diastat, the court noted, "the operation of an Epi-pen is a much simpler task."

Epi-pens are administered through a needle that can pierce clothing, even thick blue jeans... 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...

If possible, the caregiver should put on gloves before administering Diastat because the caregiver may be exposed to feces or urine... 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.

## DRUG INSTRUCTIONS CONTRADICTION

Perhaps most significantly, the federal district court found "the government's requested accommodation seems to directly contradict the manufacturer's instructions for Diastat, which are mandated by the FDA [Food and Drug Administration] to accompany the drug."

As characterized by the federal district court, "[t]hese 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." According to the court, these "exact conditions" would include "what is and is not an episode appropriate for treatment and the timing of administration in relation to the onset of an episode." Moreover, the court found the following explicit warning and instructions would "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."

### 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...

[B]ecause 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...

In the opinion of the court, under the circumstances, it was not reasonable to grant the government's request for the court to order NISRA camp staff to "administer Diastat to Megan Monica for convulsive seizures" because NISRA would be required to "disregard these cautionary instructions." Moreover, under the circumstances, part-time high school and college age employees at NISRA summer camps might not reasonably be expected to effectively implement these instructions and function as competent "caregivers" in administering Diastat in an emergency situation.

As a result, the federal district court concluded, "the government has failed to meet its initial

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burden of showing that its requests are considered reasonable accommodations under the ADA." In so doing, the court also acknowledged NISRA's efforts to provide alternative accommodations for Megan.

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.

In reaching this determination, the court noted that the "decision might be different if the government had presented statistics on how a Diastat program under similar circumstances has worked and been successful." While acknowledging the possibility that "this data does not exist," the federal court noted "this issue may need to be reexamined at some point in the future if and when such data becomes available."

### FUNDAMENTAL ALTERATION DEFENSE

Assuming the government had been able to "meet its initial burden of showing that its requests are considered reasonable accommodations under the ADA," in its defense, NISRA had argued that "the accommodation requested would fundamentally alter the nature of NISRA's services and subject NISRA to an undue amount of liability and administrative costs."

As described by the federal district court, the "fundamental alteration defense" would allow a public entity "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." In the opinion of the federal district court, NISRA had failed to prove this defense because "NISRA already offers many similar health and emergency services." Moreover, the court found NISRA had failed to present sufficient evidence to show that the requested accommodation would require hiring additional medical personnel.

NISRA had also argued "the accommodation sought by the government would subject NISRA to an undue amount of liability and administrative cost." The federal district court rejected this argument.

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.

That being said, the court reiterated, "NISRA was not required to prove any of its affirmative defenses [fundamental alteration and/or undue financial burden] because the government failed to meet its initial burden" of proof under the ADA to show that the requested accommodation was reasonable under the circumstances.

CONCLUSION

Having found no evidence that NISRA had violated Title II of the ADA under the circumstances of this case, the federal district court entered judgment in favor of NISRA.

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