

UNITED STATES DISTRICT COURT
NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION

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|---------------------------|---|-------|
| UNITED STATES, |) | |
| |) | |
| Plaintiff, |) | |
| |) | No. |
| v. |) | |
| |) | |
| NORTHERN ILLINOIS SPECIAL |) | Judge |
| RECREATION ASSOCIATION, |) | |
| |) | |
| Defendant. |) | |

UNITED STATES' COMPLAINT

The United States of America, by its attorney, Gary S. Shapiro, Acting United States Attorney for the Northern District of Illinois, alleges that the defendant Northern Illinois Special Recreation Association (NISRA) discriminates against individuals with epilepsy on the basis of disability, by denying them an equal opportunity to participate in the recreational programs NISRA provides because it refuses to administer a potentially lifesaving anti-seizure medication. This discrimination is in violation of title II of the American with Disabilities Act (ADA), 42 U.S.C. §§ 12131 *et seq.*, and its implementing regulation, 28 C.F.R. Part 35. In support of its complaint for declaratory and injunctive relief, the United States avers as follows.

Jurisdiction and Venue

1. This court has jurisdiction of this action under 28 U.S.C. §§ 1331 and 1345, and 42 U.S.C. § 12133. The court may grant the relief sought in this action pursuant to 42 U.S.C. § 12133 and 28 U.S.C. §§ 2201 and 2202.
2. Venue is proper in this district pursuant to 28 U.S.C. § 1391, in that all of the claims and events giving rise to this action occurred in this district.

Parties

3. The United States Department of Justice is a federal agency responsible for administering and enforcing title II of the ADA, 42 U.S.C. §§ 12131, *et seq.*

4. The defendant Northern Illinois Special Recreation Association (NISRA) is an inter-government, tax-exempt organization designed to serve children and adults with developmental, physical, neurological, emotional, and learning disabilities by providing year-round recreation programs. NISRA is a “public entity” within the meaning of the ADA, 42 U.S.C. § 12131(1), 28 C.F.R. § 35.104, and is therefore subject to title II of the ADA, 42 U.S.C. §§ 12131, *et seq.*, and its implementing regulation, 28 C.F.R. Part 35.

Facts

5. NISRA is formed from 13 park districts and municipal recreation departments in northern Illinois and is headquartered in Crystal Lake, Illinois. NISRA provides year-round recreational activities for children and adults with disabilities in northern Illinois. These programs are organized according to age group and disability classification, and include weekly therapeutic recreation programs, Special-Olympics training programs, social events, special weekend trips, and a variety of summer camps. These activities are run by NISRA staff and are generally hosted at one of the 13 associated park district facilities. NISRA also offers “inclusion services” for individuals with disabilities who can participate in a traditional park district program with the assistance of an aide.

6. NISRA employs no medical personnel for its programs, but it hires staff, including camp counselors and site directors, who have experience working with individuals with disabilities. Typically, one counselor is responsible for the supervision of two to four participants, but if needed, NISRA will provide one-on-one service. Counselors are also

responsible for assisting individuals who need specialized personal care, including feeding, toileting, and changing clothes or diapers. NISRA counselors and site directors attend 12 to 16 hours of orientation and training, covering general information about disabilities, adaptive activities, behavior management, and first-aid and emergency procedures.

7. NISRA staff dispense medication if a participant's parent or guardian requests it. In addition to regularly administering over-the-counter and prescribed oral tablets and liquid medications, NISRA staff: (1) administer epinephrine auto-injector shots (such as EpiPen) to children experiencing life-threatening allergic reactions; (2) dispense asthma medication to children with asthma; and (3) feed children with gastrostomy feeding tubes. The epinephrine auto-injector is pre-filled with a single dose of epinephrine and packaged in a plastic auto-injector. To use the auto-injector, NISRA staff must jab it against the outer thigh of the patient, which engages a spring-loaded hypodermic needle and delivers the epinephrine.

8. NISRA serves children and adults who have been diagnosed with epilepsy, a neurological disorder defined as a tendency for recurrent seizures that affects about three million people in the United States. Seizures are symptoms of abnormal brain activity that vary from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to convulsions. Prolonged seizures lasting longer than ten minutes are extremely dangerous and can cause serious brain injury or even death. Prolonged seizures may also manifest as cluster (repetitive) seizures lasting the same period, from which the patient does not regain consciousness.

9. NISRA staff are specifically trained on how to respond to seizures pursuant to NISRA's seizure management policy. Participants with a history of seizures must submit a

seizure plan in which their doctor describes the type of seizure(s) they experience, the medications they currently take, and the protocol to follow in the case of a seizure. If a seizure occurs, NISRA's policy requires the nearest staff member to move the other participants away from the area to preserve the person's privacy. The staff member then eases the person onto the ground and turns him onto his side. Additionally, the staff member is directed to follow the person's seizure plan to the best of his ability and to call 911 under certain circumstances.

10. M.M. is a 17-year-old female, who lives with her parents in McHenry County, Illinois. M.M. was diagnosed with epilepsy in 1994. In addition to having epilepsy, M.M. has an IQ of 69 and low muscle tone as result of a stroke she had when she was younger.

11. M.M. is a qualified individual with a disability within the meaning of the ADA, 42 U.S.C. §§ 12102(1) and 12131(2) because her epilepsy is a physical impairment that substantially limits her major life activities and her neurological functions.

12. M.M. has experienced approximately 30 tonic-clonic seizures (commonly known as grand mal seizures) over the last 10 years, with some of them lasting longer than one hour. As a result of her prolonged seizures, M.M.'s doctor prescribed her Diastat AcuDial (Diastat), which is the only FDA-approved medication for out-of-hospital treatment of emergency, prolonged seizures. Diastat is a gel form of diazepam, a central nervous system depressant (brand name "Valium") that is used to stop seizures, thereby preventing brain damage or death that could result if seizures persist. Diastat works most effectively if administered within five minutes of the onset of the seizure. The longer it takes to administer Diastat, the less effective it is in arresting an ongoing seizure.

13. Diastat is administered rectally using a pre-filled plastic syringe with a flexible plastic tip. This form of administration allows the medication to act quickly and safely. The most common side effect of Diastat is sleepiness, and there are no adverse side effects when administered incorrectly, such as when the person is not actually experiencing a seizure. Following standard procedures, as prescribed by the treating physician, lay persons can easily and safely administer the medication when a prolonged seizure or cluster of seizures occurs. Diastat was specifically developed to be administered by people without medical training, such as parents, teachers, camp counselors, and caregivers, and can be used at home, school, work, or when traveling.

14. M.M.'s doctor developed a seizure plan that describes what her seizures look like, how to treat her seizures, and when to call 911. This plan directs that Diastat be administered immediately upon the onset of a tonic-clonic seizure.

15. M.M. has received Diastat approximately 20 times over the last 15 years. M.M.'s mother, father, and several of her siblings all have administered Diastat at least once, including her youngest sister who was 13 years old at the time. After receiving Diastat, M.M.'s seizures usually begin subsiding within two to three minutes. She has never experienced any adverse side effects from Diastat.

16. In 2007 and 2008, M.M. participated in NISRA's summer camp program, as well as other NISRA programs during the school year. At that time, NISRA agreed to administer Diastat if needed, but at no time during this period did M.M. suffer a seizure that required Diastat.

17. After the 2008 summer camp session, however, NISRA changed its policy to no longer administer Diastat. NISRA's current policy is to follow the participant's seizure plan as closely as possible, but instead of administering Diastat, it will call 911 under circumstances the parents identify.

18 M.M.'s parents requested that NISRA continue to accommodate M.M. by administering Diastat if needed, but NISRA refused. Instead of allowing its staff members to administer Diastat, NISRA offered that M.M.'s parents could hire a caretaker or send a family member to accompany M.M. and administer Diastat, if needed. If no caretaker was provided, NISRA told M.M.'s parents that it would follow its standard policy for seizure management, and if there was an emergency, it would call 911.

19. As a result, M.M. did not attend any NISRA programs in 2009 or 2010 because her parents did not want to risk M.M. having a tonic-clonic seizure without the assurance that M.M. would receive Diastat when it could save her life rather than whenever paramedics might arrive later.

20. Notwithstanding NISRA's policy against administering Diastat, M.M.'s parents decided to take a chance and enroll M.M. in the 2011 NISRA summer camp because she had not experienced a tonic-clonic seizure in the previous five years and had been entirely seizure free for six months. Although M.M.'s parents were concerned about sending her to camp without having Diastat administration available, they did so because they did not want M.M. to miss out on an important opportunity to develop socially and have fun. M.M. attended 2011 summer camp without incident.

21. Since the 2011 summer camp, however, M.M. has had several additional tonic-clonic seizures. M.M. desperately wants to participate in future NISRA summer camps, because it is the only summer camp available to her. Given the recent onset of her prolonged seizures, however, NISRA's continued refusal to administer Diastat makes M.M.'s participation in any NISRA camp or program very risky to her health.

22. N.R. is an eight-year-old girl who lives with her parents in Crystal Lake, Illinois. N.R. was diagnosed with epilepsy in 2005. Other than being highly allergic to certain foods, N.R. has no other major illnesses and no cognitive deficiencies.

23. N.R. suffers from several different types of seizures and has a history of prolonged seizures, with her longest lasting 90 minutes. As a result of her prolonged seizures, N.R.'s doctor developed a seizure plan that directs that Diastat be administered in two cases: (1) immediately upon the onset of a tonic-clonic seizure; or (2) when she is observed staring (partial complex seizure) and unresponsive for over one minute.

24. N.R. is a qualified individual with a disability within the meaning of the ADA, 42 U.S.C. §§ 12102(1) and 12131(2) because her epilepsy is a physical impairment that substantially limits her major life activities and her neurological functions.

25. Because of N.R.'s epilepsy, she qualifies for NISRA's inclusion services where NISRA provides a full-time aide to assist N.R. while she participates in a Crystal Lake Park District program. N.R. registered to participate in the Crystal Lake Park District's 2011 summer camp and requested that the NISRA aide be allowed to administer Diastat if needed. NISRA refused N.R.'s request and informed her parents that the NISRA aide would only monitor N.R. for signs of seizure and would call 911 if a seizure occurred.

26. Notwithstanding NISRA's refusal to administer Diastat, N.R.'s parents allowed her to participate in the 2011 summer camp because N.R. had not had a tonic-clonic seizure in the previous four years. Although N.R. had no seizures during and since the 2011 summer camp, her parents remain concerned about what will happen if N.R. needs Diastat at camp and cannot get it.

27. N.R.'s parents want N.R. to participate in future Crystal Lake Park District summer camps, but they also want NISRA to agree that its aide will administer Diastat if needed.

Violations of ADA

28. The allegations of Paragraphs 1 through 27 of the complaint are hereby realleged and incorporated by reference.

29. NISRA's policy refusing to administer Diastat to individuals with epilepsy violates title II of the ADA, 42 U.S.C. §§ 12132, and its implementing regulations, 28 C.F.R. Part 35, because defendant's conduct:

1. excludes individuals with disabilities from participation in and denies them the benefits of the services, programs, or activities of a public entity, in violation of 42 U.S.C. § 12132 and 28 CFR §35.130(a);
2. does not afford qualified individuals with disabilities an opportunity to participate in or benefit from the services, programs, or activities of a public entity that is equal to that afforded others, in violation of 42 U.S.C. § 12132 and 28 CFR §35.130(b)(1)(ii); and
3. fails to make reasonable modifications in policies, practices, and procedures when the modifications are necessary to avoid discrimination on the basis of disability, in violation of 42 U.S.C. § 12132 and 28 C.F.R. § 35.130(b)(7).

Prayer for Relief

WHEREFORE, the United States prays that the court:

A. Grant judgment in favor of the United States on its complaint and declare that the defendant has violated title II of the ADA, 42 U.S.C. §§ 12131, *et seq.* and the relevant implementing regulations;

B. Enter a preliminary and permanent injunction requiring defendant to administer Diastat anti-seizure medication to participants in NISRA programs as medically required; and

C. Order such other appropriate relief as the interests of justice require.

Respectfully submitted,

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