

School Advisory Toolkit for Families

This guide offers collaborative methods for educators and parents of children with type 1 diabetes to ensure that every child enjoys the best possible school experience.



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About the Author and the Goal of This Guide

Harold Wolff is the parent of two sons: Michael, who was diagnosed with type 1 diabetes (T1D) at age three and a half, and Brian, who was diagnosed at age 26. Harold taught students in grades 4 through 12 for the first half of his educational career. For the last 16 years of his career, he was the principal of a middle school with 1,500 students.

These experiences give Wolff a unique perspective on the issues of school and child/parent relationships as they relate to T1D management. Although there is currently information available on how to deal with school personnel, this guide provides a balanced approach to how parents of a child with T1D and the school can work together to provide a safe, caring, and positive learning environment for the child/student. The goal is for both the parent's and school's points of view to be communicated, heard, and understood and to encourage a cooperative effort to provide the very best school experience for the child with T1D.

Manual Overview

As a parent, you know that your child spends most of his day in the school setting, in the care of teachers, nurses, and other school personnel. Most parents are comfortable with this environment, as most students' healthcare needs consist of Band-Aids for the occasional scrape, oral medications, and the occasional ice pack. As the parent of a child with T1D, however, you know that the day-to-day disease management is intensive and that the school must play an important role in this care.

JDRF understands the importance of your child's care in the school setting. After receiving several requests from parents for help in their children's schools, JDRF conducted an extensive research report. This report led us to develop this toolkit in conjunction with Harold Wolff and with contributions from Tamara Burns, JDRF Triangle/Eastern NC Chapter volunteer and mother to a child with T1D. We thank Tamara for her contributions to the original School Advisory Toolkit, as well as Lynn Langbein—JDRF Capitol Chapter and mother to a child with T1D—for her contributions to Appendix I, and Nanette Corriere—JDRF Westchester County Chapter and mother to a child with T1D—for her contributions to Appendix II. We also thank Lisa Shenson for her contributions in identifying state-based laws and policies. Lisa is a member of the JDRF Greater Bay Area Chapter and mother to a child with

T1D. We hope this guide will equip you for working with your child's school to ensure that proper T1D care is provided.

For ease of reading and to avoid gender bias, this manual alternates between masculine (he) and feminine (she) pronouns.

For further information or support with T1D in the school setting, please reach out to your local chapter. You can find the chapter closest to you by going to jdrf.org and selecting the Locations tab near the top of the home page.

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Communicating with Schools

- A message to school staff
- A message to parents
- The right approach—the cooperative and respectful way
- The wrong approach—the adversarial way
- How to handle difficult situations that may arise



A Message to School Staff

Realistic expectations of school personnel (parents should read this, too)

You have a child with T1D enrolled in your school and you want him to have the very best school experience possible. You have every reason to expect that the child's parents will work with you in a friendly and cooperative manner and provide as much support and assistance as they are able. You also have every reason to expect that the child's parents will appreciate your efforts to provide a safe and caring learning environment and understand the overwhelming responsibilities that teachers and the school hold. If you make a good-faith effort to provide for the child with T1D needs, the parents should understand if, occasionally, you ask for their time, help, and support.

Working with parents in a cooperative, friendly, and mutually respectful manner requires that you understand the parents' points of view. Parents obviously need to take care of their children, BUT the parents can't do it all. Parents should do their part in providing information, snacks, supplies, emergency directions, etc., but the school needs to understand that even the best and most caring parents can't anticipate all of the school needs of their children. Parents often have jobs, family responsibilities, and stresses that can sometimes be overwhelming.

Now, add to the mix a child with T1D, and suddenly parents are confronted with the highly emotional task of raising a child with a serious and potentially life-threatening chronic disease. Feelings of guilt, anxiety, and fear are only the tip of the iceberg for these parents. Sleepless nights become a regular occurrence; parents sometimes stay up all night worrying and checking blood-glucose levels to make sure their child doesn't have a serious hypoglycemic reaction. They also must do the following:

- Learn to count carbohydrates and sometimes change their family's diet
- Learn about long- and short-acting insulin
- Learn to give shots or use an insulin pump
- Learn to check their child's blood-glucose level and interpret the results
- Understand how exercise, illness, and stress affect blood-glucose levels
- Mediate rivalries and feelings of jealousy between their children
- Build the self-esteem and understand the range of emotions of a child who suddenly is very different from others
- Combat ignorance and prejudice on a daily basis concerning their child's T1D

... all this while trying to remain the calm, dependable mother or father they have always been.

School Personnel: the parents would like you to know that they care about their child and want to do what's best for him, but they can't be everywhere all the time and can't do it all. They need your cooperation, assistance, and understanding of what they are dealing with on a daily basis.

A Message to Parents

Realistic expectations you have of school personnel (school staff should read this, too)

Of course, you want the very best school experience possible for your child. You have every reason to expect that your child will be welcomed at school and that school personnel will happily provide a caring and safe place in which your child learns and grows to the best of her ability. It is true that your

Parents: school personnel would like you to know that they care about your child and want to do what's best for her, but they can't be everywhere all the time and can't do it all. They need your cooperation and understanding of how much they do.

child's school has legal obligations that mandate certain kinds of services for your child, and if the school does not partner with you in an appropriate manner, pursuing legal means (e.g., a 504 Plan, due-process hearing) may be necessary. But please be assured that your child will thrive better if she observes you and the school working in a cooperative, friendly, and mutually respectful manner. This requires that you understand the school's point of view in addition to your own.

The school has legal and moral obligations to your child, but the school can't do it all. The school staff should make a good-faith effort to provide for your child with T1D, but keep in mind that they are only human. Even the best and most caring teachers and staff can't magically make a nurse appear if one is not available. School personnel are incredibly busy with endless responsibilities. What goes on in a school and in a teacher's classroom on a daily basis is mind-boggling.

Teachers are not only responsible for the medical needs of your child but of other children as well. Teachers are responsible for creating a positive learning environment, planning lessons, delivering effective and interesting instruction, taking attendance, planning field trips, participating in other school activities (coaching, sponsoring clubs, supervising evening activities, etc.), continuing their own education, grading papers, communicating with parents and special education teachers, attending faculty meetings, filling out paperwork, meeting state and federal mandates, and dealing with the social, emotional, physical and intellectual needs of their students.

While instructing, teachers are constantly:

- Observing student reactions and gauging understanding of what is being taught
- Monitoring and dealing with student behavior
- Adjusting instruction for students' individual needs and styles of learning
- Responding to instructions or interruptions from the office
- Ensuring the safety of students in the classroom (e.g., science labs)
- Making sure that band and orchestra students get to their lessons on time

... and all this while leaving no child behind. The nurse, office staff, and administrators are also working hard at their own jobs and are just as busy as the teachers.

The Right Approach—The Cooperative and Respectful Way

It's four to five weeks before school starts. A parent calls the school and communicates to the secretary that her daughter has just been diagnosed with T1D. The parent requests a meeting with the principal (and if possible, the nurse and teacher) when it is convenient. The parent acknowledges that this is a busy time of year for school staff, but explains that it is important that they meet before the start of the school year to work together to come up with procedures to ensure the safety of her daughter.

At the scheduled meeting: the parent acknowledges that the school is a wonderful place, that everyone is busy, and that she will be adding responsibilities. She comments on how much she appreciates what all of the people in the room will be doing for her daughter, as their time is valuable. She expresses her hope that together, she and the school staff will be able to create a plan to provide the best and safest learning environment possible for everyone.

The parent also communicates that she has a full-time job but knows that she, on occasion, will have to help out (e.g., chaperone a field trip or perhaps come to the school to give blood tests and/or shots). The parent provides information to help the school gain an understanding of T1D and how to care for a child with T1D at school. The parent provides information

about when the daughter will need lunch, physical education, and snacks. If a physical education class or lunch for the daughter's grade level is not available during these times, the parent understands and asks if they could work together to provide the best schedule that is possible. The principal, teacher, nurse, and parent all follow through on their agreed upon roles—and not only does the daughter learn and grow in a most positive school environment, she also learns how to work cooperatively and respectfully with others.

The Wrong Approach— The Adversarial Way

It's registration time at the beginning of the school year. The school is crawling with students and parents, and the school administrators, teachers, and secretaries are quite busy. A parent brings her daughter with T1D into the office, states that her daughter is diabetic, and demands an immediate meeting with the principal, nurse, and teacher.

Somehow, the principal, nurse, and teacher manage to put aside their other pressing duties on this busy Registration Day and meet with the parent and child. The parent is emotional and demands that the school take care of her daughter—letting the daughter come to the nurse's office whenever she wishes and eat snacks whenever she wishes. The parent also tells the school that she “knows her rights” and that the school must provide a full-time nurse to take care of her daughter and that if the nurse is out, the school should hire a substitute nurse. She also says flat-out that she is a busy mother who works and won't be available to go on any field trips or help out in any way.

The principal, nurse, and teacher have an immediate reaction. They are already feeling overwhelmed with all that they have to do—to hear that this student will need to be closely monitored and that low blood glucose is a life-threatening event is dire and frightening news. The teacher feels stress and even fear and wonders if she is capable of handling an emergency of this nature. How will she remember all that she's supposed to for this child?

The “fight-or-flight” response kicks in and the school staff become defensive. The principal tells the parent that her child needs to be home-schooled and that her child can't attend this school unless she is totally independent and can take care of herself. Or the nurse says that she is too busy; the parent will have to come in four times per day to test the child and give her any necessary insulin shots.

The parent again threatens that she knows her rights and she'll get a lawyer to force the school to cooperate with a 504 Plan. A long-term adversarial relationship has begun.

How to Handle Difficult Situations That May Arise

Unexpected situations may arise during your child's school years. Many of these situations may take you by surprise. Teachers, administration, rules, or other things may change suddenly or over time. These changes may cause you to jump to conclusions, but try not to react before you have all of the information. Some key things to remember when facing an unexpected challenge are:

- Remain calm.
- Take a deep breath.
- Gather all the facts.
- Offer another way to handle things (seek win-win solutions).
- Seek support (e.g., local JDRF chapter).

Diabetes Basics

- What is T1D?
- What is type 2 diabetes?
- T1D facts
- Diabetes control & management
- High blood glucose-definition, symptoms
- What to do about high blood-glucose levels
- Low blood glucose-definition, symptoms
- What to do about low blood-glucose levels
- What is glucagon?
- Checking blood-glucose levels
- Insulin delivery methods
- Effects of exercise, illness, stress, and growth on blood-glucose levels



What Is T1D?

(a simplified explanation)

T1D often develops in children, adolescents, and young adults, so it used to be called “juvenile diabetes.” Now we know that T1D can be diagnosed at almost any age. T1D is not contagious. You cannot catch T1D from someone who has it. Researchers continue to study how and why T1D occurs in certain children and families. Although T1D cannot be cured, it can be controlled.

About blood-glucose levels

A healthy pancreas produces insulin, a hormone that the body uses to change glucose in the blood into energy. Glucose in the blood comes from the food and drink a person consumes. A person with T1D doesn't produce any insulin. Without insulin, the glucose builds up in the blood, causing high blood glucose, or hyperglycemia. Blood-glucose levels that are too high and untreated for long periods of time can lead to keto-acidosis, a very serious condition. Very high blood glucose for an extended period of time can eventually lead to coma and death.

In people without T1D, the pancreas maintains a “perfect balance” between food intake and insulin. When a person eats, the pancreas puts out the exact amount of insulin needed to turn the glucose into energy. If the person eats a lot, the pancreas puts out a lot of insulin. If the person eats just a little, the pancreas puts out just a little insulin.

Insulin needs

Since people with T1D can't produce their own insulin, they must put insulin into the bloodstream through injections or an insulin pump. If people with T1D inject too much insulin (or eat too little), they may have a hypoglycemic reaction. Hypoglycemia (low blood glucose) is the most common problem in children with T1D. It can be very serious and requires immediate action.

People with T1D often struggle to determine how much insulin to inject. In a simple and perfect world, this question would have an easy answer (e.g., always eat a certain amount of food and inject a certain amount of insulin). However, in reality there is no way to know how much insulin to inject with 100% accuracy. Many factors influence how much insulin people need to get to the desired “perfect balance” of glucose and insulin. These factors include foods with different absorp-

tion rates as well as the effects of stress, illness, and exercise. Also, as children grow, their insulin needs change. Since determining how much insulin the body needs to “balance” the amount of glucose is really a best guess, sometimes the guess is inaccurate, and high or low blood glucose results.

Risk of complications

High blood-glucose levels over a number of years can cause serious damage to the body's organ systems. This damage may cause complications affecting the heart, nerves, kidneys, eyes, and other parts of the body. A number of studies, however, have proven that careful monitoring and control of blood-glucose levels greatly reduce the threat of these complications. Researchers are also making progress at developing new treatments and technologies to help people with T1D stay healthy. It's important to remember that people with T1D can lead active and productive lives, just like anyone else.

T1D is not contagious. You cannot catch T1D from someone who has it. Researchers continue to study how and why T1D occurs in certain children and families. Although T1D cannot be cured, it can be controlled.

What Is Type 2 Diabetes?

(a simplified explanation)

People with type 2 diabetes (T2D) produce some of their own insulin, but the insulin is either insufficient in quantity or ineffective in its ability to stabilize blood-glucose levels. Ineffective action of insulin is called insulin “resistance.” Many factors can cause insulin resistance; a major cause is known to be obesity. People with T2D can sometimes manage their disease with diet and exercise. Some individuals with T2D can take an oral medication that improves the effectiveness of the insulin, while others need to inject additional insulin.

Most school-age children with diabetes have T1D. Unfortunately, however, as more and more of our nation's children become overweight and sedentary, T2D is occurring more frequently in school-age children.

T1D Facts

T1D is an autoimmune disease in which the body's immune system attacks and destroys the insulin-producing cells of the pancreas. While its causes are not yet entirely understood, scientists believe that both genetic factors and environmental triggers are involved.

Affects children and adults

T1D usually strikes children, adolescents, and young adults, but it can be diagnosed in adults as well. It comes on suddenly, causes dependence on injected or pumped insulin for life, and carries the constant threat of devastating complications.

Needs constant attention

To stay alive, people with T1D must take multiple insulin injections daily or continually infuse insulin through a pump. They must also test their blood glucose by pricking their fingers for blood multiple times a day. While trying to balance insulin doses with their food intake and daily activities, people with this form of diabetes still must always be prepared for serious hypoglycemic (low blood glucose) and hyperglycemic (high blood glucose) reactions, both of which can be life limiting and life threatening.

Not cured by insulin

While insulin injections or infusions allow a person with T1D to stay alive, they do not cure T1D, nor do they necessarily prevent the possibility of the disease's devastating effects, which may include kidney failure, blindness, nerve damage, amputations, heart attack, stroke, and pregnancy complications.

Difficult to manage

Despite paying rigorous attention to maintaining a meal plan and exercise regimen and always injecting the proper amount of insulin, people with T1D face many other factors that can adversely affect efforts to tightly control blood-glucose levels. These factors include stress, hormonal changes, periods of growth, physical activity, medications, illness/infection, and fatigue.

Statistics

- As many as three million Americans may have T1D.
- Each year, more than 15,000 children and 15,000 adults—approximately 80 people per day—are diagnosed with T1D in the United States.
- The rate of T1D incidence among children under the age of 14 is estimated to increase by three percent annually worldwide.

Warning signs

Warning signs of T1D may occur suddenly and can include extreme thirst, frequent urination, drowsiness or lethargy, increased appetite, sudden weight loss, sudden vision changes, glucose in the urine, fruity odor on the breath, heavy or labored breathing, and stupor or unconsciousness.

What is it like to have T1D?

Ask people who have T1D, and they will tell you: it's difficult. It's upsetting. It's life threatening. It never goes away. But, at the same time, people with T1D serve as an inspiration by facing the disease's challenges with courage and perseverance and don't let it stand in the way of achieving their goals.

"Both children and adults like me who live with T1D need to be mathematicians, physicians, personal trainers, and dieticians all rolled into one. We need to be constantly factoring and adjusting, making frequent finger sticks to check blood glucoses, and giving ourselves multiple daily insulin injections just to stay alive."

- JDRF International Chairman Mary Tyler Moore

"It is a 24/7/365 job. We never get to relax and forget about food, whether we've exercised too much or too little, insulin injections, blood-glucose testing, or the impact of stress, a cold, a sunburn, and on and on. So many things make each day a risky venture when you live with T1D."

- Mary Vonnegut, adult, Rhode Island

"Unlike other kids, I have to check my blood glucose 8 to 10 times a day; everything I eat is measured and every carbohydrate counted. My kit goes with me everywhere I go.... Too much exercise or not eating all my food can be dangerous. I think I'm too young to have to worry about all this stuff."

- Jonathan Platt, 8, California

"It controls your life in ways that someone without it doesn't even see. For me, the worst part of living with T1D is the fear that my three children or their children might develop the disease."

- Nicky Hider, adult, New York

T1D Control and Management

Treating T1D

The main goals of treating children with T1D are:

- Maintaining normal growth and development
- Keeping blood-glucose levels within a target range (not too high, not too low)
- Promoting healthy emotional well-being

The key to good T1D control is a careful balance between food, exercise, and insulin. It's a juggling act to keep blood-glucose levels within the target range. Therefore, children with T1D must stick to their scheduled blood check, insulin injection, and snack times. Even small changes from a child's T1D care plan schedule can cause blood-glucose levels to rise or fall.

Remember: food raises blood-glucose levels, while insulin and exercise lower them. A good T1D treatment plan includes:

- Eating reasonably, consistently, and on schedule
- Testing blood-glucose level regularly
- Adjusting insulin based on blood-glucose level and activities
- Exercising regularly

High Blood Glucose—Definition, Symptoms

High blood glucose, or hyperglycemia, occurs when the body has too much food or glucose, or too little insulin. The following are all potential reasons why a person with T1D might have high blood glucose:

- Not enough insulin taken
- Eating more than usual
- Eating earlier than usual
- Eating food with higher glucose content without injecting extra insulin
- Injecting insulin at a site on the body where the absorption rate is slower or at a site that is over-used
- Missing or skipping an insulin dose

- A clog in insulin pump tubing
- Less exercise than normal
- Stress
- Illness or injury
- Other hormones
- Medications

High blood glucose generally does not immediately put the person with T1D in danger. However, high blood-glucose levels over long periods of time can lead to serious complications. The complications for diabetes primarily involve small blood vessels (microvascular) or large blood vessels (macrovascular). Microvascular disease includes eye disease, kidney disease, and nerve disease. Macrovascular disease includes heart disease and stroke. Disease leading to amputation usually involves both loss of sensation (nerve disease) and large vessel disease.

Very high blood-glucose levels can lead to diabetic ketoacidosis (DKA), or a “diabetic coma.” DKA occurs when the cells can't get the energy they need from glucose, and the body begins to burn fat and body tissue for energy. This causes the release of by-products called ketones, which are dangerous when released at high levels. Ketones become like poison to the body and are passed in the urine as they build up in the blood.

A person with T1D and high blood glucose may exhibit one or more of the following symptoms:

- Thirst (dehydration)
- Frequent urination
- Blurry vision
- Stomach pain
- Increased hunger
- Nausea
- Drowsiness, lethargy, exhaustion
- Confusion
- Sweating
- Fruity, sweet, or wine-like odor on breath
- Vomiting
- Inability to concentrate
- Weight loss (a longer term symptom) that eventually leads to coma

What to Do about High Blood-Glucose Levels

The following recommendations are general treatments for high blood glucose. Specific actions—such as giving additional insulin—should be determined by the caregiver responsible for T1D management, in consultation with the healthcare provider prescribing the diabetes medicines.

1. If blood-test result is slightly above normal*:

- Continue regular activity.
- Drink water or glucose-free drinks.
- Monitor blood-glucose levels by checking regularly.
- Chart blood-glucose test results.

2. If blood-test result is moderately high:

- Don't engage in strenuous exercise.
- Drink water or glucose-free drinks.
- Inject additional insulin if instructed by physician or parents.
- Monitor blood-glucose levels by checking regularly.
- Chart blood-glucose test results.

3. If blood-test result is very high:

- Don't engage in strenuous exercise.
- Drink water or glucose-free drinks.
- Inject additional insulin if instructed by parents or physician.
- Test ketone level if advised by parents or physician. If high, contact parent or physician immediately.
- Monitor blood-glucose levels by checking regularly.
- Chart blood-glucose test results.

* Please discuss with your physician what would be considered a normal blood-glucose range for your child.

Low Blood Glucose—Definition, Symptoms

Low blood glucose (hypoglycemia) is the most common and most dangerous condition for many people with T1D. Very low blood glucose may lead to insulin shock, which can be life threatening if not promptly treated. Low blood glucose occurs when the body has too little food/glucose or too much insulin. The following are all potential reasons why a person with T1D might have low blood glucose:

- Too much insulin taken
- Eating less than usual
- Eating later than usual
- Insulin was injected at a site on the body where the absorption rate is faster than usual
- Injecting extra insulin after forgetting about a previous dose
- More exercise than normal
- Illness or injury
- Other hormones
- Medication interaction

The following is a list of general symptoms that indicate low blood glucose (the person with T1D may exhibit one or more of these):

- Dizziness
- Nervousness
- Personality change/irrational behavior
- Blurry vision
- Shakiness
- Nausea
- Crying
- Sluggishness
- Sweating
- Poor coordination
- Hunger

- Lightheadedness
- Irritability
- Drowsiness
- Erratic response to questions
- Inability to concentrate

Severe symptoms (symptoms as listed above, plus):

- Convulsions
- Unconsciousness

What to Do about Low Blood-Glucose Levels

A blood-glucose meter reading below the target range specified by the physician indicates low blood glucose. The following are general treatments for low blood glucose. The physician and parents (for a child) should determine what course to follow. Please note that people with T1D have symptoms of low blood glucose at various readings. Some people with T1D feel perfectly fine at readings below 70. Others begin to show low blood-glucose symptoms at readings somewhat above 70.

1. If blood-glucose level is slightly low and the person is alert and lucid:

- Do not exercise.
- Eat. After eating, check blood-glucose level again to make sure it is within the target range. The person may require another snack later in the day.
- Continue to check blood-glucose levels regularly.

2. If blood-glucose level is low and the individual is showing signs of low blood glucose but is still able to eat:

- Immediately eat or drink a fast-acting source of glucose (e.g., juice, glucose gel, or glucose tablets). More food may be needed after that (e.g., crackers or other complex carbohydrate).
- Continue to check blood glucose-levels regularly.

3. If blood-glucose level is low and the individual is unconscious, convulsing, and/or unable to swallow:

- Remain calm.
- DO NOT administer food or drink to someone who has an altered mental status or is unconscious, as it may obstruct the airway.
- Call 911.
- Administer emergency glucagon shot. It may take up to 10 minutes for the shot to cause the blood glucose to rise, and for the person to respond. The shot can cause some people to vomit, so make sure to keep the person positioned on his side to prevent choking in case vomiting occurs.
- Continue to check blood-glucose levels regularly.
- Give additional food (e.g., crackers or other complex carbohydrate) when able to eat, if needed, in order to keep blood-glucose level in target range.

What Is Glucagon?

People with T1D who experience severe low-blood-glucose emergencies may require glucagon. Glucagon raises the blood glucose when a person with T1D is unable to swallow liquid or food because of severe sleepiness, unconsciousness, or seizure activity. Glucagon, like insulin, must be injected with a syringe into the skin. It is a hormone that helps the liver to release stored glucose in order to raise blood-glucose levels. If there is no stored glucose in the liver, glucagon will not work.

Glucagon kits

Glucagon is packaged in a kit with a vial of powder containing the medicine and a syringe filled with liquid to mix with the medicine. Directions for mixing and injecting the medicine are in the package. Read the directions carefully and ask your healthcare provider for more explanation, if necessary.

Do not mix glucagon after the expiration date printed on the kit and on the vial. Check the date regularly and replace the medicine before it expires. After mixing glucagon, discard any unused portion, regardless of the expiration date.

Tip: expired glucagon kits may be a good way to practice mixing the powder and liquid; after practicing dispose of the expired glucagon.

Checking Blood-Glucose Levels

People with T1D must check their blood-glucose level throughout the day using a blood-glucose meter. The meter tells them how much glucose is in their blood at that particular moment. Based on the reading, they take an insulin, eat, or modify activity to keep blood glucose within a target range. Regularly checking blood-glucose levels is an essential part of T1D care.

Methods for checking blood-glucose levels

Checking, or testing, involves taking a drop of blood, usually from the fingertip, and placing it on a special test strip in a glucose meter. Blood-glucose meters are easy to use, and even young children often learn quickly how to do their own blood-glucose checks. In order to properly manage their diabetes, individuals with T1D check their blood-glucose level multiple times per day. For example, they may test before eating lunch and before and after strenuous exercise.

Blood-glucose level is measured in milligrams per deciliter (mg/dL). A normal blood-glucose level is between 70 and 120 mg/dL. Keeping blood-glucose levels within this range may be difficult in children with T1D. Therefore, an individual's doctor may adjust the target range (for example, 80 to 180 mg/dL).

However, people with T1D can't always maintain their blood-glucose level within the target range, no matter how hard they try. A person's varying schedules and eating habits, as well as the physical changes that occur as they grow, can send blood-glucose levels out of range for no apparent reason. A person with T1D should never be made to feel that it is their fault if their blood-glucose level is out of range.

The latest technology in blood-glucose checking

As of 2006, a new device called a continuous glucose monitoring (CGM) system is available to test blood glucose. It works much like an insulin pump and constantly displays an individual's blood-glucose level on a screen. This system still requires a few finger pokes during the day but greatly reduces the number of meter tests. The CGM attaches to the body like an insulin pump, and the site must be changed at least every three to five days.

Insulin Delivery Methods

Syringes, insulin pens, and insulin pumps all serve the same purpose: to deliver insulin to a person with T1D, who does not produce insulin on her own.

Insulin injections

To stay alive, people with T1D must inject insulin many times a day. The exact number of injections varies from person to person. Insulin injections typically occur at regularly scheduled times during the day. Syringes or insulin pens are both used for injections, but both essentially do the same thing. Some people find the pen to be more convenient when they only need a single kind of insulin. Some children also find the pen needles more comfortable than the syringe needles. The age at which children are able to administer their own injections varies. After working through the initial trauma of being diagnosed with T1D, however, most children eventually inject their own insulin.

Insulin pumps

An alternative to insulin injections is the insulin pump. The pump is a computerized device, about the size of a beeper or pager, often worn on a belt or in a pocket. The pump delivers a continuous low (basal) dose of insulin through a cannula (a flexible plastic tube), which attaches to the body through a small needle inserted into the skin. The cannula is taped in place and the needle is removed. Common insertion sites on the body include the thighs, buttocks, upper arms, stomach, and other areas with fatty tissue.

When a person wearing a pump eats, she pushes a button on the pump to deliver an extra amount of insulin called a bolus.

The advantages of the pump include:

- Greater flexibility with meals, exercise, and daily schedule
- Improved physical and psychological well-being
- Smoother control of blood-glucose levels

The disadvantages of the pump include:

- Risk of infection
- Risk of more frequent hypoglycemia (low blood glucose)
- Risk of ketosis and ketoacidosis (a symptom of very high blood glucose)
- Constant physical reminder of T1D

A person with T1D who uses an insulin pump may need to test her blood glucose more frequently.

Personal choice

Choosing an insulin delivery method is a personal decision for a person with T1D, made by the individual, family (if a child), and medical provider. The same method may not be the right choice for everyone.

Effects of Exercise, Illness, Stress, and Growth on Blood-Glucose Levels

Exercise, illness, stress, and growth all affect blood glucose levels in a child with T1D.

Exercise makes insulin work more effectively because it takes less insulin to balance the carbohydrates consumed. Therefore, children who begin to exercise more may find that taking their typical doses of insulin before eating a typical amount of food may result in lower blood-glucose levels. (Note: every child is unique, and several factors affect blood-glucose levels, so exercise will not always result in lower blood-glucose levels.)

At school, this situation occurs in physical education classes, where activities and intensity levels vary daily. Sometimes students are learning how to play a game, and the physical intensity level is low. Other days, students spend more time playing games, running, or doing other strenuous activities. On days with more strenuous activity, children with T1D should be more aware of how they are feeling and have extra snacks and insulin on hand. Physical education teachers should monitor the student more closely before and during the activity.

A child may also be more active during recess and field trips. Older children with T1D who participate in a sport need to plan for this additional activity. They may reduce insulin intake or eat extra food before the activity begins.

Illness and stress, on the other hand, often cause blood-glucose levels to rise. A child who doesn't feel well may have trouble performing in class. She may have difficulty concentrating, for example. In such cases, the teacher can help reduce some of the stress by providing extra time for students with T1D to complete tests or other work. Teachers may also need to be more patient as the student works to grasp new ideas and concepts.

Sometimes a child will achieve (at least for a short time) the "perfect balance" of insulin and food intake. Life can be rewarding and even close to normal for several months or longer. Then something as simple as a growth spurt could suddenly throw everything off. Early adolescence is an especially difficult time: the body grows, and hormones turn boys and girls into men and women. Children may have more issues with blood glucose at this time and require more help emotionally and physically, both at home and at school.

Parent/School Partnership

- An adult and a backup
- Recommended parent responsibilities
- Recommended administrator responsibilities
- Recommended school nurse responsibilities
- Recommended student responsibilities
- Recommended teacher/ staff member responsibilities
- Other staff responsibilities (i.e., PE teacher and coach, school counselor, food-service staff, bus driver)
- The most important rules

**See Disclaimer on page 1 of this manual.*



Parent/School Partnership

It is essential to establish a partnership with your child's school in order to create a supportive environment in which he can learn and thrive. The parents', students', and school's needs must be mutually communicated, heard, and understood.

From the first day your child returns to school post-diagnosis, you should make every attempt to establish a positive partnership with the school. Be sure on the first day to explain the vast differences between type 1 and type 2 diabetes to your child's teacher. While most people know of diabetes, much of their knowledge is usually about T2D. The Diabetes Basics section of this manual is designed to help with the education of teachers and even school nurses about T1D. The school nurse may or may not have had previous experience with other children with T1D; regardless, it is important for the school nurse to understand that each person's experience with the disease is different.

In cases where there is no school nurse on site, another adult in the school—usually a health aide, teacher, or administrator—should be designated as the “go-to person” for your child. That adult needs to learn all he or she can about your child's T1D-management routine in order to support your child throughout the school day.

A key part of a positive parent/school partnership is a clear understanding of who will be responsible for each task. In this section you will see a suggested list of responsibilities for all parties involved. You should feel free to tailor this list to your personal situation.

Here are a few more ideas for nurturing the partnership with your child's school:

- Keep the lines of communication open and show that you appreciate the partnership.
- Email care team members after the first meeting thanking them for attending and offering them your complete contact information and any useful local information. Let them know they can contact you with any questions at any time.

- When and if appropriate, inform them of the presence of JDRF in your community and the work the organization is doing to find a cure.
- Check in with the teacher about your child's T1D regimen regularly, and separately from academic conferences.
- Check in regularly with the school nurse, as she may be aware of other concerns.
- Check in about replenishing supplies as necessary.
- From time to time, eat lunch with your child at school to meet the lunchroom staff and monitors.
- After each grading period teachers may change or unused information may be “compartmentalized;” consider holding another informational or training session with new staff.
- Send a holiday greeting thanking administration and all care team members for their participation and constant care.

An Adult and a Backup

Ideally, at least one adult and one “backup” should be trained to check your child's blood glucose and recognize and treat low blood glucose (hypoglycemia) and high blood glucose (hyperglycemia). These adults should also know when and how to check for ketones and what to do if the ketone level is abnormal. If the child is mature enough to treat himself, he should be allowed to do so, but the student should remain under the supervision of an adult at all times during a hypoglycemic reaction and should not be allowed to walk alone to another part of the school to test blood glucose or get treatment.

If the parent or child requests it, the school should provide a location in which the child can check his blood glucose or take insulin privately (but still with adult supervision, if needed). The two adults should also be trained to give a glucagon injection in case of emergency. The responsibility for glucagon administration by school staff is similar to school staff being prepared to give a shot (Epipen or similar) to a child in the school who is allergic to bees.

Further responsibilities of adult caregivers should include:

- Knowing the student's meal plan and working with the parent to accommodate special events/meals if possible
- Allowing the student to see the school nurse or other school medical personnel whenever needed
- Allowing the student to eat a snack anywhere as needed, and to use the restroom and drink water at any time
- Allowing the student to miss school for doctor's appointments to monitor T1D without incurring negative consequences
- Providing a safe and secure location for storage of insulin and glucagon, and allowing the student immediate access to diabetes supplies at any time
- Ensuring the student's full participation in all sports, extracurricular activities, and field trips, with any necessary supervision provided
- Providing aids to help the student academically, if needed. Examples of situations in which this might be necessary include making up for class time missed due to T1D care or academic problems that can be traced to frequent hypo- or hyperglycemia

Recommended Parent Responsibilities

- Inform the school/administrator that your child has T1D.
- Provide the information needed for training of school staff (samples provided in Diabetes Basics and Educate the Educator sections of this guide).
- Work with the administrator and/or school nurse to provide this training.
- Understand teacher and school personnel schedules and that all staff members involved with your child may not be able to attend the same training time, so training may have to be given more than once.
- Work with the principal or building administrator to identify school staff (hopefully including main academic teacher) for more in-depth training.
- Provide specific information about your child (include your child's picture on forms).
- Work with school staff to determine when and where blood testing is to take place.
- Clearly communicate (verbally and in writing) your permission for school staff to call 911 whenever they deem it necessary and to administer glucagon—no questions asked.
- Clearly communicate that the school has your permission to share the needed medical information about your child with everyone who needs to know.
- Provide multiple emergency contact people and phone numbers including your physician.
- Be sure to communicate with school staff any changes that occur concerning your child and her T1D management.
- Provide all the necessary equipment, supplies, snacks, and emergency items needed. You will also want to set up a system with teachers and other staff to alert you when supplies or snacks are getting low. A school kit might include:
 - Vials of your child's insulin, clearly labeled with child's name
 - Syringes
 - A second glucose meter to keep at school—including batteries and test strips
 - One or more glucagon kits (renew each year as they expire)
 - Glucose tablets, juice boxes, or another form of fast-acting sugar
 - Cake icing or glucose gel
 - Snacks containing protein, such as peanut butter crackers
 - A mini carb-counting guide (found at most bookstores)
- Work with the principal to develop a process to cooperatively and amicably address disagreements or issues if and when they arise.
- Encourage your child to wear a medical alert ID.

- Make sure that your child understands that she is not to take unfair advantage of modifications or accommodations provided (e.g., trying to get out of physical education activities when she feels just fine).
- Accept the fact that it may be your child who is resistant to the assistance or procedure that school personnel are trying to provide. Don't blame, but work with school personnel to resolve these issues.
- Provide an emergency/disaster kit for any situation that might require your child to stay at school for a longer than expected period of time.
- Work with appropriate school personnel to develop a 504 Plan. Remember that a 504 Plan provides reasonable accommodations for your child. Also remember that the goal is to provide accommodations that your child really needs or would need in a special circumstance (e.g., standardized testing).
- Communicate with and help train staff members new to your child during the school year (e.g., after-school club sponsor if your child joins a club after the school year begins).
- When appropriate, include your child in all discussions and decisions made about her.
- Clearly state to your child who should be contacted at school if she feels ill.
- Promote, encourage, and teach your child the skills to become more and more independent in her T1D management and care. Discuss the level of independence of your child for blood testing and shot/insulin pump management (depends on age level/maturity of child) with school staff.
- If the school and school personnel are making a good-faith effort to do all that is possible for your child, help out as much as you can when the school requests your assistance. (For example, legally, the school may be responsible for providing a nurse to provide for your child's needs. But if the school nurse is ill and school personnel are unsuccessful in arranging for a substitute, thank them for trying and then give up your day to go to school and provide services for your child.)
- Help out at some after-school or extracurricular events when your child is participating. These are especially difficult times for schools to provide the appropriate trained staff members.

Recommended Administrator Responsibilities

- Become knowledgeable about diabetes, especially the differences between type 1 and 2.
- Meet with the parent/student at the beginning of the year or when the child is diagnosed to set up the year-long plan for management and care.
- Identify and arrange for training of appropriate school staff. Besides the more obvious classroom teachers, don't forget the band teacher, coach, librarian, any special education teachers, bus driver, substitute bus driver, lunchroom supervisors, hall monitors, etc.
- Identify school staff (including main academic teacher) for more in-depth training. These staff members are then available to provide an extra level of care when the nurse is not available.
- Work with parent and school staff to determine where blood testing is to take place.
- Provide leadership to foster and support a positive learning environment for the student; act as an advocate for the student; clearly communicate to teachers and other staff members in contact with the student your expectations for them to cheerfully follow through on the modifications and accommodations set up for the student.
- Set up an "emergency" system that clearly communicates to the student what to do if an adult in the building refuses to allow the student to do what is needed. Make sure that the student understands that there will be no disciplinary action taken against the student for following through on the agreed upon actions (e.g., leaving class to come to the nurse's office even if a substitute teacher says that the student cannot leave class). Remind the student not to take advantage of these "special" rules.
- Work with the parent to develop a process to cooperatively and amicably address disagreements or issues if and when they arise.

- Work with the parent to address the emotional issues involving the student. Identify/introduce the child to school support staff (e.g., counselor, social worker, and administrator) to whom the child should go to for emotional help.
- Ensure the student's confidentiality and right to privacy are maintained.
- At quarter, trimester, and semester times, ensure that teachers and staff members new to contact with the student are trained/reminded.
- Ensure that the office secretary/aide who meets substitute teachers when they arrive reminds the substitute teacher to be sure to look in the substitute folder for the names and information about students with medical needs.
- Ensure that every teacher has a substitute folder that includes the names, information, and pictures (if possible) of students with medical needs.
- Understand and implement federal and state laws regarding students with diabetes.
- Genuinely welcome the parent and student to your school.
- Support the parent/child in working with reluctant teachers or other school staff.
- Work with the parent and other appropriate personnel to develop a 504 Plan.
- Ensure that the student receives the needed modifications and accommodations.

Recommended School Nurse Responsibilities

- Clarify roles and responsibilities with trained school personnel (roles for the other trained school personnel are listed in the rest of this section).
- Maintain or gain familiarity with current standards of care for children and teens with T1D.
- Work with an interdisciplinary team to implement the healthcare plan and Section 504, Individualized Education Program (IEP), or other education plan, and then monitor compliance.
- Coordinate care at school and school-sponsored events for students with T1D, and serve as a liaison between the school and the students' families or make sure there is a trained school staff member who is responsible for this coordination.
- Train or coordinate training of school personnel in T1D care.
- Perform or assist with students' T1D care in accordance with their healthcare plans, including blood-glucose monitoring and insulin and glucagon administration.
- Be available on site throughout the school day and when students with T1D are involved in field trips, extracurricular activities, or school-sponsored events or make sure trained school personnel are available in your absence. Carry emergency diabetes supplies.
- Serve as a resource for school personnel regarding up-to-date information about T1D.
- Be an advocate for the student with less-accommodating school staff.
- Respect each student's confidentiality and right to privacy.
- Communicate regularly with the parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other diabetes supplies are low and need replenishing.

Recommended Student Responsibilities

- Participate and contribute to the best of your ability in the discussions of how the school will help you manage your T1D.
- Clearly communicate to school personnel how you are feeling.
- Understand what you are to do if an adult at school doesn't give you permission for something you know you need to do (e.g., doesn't let you test your blood or go to the nurse for food).
- Learn what to say to students who make inappropriate or mean comments to you about your T1D.
- Know how you will handle the situation if food that isn't good for you is passed out during class or other times.
- Do not take advantage of the accommodations and modifications that the school is providing.
- Make sure you have your supplies (blood-testing meter, etc.) with you when needed.
- Talk to the school counselor, social worker, or other appropriate school staff member about problems you may be having. These can be long-term emotional problems or even simple problems, such as if you'd rather have your snack at 10:30 a.m. instead of 10:45 a.m.
- Work to become as independent as possible in your own T1D care and management.
- Do not let any other student touch, use, or have any of your T1D supplies (e.g., syringes, glucose tablets).
- Don't be afraid to let good friends know about your T1D and how they might help if you ever need assistance.

Recommended Teacher/Staff Member Responsibilities

- If the student with T1D states he doesn't feel well, NEVER send the student to the nurse's office without another student or adult accompanying him!
- Genuinely welcome the student with T1D into your classroom and create a supportive environment for him.
- Assure the parent that you will do everything in your power to keep the child safe.
- Willingly give time to be trained in understanding T1D and the care of the student.
- Be an advocate for the student with less-accommodating school staff.
- Create a system for a regular reminder to yourself to be vigilant and observant concerning the student with T1D. Use the same system to remind yourself of low- or high-blood-glucose symptoms and emergency responses.
- Create a system to make sure that when field trips or other special/different kinds of activities are planned, the health-care needs of the child with T1D are remembered and addressed.
- Provide agreed-upon modifications and accommodations to the student. Don't make the student and parents jump through hoops if another modification/accommodation needs to be added to the agreed-upon list. Find ways to help the student feel less "different."
- When you are out of the classroom, ensure that the substitute or other person covering your classroom knows what to look for, what to do, and what modifications or accommodations are necessary. Have a Substitute Teacher Folder in an obvious place and include the appropriate information on the student with T1D. See Substitute Teacher Form in the Educate the Educator section.
- Communicate regularly with the student's parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other needed supplies need to be replaced.
- Respect each student's confidentiality and right to privacy.
- Work with the parent and child to determine how to address T1D issues that may arise in the classroom.

Other Staff Responsibilities

PE teacher and coach

- Read and carefully follow the written care plans, including the 504 or IEP and the healthcare plan.
- Clearly understand the impact of exercise/high-intensity physical activity on the blood-glucose levels of a student with T1D.
- Always have available a cell phone or other communication device to contact the school office or 911 in case of an emergency (e.g., low blood glucose/insulin shock) when outside the school building, in athletic facilities, or at away games.
- Always have quick-acting food/drink on hand (e.g., glucose tablets, orange juice).
- At away games, have glucagon available and train and practice its administration.
- Train and practice in the use of the student's blood-testing equipment.
- Communicate regularly with the student/athlete with T1D to discern her readiness/ability to participate in physical activity or game situations; listen to what the student with T1D says and follow her lead.
- Allow the student/athlete with T1D to carry water and food with her at all times and eat/drink in class or at practice/games.

School counselor

- Learn about, support, and respond to—as appropriate—the emotional needs of students with T1D.
- Promote and encourage independence and self-care consistent with students' abilities.

Food service staff

- Provide students with T1D and their families with lunch menus in advance that include the nutritional content of menu selections (including calories and grams of carbohydrates, glucose, protein, and fat).
- Ensure that students with T1D have easy and timely access to food and enough time to finish their meals.
- Allow students with T1D to eat first if low blood-glucose (hypoglycemia) symptoms are present.

Bus driver

- Know which students on your bus route have T1D.
- Have emergency instructions regarding diabetes care on the bus.
- Be aware of where students normally keep their supplies.
- Permit students with T1D to eat snacks on the bus, if necessary.

The Most Important Rules

Rule # 1

The number one and most important rule is: when a student with T1D says he doesn't feel well or thinks he is having a blood-glucose problem, NEVER, EVER send the student to the nurse's office without another student or adult accompanying him! This one is worth repeating. A student with T1D who is beginning to have an insulin reaction (low blood glucose) may not be capable of getting to the office on his own. Remember that some of the symptoms of low blood glucose are erratic behavior, confusion, and inability to concentrate.

It is imperative that a student with T1D has an adult or dependable student go with him to ensure that the student makes it to the office. Failure to follow through on this rule could result in a life-threatening emergency. It is also a good idea to use the intercom or classroom phone (or the teacher's cell phone) to call the nurse's office to let him or her know that the student is on the way.

(If possible, a better practice would be to have the treatment/nurse come to the student versus the student going to the treatment/nurse.)

Rule # 2

The second rule is: when in doubt, if a student with T1D is experiencing a blood-glucose problem, and a blood-testing meter is unavailable to determine whether the blood-glucose level is high or low, treat for low blood glucose. In other words, when in doubt, have the student eat. Test as soon as possible to determine a further course of action.

Rule # 3

If a student with T1D is beginning to shake, lose consciousness, or experience convulsions, lay the student on the floor on his side. This is to prevent further injury to the student and to prevent choking.

Educate the Educator: Staff Training

- Identification of staff for training
- T1D care team school-year plan
- T1D care team meeting talking points
- Sample letter for the T1D care team
- Sample letter for classmates' families
- T1D-management overview for staff/substitute teachers
- Potential academic and school rule modifications
- Emotional issues involving the student
- Extracurricular/after-hours school events
- Tips for coaches
- Notification/training of substitute teachers
- Field trip checklist
- Educational tools and templates



Educate the Educator

In caring for children with T1D, educational professionals must understand the importance of their involvement in the child's T1D management. Young children, including school-aged children, need assistance with their T1D care, while middle and high school students can often manage their own T1D more independently. Each student is different; thus, education and training on how to care for a child and adolescent with T1D must be an ongoing group effort of the parents, school staff, and the student with T1D.

When a student has been newly diagnosed, it is critical that the parent initiate a partnership with the school to care for his T1D. Many teachers may only have had past experience with older relatives with T2D. For this reason, it is important to start with the basics in your training. Included in this section are training tools that might assist with educating your child's teacher and training school staff in T1D management.

Effective T1D management at school has numerous positive outcomes. It can:

- Promote a healthy, productive learning environment for students with T1D.
- Reduce the number of absences of students with T1D.
- Reduce classroom disruptions and disturbances.
- Help ensure an effective response in case of a T1D-related emergency.

Identification of Staff for Training

The following is a list of staff members who should be considered for T1D training.

- Principal
- Assistant principal
- Dean
- Nurse
- Health aide
- Guidance counselor
- Social worker
- Psychologist
- Academic teacher(s)
- Physical education teacher
- "Specials" teachers (music, art, etc.)
- Librarian
- Classroom aides
- Cafeteria manager and lunchroom monitors
- Hall monitors
- Bus drivers/bus driver manager
- Coaches
- Sponsors of clubs that the student might join
- Secretaries
- Band/orchestra teacher

T1D Care Team School-Year Plan

(Your child's name) T1D Care Team

Plan 20xx–xx School Year

Step 1: Contact school to request care team meeting, teacher assignment, and schedule for the next school year.

When: April/May

Step 2: Provide introduction to T1D/T1D care, emergency kits and instructions to:

Who: Nurse and administration. Nurse should provide copies of care plan.

When: Shortly after contacting school to set up meeting. Familiarity with these materials before the meeting will lead to more active and productive team meetings.

Step 3: T1D Care Team Meeting—Preliminary Session

Who: Classroom teachers, administration, nurse, and parents

When: Preferably before the end of the school year

- Inquiry: what is your familiarity with T1D?
- Overview of materials: what is T1D? What is involved with daily care?
- Tools: glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
- Overview of materials: highs and lows, symptoms, emergencies, treatment, effects
- Influences: schedule (timing, activity), meals/snacks, other hormones, illness

Additional topics:

- Request that *Taking Diabetes to School* by Kim Gosselin be read to class, if age appropriate.
- Determine how and where to perform classroom blood-glucose checks.

- Determine schedule strengths/weaknesses.
- Discuss timing/strategies of snacks and meals.
- Discuss situations requiring communication/coordination: celebrations, lessons with food, treats, birthdays, field trips, field day, delayed start, early dismissals, substitutes, nurse/specials substitutes, fire emergencies/drills, lockdown emergencies/drills.

Step 4: T1D Care Team Meeting—Group Session

Who: Classroom and specials teachers, nurse, administration, counselor, parents, child

When: Prior to the start of the new school year

- Inquiry: what is your familiarity with T1D?
- Overview of materials: what is T1D? What is involved with daily care?
- Tools: glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
- Overview of materials: highs and lows, symptoms, emergencies, treatment, effects
- Glucagon demonstration and exercise
- Influences: schedule (timing, activity), meals/snacks, other hormones, illness
- Question and answer period

Step 5: Follow-up

- Email links to additional resources/more detailed information (following meeting).
- Email nurse for progress/issues report (at one week, two weeks, one month, three months).
- Email reminder to send home perishables in emergency snack kits over the holidays.
- Replenish perishables in emergency snack kits upon student's return in January.
- Email reminder for kits and supplies to be sent home the last day of school.
- Check in frequently and offer thanks readily.

T1D Care Team

Meeting Talking Points

- Student has T1D and requires insulin so her body can use the food she eats. Daily care requires a regimen of checking blood-glucose levels throughout the day to monitor the effects of food intake, insulin, time, activity, other hormones and illness.
- She uses a blood-glucose monitor or meter. The meter sends the level to her insulin pump using radio-frequency communication. We've programmed the pump with settings so that it can calculate a dosage of insulin based on that blood-glucose level, "active" insulin, and the grams of carbohydrates to be eaten. Her supplies are kept in her backpack and backup supplies are located in emergency kits throughout the school. Emergency glucagon injection kits with instructions (orange) are in her backpack, nurse's office, and physical education pack.
- A "normal" blood-glucose level is 80 to 120 mg/dL. (Child's name) "target" level at school is 100 to 200 mg/dL. Low blood-glucose levels occur when there is too much insulin and/or too much activity and not enough glucose in the body. Immediate action (giving sugar) is necessary to prevent nerve/brain damage, loss of consciousness, and/or seizure. It can take 10 minutes for glucose to get into the bloodstream, so a short break or rest is also helpful. Signs to look for include pallor, nausea, frustration, and uncharacteristic or emotional behavior. She typically feels shaky. Prolonged periods of high blood-glucose levels (above 240 mg/dL) occur when there is not enough insulin and can cause acid levels to build up in the body, which can cause vomiting, dehydration, or coma.
- Therefore, we must commit to a daily regimen designed to prevent avoidable emergencies, and we must prepare for influences that can put (child's name) at risk, such as changes to the schedule—timing, activity, meals and snacks—as well as illness, hormonal changes, and stress.
- Glucagon demonstration and exercise

A few reminders

- Checks can be done anywhere and at anytime. It's best to wash hands or use an alcohol wipe prior to checking. Her trash capsule is emptied at home.
- If the child feels low, it's OK and preferable to drink a juice box before checking.
- Treat lows immediately according to guidelines on daily sheet. Do not call home first.
- (Child's name) should have backpack with her always. No one else should carry it or open it.
- Her food is "counted," so she must finish all food that is packed. Call if there is a spill or problem.
- If in doubt, ALWAYS call.
- If her pump alarm goes off, it has a message—time to check blood glucose, low insulin, or low battery. She should respond with the appropriate action.
- If she has been ill or fighting off an infection or after a break, occasionally extra blood-glucose checks may be necessary. Otherwise, she will check before snack or lunch and administer a bolus of insulin. She will also check before getting on the school bus.
- ALWAYS be on the lookout for things that threaten the regimen. Please email a parent or call with changes to the schedule that affect the activity level and/or timing of snack or mealtime, so you can ensure the child's safe participation in activities such as assemblies, standardized testing, celebrations, lessons with food, treats, birthdays, field trips, field day, delayed starts, early dismissals, substitutes, nurse/specials substitutes, fire drills, and lock-down drills.

Thank you for your care and support!

Sample Letter for the T1D Care Team

Dear (School Name) T1D Care Team:

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with type 1 diabetes (T1D) but do not know much about the actual disease. It is our desire to share some information that will give you both comfort and confidence as you support (child's name) in caring for her T1D at school.

(Child's name) is very comfortable talking about her T1D. She doesn't like to consider herself to be "different" from other children, and we strive to make the mechanics of her care so routine that it seems invisible to those not looking for it. She is accustomed to the requirements at each snack and mealtime: checking her blood glucose beforehand, eating and finishing "counted" foods, and "pumping" insulin. Occasionally, she may need an extra snack or water. Otherwise, she can do all of the same things as anyone else.

During the school year, there are special occasions, learning experiences, and celebrations that include food and treats. With minimal planning and coordination, we can easily develop a plan for any event, activity, or change in schedule—but advance notice isn't always possible. Since (child's name) inclusion hinges on our ability to coordinate her participation, please know that we are just a phone call away at any time for questions, concerns, or feedback.

Many thanks for your care and support,

Parent's name

Our contact information is:

Home: _____

Dad's work: _____

Mom's work: _____

Dad's cell: _____

Mom's cell: _____

Physician: _____

Physician's address: _____

Physician's phone number: _____

Continued

What is type 1 diabetes (T1D)?

Diabetes is a chronic disease that impairs the body's ability to use food properly. Under normal circumstances, the hormone insulin, which is produced in the pancreas, moves glucose to the cells of the body to convert food into energy. In people with diabetes, either the pancreas doesn't make insulin (type 1) or the body cannot use insulin properly (type 2). Without insulin, glucose—the body's main energy source—builds up in the blood and causes severe damage.

Children with diabetes usually have insulin-dependent (type 1) diabetes, in which the pancreas doesn't make insulin. They need daily insulin injections or wear an insulin pump to enable their bodies to use food properly. Two kinds of problems occur when the body doesn't make insulin.

Hyperglycemia occurs when the blood-glucose level gets too high—for example, when the body gets too little insulin or too much food. Blood glucose also rises when a person with diabetes is ill or under extreme stress. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may result in ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin.

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when the blood-glucose level gets too low—for example, when the body gets too much insulin, too little food, or too much activity or stress. Hypoglycemia is the most common problem in children with diabetes. Usually it is mild and can be easily treated by giving the child a sweet food or drink.

Type 1 diabetes is not contagious. You cannot “catch” it from someone who has it. T1D can run in families. Researchers are still studying how and why T1D occurs in certain children and families. Children cannot outgrow T1D. Although there isn't a cure for T1D, it can be controlled. Research has shown that maintaining good control of blood-glucose levels can possibly prevent or at least postpone some of the long-term complications of diabetes.

Type 1 diabetes care is more flexible today than it used to be. With good medical care and support from other children and adults, children with T1D can lead healthy, active, fulfilled lives.

Sample Letter for Classmates' Families

Dear Fellow Parents of Mrs. Webster's Third Grade Class:

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes (T1D) just after her second birthday. Most people know someone with diabetes but do not know much about the disease. Since (child's name) is in your child's class, we wanted to provide some information for you to share with your child. Also, Mrs. Webster will read a book to the class, *Taking Diabetes to School* by Kim Gosselin, and have (child's name) talk about what she does to take care of her T1D.

(Child's name) is very comfortable talking about her T1D, wearing an insulin pump, and taking her backpack of supplies with her wherever she goes. She doesn't consider herself to be different from other children, and we refrain from referring to her as a "diabetic." She is accustomed to a daily routine that helps to control her T1D. At each snack and mealtime, she must check her blood-glucose level, eat and finish "counted" foods, and calculate a dose of insulin to match her intake. To make the calculation, we must count up the total grams of carbohydrate that she will eat, and her pump's computer determines the right amount of insulin.

When there is a class celebration or if you send in treats for the class, we can plan for (child's name) to take part if we know the "count" to use. She is not on a restricted or special diet. (Child's name) can eat anything sweetened with glucose, Splenda, or Nutrasweet, but she avoids other artificial sweeteners and glucose alcohol since they cause severe digestive discomfort. Thank you for your cooperation in planning for an amazing year for all of our children!

We hope you will call us if you have any questions. Thank you!

Sincerely,

Parents' names

Phone number

What is T1D?

Type 1 Diabetes is not contagious. You cannot "catch" it from someone who has it. T1D can run in families. Researchers are still studying how and why T1D occurs in certain children and families.

Type 1 diabetes is a chronic disease that impairs the body's ability to use food properly. The hormone insulin, which is produced in the pancreas, helps the body to convert food into energy. In people with diabetes, either the pancreas doesn't make insulin (type 1) or the body cannot use insulin properly (type 2). Without insulin, glucose—the body's main energy source—builds up in the blood.

Continued

Children with diabetes usually have insulin-dependent (type 1) diabetes (T1D), in which the pancreas doesn't make insulin. They need daily insulin injections to enable their bodies to use food properly.

Two kinds of problems occur when the body doesn't make insulin. Hyperglycemia occurs when the blood-glucose level gets too high—for example, when the body gets too little insulin or too much food. Blood glucose also rises when a person with diabetes is ill or under extreme stress. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may result in ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin ([child's name] drinks extra water and may have to skip a snack).

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when the blood-glucose level gets too low—for example, when the body gets too much insulin, too little food, too much activity or stress. Hypoglycemia is the most common problem in children with T1D. Usually it is mild and can be easily treated by giving the child a sweet food or drink ([child's name] uses fruit snacks or a juice box).

Children cannot outgrow T1D. Although there is no cure for T1D, it can be controlled. Research has shown that maintaining good control of blood-glucose levels can prevent or postpone some of the long-term complications of T1D.

Type 1 diabetes care is more flexible than it used to be. With good medical care and support from other children and adults, children with T1D can lead healthy, active, fulfilled lives.

T1D Management Overview for Staff/Substitute Teachers

Overview—daily care

Eight-year-old (child's name) is a child with insulin-dependent diabetes (T1D) attending the third grade at (school name). She wears an insulin pump that continuously gives her insulin. Her mini backpack contains the necessary items to perform the frequent blood-glucose checks that help to control her T1D, avoid low-blood-glucose emergencies, and prevent long-term complications. Both must be with her at all times.

(Child's name) is capable of checking her blood-glucose level and programming her pump under supervision. At this age, she requires support evaluating numerical results to determine the action required. Every day, she must maintain a regimented schedule and prepare for any changes or adjustments to that schedule. Since her pump calculates insulin amounts based on the grams of carbohydrates eaten at each snack and meal, it is extremely important to make sure that she always finishes all of the food that is "counted."

All adults who come in contact with the child (classroom and specials teachers; substitutes and school administration) should be made aware of the child's medical condition, symptoms of low and high blood glucose, and emergency care. On a daily basis, those familiar with (child's name)'s personality, demeanor, and behavior should keep in mind recognizable symptoms of low blood glucose and act immediately when symptoms are exhibited, reminding her to consider how she feels, and having her perform a blood-glucose check if in doubt. Ignoring symptoms or using a "wait and see" approach can quickly lead to an otherwise avoidable emergency situation such as discussed below.

(Child's name)'s target blood-glucose range is _____ during school hours. Sudden drops in blood-glucose levels lead to "insulin reaction," low-blood-glucose emergencies. Levels below 65 mg/dL cause brain and/or nervous system damage; levels below

45 mg/dL can cause seizure, coma, or even death. Daily log sheets kept in her mini backpack display up-to-date blood-glucose level guidelines/charts to consult whenever a check is performed, making it easy to prevent emergencies and administer treatment for "lows". High blood-glucose levels are less worrisome over a short period of time and should be treated with extra fluids and/or corrected with insulin when discovered, unless accompanied by nausea.

In the case of a seizure, convulsions, or loss of consciousness due to severely low blood glucose, a glucagon injection must immediately be administered by the school staff. 911 should be called before administering the glucagon, but there should be NO delay in administering the glucagon while waiting for the ambulance to arrive.

Potential Academic and School Rule Modifications

Academic and school rule accommodations and modifications should be tailored to the unique needs of each student with T1D. Factors such as age and maturity, illness, and stress can impact when accommodations and modifications might be necessary. Accommodations and modifications may include:

- Allow food to be stored/eaten in the classroom.
- Allow insulin injection in classroom or nurse's office.
- Allow the student to carry a minipack for T1D supplies.
- Allow food to be stored in student's locker.
- Allow student to have/eat food on field trips or other outside school activities.
- Allow student to have a water bottle or quick access to water.
- Allow student to test blood-glucose level in the classroom and/or other school areas and/or to leave the classroom to go to the nurse's office as often as needed.
- Allow student access to bathroom as often as needed.
- Allow student to be first in the lunch/cafeteria line.

- Allow student to determine level of participation in strenuous physical activities without penalty.
- Allow student to keep a cell phone on his person. (Clearly define that the only appropriate use of the cell phone is for diabetic emergencies. At all other times, school rules for cell phone use should be followed!)
- Provide storage areas for food or equipment.
- Provide additional time for academic tests (including standardized tests).
- Allow student to test blood-glucose level/eat before tests (including standardized tests).
- Allow student extra time for homework completion.
- Provide modified homework or tests.
- Provide additional academic help (and assign no penalties) after illnesses/absences/missing instruction due to T1D issues.
- Assure that the nurse and other staff are appropriately trained in T1D care and management and emergency treatment.
- Assure student's full participation in all school activities with necessary assistance.
- Provide counselor or social worker services.
- Delay testing if blood-glucose level is too high or too low.

The parent(s), student, principal, and/or guidance counselor should discuss the modifications/accommodations with the student and the need for the student to not take advantage of any changes in classroom and school rules.

Emotional Issues Involving the Student

When a student is diagnosed with T1D, his whole life changes in an instant. All of a sudden he can't eat and drink all of the things his friends are eating and drinking. After the baseball game, everyone runs to the ice chest to get a soda, but he has to find diet soda. He may be looking forward to a class or activity all day, but then his blood glucose acts up and he has to miss it. As if these challenges were not enough, he also has to deal with prejudice and teasing from other students, and sometimes even adults, who don't understand the disease.

Although some students are very open about their T1D, most don't like to be considered "different." Once again, the age when T1D onset occurs, and the age, maturity level, personality, and emotional state of the student all affect how he will adjust to life with T1D. T1D is stressful at any age, but particularly during adolescence when a student is most craving his independence. Conflicts between the student and his parents and teachers are almost inevitable, but having an understanding support network to help him work through these issues can do wonders for his emotional well-being.

Creating a support network requires discussions between the parent(s), student, nurse, administrator, guidance counselor, and teachers; these should always include consideration of emotional and social issues. The student's desire for privacy should be respected whenever possible. Some emotional/social issues to consider include the following:

- Where will testing of blood-glucose levels take place?
- Where will snacks be eaten?
- Will the student simply state to the teacher that he needs to go see the nurse, or does a signal need to be established between student and teacher for the student to communicate this need? (Either way, don't forget to send another student or adult with the student with T1D!)
- Will classmates be told/educated about T1D and the student with T1D?
- Who will do the talking/educating, and how?
- How will parties/food be handled so that the student is not left out or put in an embarrassing situation?
- Will the student wear an insulin pump during physical education class? If not, where will it be stored?
- Will the student wear a medical ID bracelet?
- How will the school and/or the parent deal with the student if he resists care, does not take his insulin, refuses to check blood-glucose levels, reports false glucose levels, etc.?
- If the student with T1D manipulates his insulin/food intake to gain or lose weight, how will that be handled?
- How will depression or anger issues be handled?

Extracurricular/After-Hours School Events

Students with T1D, like other students, should be encouraged to participate in extra-curricular activities. Being in the play, working on the yearbook, playing a sport, participating in intramurals, joining a club, joining the band, attending the school dance/activity night—all of these activities contribute to the future success of any student and can support the student with T1D both physically and emotionally.

It is important to have a staff member who is informed, trained, and capable of caring for the student with T1D in the case of low- or high-blood-glucose issues at any of these extra-curricular or after-hours school activities. For most of these activities, the sponsor or leader of the activity would be the ideal choice to support the student's T1D management. In the case of a school dance/activity night or similar kind of event, it would certainly be reasonable to expect that parents might want to volunteer to attend.

Tips for Coaches

How to help a young athlete with T1D:

- Review the athlete's T1D management plan.
- Know how to check blood-glucose levels.
- Know how to recognize and learn to treat hypoglycemia (low blood glucose), including how to administer glucagon.
- When the student experiences and treats low blood glucose, it is still critical to have her sit out for a period of time in order to recover and allow the body time to bring the blood glucose up within the target range.
- Know how to recognize and learn to treat hyperglycemia (high blood glucose), including how to administer insulin.
- Allow the athlete to eat whenever and wherever necessary.
- Allow extra trips to the bathroom or water fountain if needed.
- Allow the athlete to miss occasional practices for medical appointments.
- Pump sites can be a sensitive topic with regard to athletics; be aware that the student must determine if/where to wear their pump during practice/competition.

Notification/Training of Substitute Teachers

In the ideal school world, all substitute teachers at a school would receive the same diabetes training that regular teachers receive. Unfortunately, there is sometimes a good deal of turnover in available substitute teachers during a school year. "Regular" substitutes move and/or get full-time teaching positions. New people move into the area during the school year and apply to be a substitute teacher. It is difficult to keep up with these changes and ensure that all substitute teachers in a building are fully aware and trained to deal with students with T1D.

Due to these challenges, the school should do the following:

- Ensure that the secretary who meets substitutes as they arrive has set up a system for alerting subs when a student with T1D will be in one or more of their classes. These substitute teachers should be told specifically to look for the T1D information sheet in each teacher's substitute folder. The secretary should emphasize to the sub Rule #1: if the student with T1D states he doesn't feel well, NEVER, EVER send the student to the nurse's office without another student or adult accompanying the student!
- Ensure that every teacher with a student with T1D in his classroom has a substitute teacher folder with emergency information about the student with T1D.

Field Trip Checklist

- Contact parent to discuss duration and location of field trip to determine the student's needs, the location, and contact numbers of parents during the field trip, and to get an updated contact list with emergency phone numbers.
 - Ensure that at least one chaperone is trained in the student's T1D regimen.
 - Ensure that the student has the right amount and types of food (lunch and snack) plus extra food and plenty of water.
 - Ensure that the student has fast-acting (high-sugar) liquids (e.g., orange juice, cola), glucose tablets, and glucagon in case of low blood glucose.
 - Ensure that the student has a blood-glucose meter, testing strips, lancets, antiseptic wipes (staff should bring gloves if student will not test independently), and logbook.
 - Ensure that the student has enough insulin, the right types, and syringes.
 - If the student wears an insulin pump, be sure he has the pump and related supplies.
 - Other, as specified by parent or student's physician
-

Notes:

Substitute Teacher: Emergency Medical Form

The following student has T1D. Please read this information carefully, as failure to react properly can result in a potentially life-threatening situation.

Name of student _____

Student is in my class during the following time period(s):

Student should never be sent to the nurse or out of class without another adult or trusted student with him/her!

**Picture
of
Student**

Symptoms indicating that a problem may be occurring:

Dizziness	Nervousness	Personality change
Blurry vision	Shakiness	Nausea
Crying	Sluggishness	Pale coloring
Irrational behavior	Sweating	Poor coordination
Hunger	Confusion	Headache
Lightheadedness	Irritability	Drowsiness
Erratic response to questions	Unable to concentrate	Thirst
Frequent urination	Stomach pain	Lethargy
Exhaustion	Fruity odor on breath	Vomiting
Convulsions	Unconsciousness	Other (provided by parent or physician) _____

(Common symptoms for this child have been circled)

If one or more of the above symptoms are occurring, call for immediate assistance. Use the school intercom system, in-class telephone, or a cell phone, or immediately send another adult or trusted student to get help. If needed, obtain help from a nearby teacher. If the student with T1D is unconscious or having convulsions, you should immediately:

1. Place the student on the floor, preferably on her side.
2. Call for *immediate* school assistance.
3. Call 911.

The following are special accommodations for this child (e.g., ok to eat in class, go to restroom).

High Blood Glucose Help Sheet

Symptoms:

Thirst (dehydration)	Frequent urination
Blurry vision	Stomach pain
Increased hunger	Nausea
Lethargy, drowsiness, exhaustion	Confusion
Sweating	Fruity, sweet, or wine-like odor on breath
Vomiting	Inability to concentrate

Response:

1. If blood-test result is slightly high _____ (insert blood-glucose level):

- Regular activity may continue.
- Drink water or sugar-free drinks.
- Monitor by testing regularly to see if blood glucose continues upward.
- Chart test results.

2. If blood-test result is moderately high _____ (insert blood-glucose level):

- No strenuous exercise.
- Drink water.
- Possible additional insulin (by chart or by instructions from physician or parent)
- Monitor by testing regularly to see if blood glucose continues upward or comes down.
- Chart test results.

3. If blood-test result is very high _____ (insert blood-glucose level):

- No strenuous exercise.
- Drink water.
- Additional insulin (by chart or by instructions from physician or parent)
- Ketone test if advised by physician or parent
- **If student has ketones, contact parent immediately.**
- Monitor by testing regularly to see if blood glucose continues upward or comes down.
- Chart test results.

***Please have your child's doctor enter blood-glucose ranges above.**

Low Blood Glucose Help Sheet

Mild to moderate symptoms:

Dizziness	Nervousness	Personality change
Blurry vision	Shakiness	Nausea
Crying	Sluggishness	Pale coloring
Irrational behavior	Sweating	Poor coordination
Hunger	Confusion	Headache
Lightheadedness	Irritability	Drowsiness
Erratic response to questions	Unable to concentrate	

Severe symptoms:

Convulsions
Unconsciousness

Response:

1. If blood-test result is slightly low and student is alert and lucid:

- No exercise.
- If it's almost lunchtime, eat lunch (student should be accompanied to make sure he gets to lunchroom and is eating); after eating, student should test again to be sure blood glucose-level is back within target range; may need an additional snack somewhat later in day.
- Any other time, eat a snack; after eating, student should test again to be sure blood-glucose level is back within target range; may need an additional snack somewhat later in the day.
- Continue to monitor by testing regularly to see if blood glucose comes up.

2. If blood-test result is low and student is showing signs of low blood glucose but is able to eat:

- Immediate food intake (quick-acting source of glucose, e.g., juice, glucose gel, or tablets)
- Additional food intake may be necessary (e.g., crackers).
- Direct monitoring of student by nurse or trained personnel until blood-glucose level returns back within target range.

3. If blood-test result is low and student is showing signs of low blood glucose and is UNABLE to eat (student may be unconscious and/or experiencing convulsions and/or unable to swallow):

- Position student on floor on side to prevent falling/injury or choking.
- Call nurse or other knowledgeable staff member.
- Call 911.
- Administer emergency glucagon shot.
- Call parent/ask office to call parent.
- Direct monitoring of student by nurse or trained personnel is necessary until blood-glucose level returns back within target range.
- Additional food when student is able (e.g., crackers) if needed to keep blood-glucose level in target range.

Emergency Contact Information

1 Student's Full Name _____

2 Mother _____

Home Phone _____ Work Phone _____ Cell Phone _____

3 Father _____

Home Phone _____ Work Phone _____ Cell Phone _____

4 1st Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

5 2nd Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

6 Physician/Endocrinologist _____

Office Phone _____ Other Contact Phone _____

7 Hospital of Choice _____

Address _____

Phone _____

8 Insulin information/dosages _____

9 Other medical issues or other medication taken _____

The Rights of Your Child with T1D

- Your child's rights
- Section 504
- Legal rights of the child with T1D
- Common 504 Plan questions
- References for those who desire more information



Your Child's Rights

An important part of building a good working relationship with your child's school is a discussion regarding the rights of your child. It is important that you are aware of these rights and the laws that protect your child relevant to her education. While most of you will never have a problem with your school, it is still a good idea to have a plan in place that protects your child and her educational services.

There are at least three federal laws that address a school's responsibility to provide care to students with T1D:

1. Section 504 of the Rehabilitation Act of 1973 (also known simply as Section 504)
2. The Americans with Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008
3. The Individuals with Disabilities Education Act (IDEA)

This section will give a general overview of these laws and how they protect your child. Additionally, this section will provide you with the knowledge of how to be an effective advocate for your child and initiate the programs and plans that protect her while in the school setting. Additional information on these three laws and in what circumstances these laws apply can be found in Appendix I of this School Advisory Toolkit.

Disclaimer

The JDRF volunteers and staff compiling this manual are not attorneys and do not purport to give legal advice. While the information provided in this manual is believed to be accurate and up to date, JDRF makes no representations as to the accuracy or completeness of the information contained in this manual. Consult an attorney for specific advice relating to your situation.

For more information about your child's rights and the federal laws that govern services for children with diabetes, please see Appendix I.

Section 504

According to this law, parents of qualifying children have the right to develop a Section 504 Plan with their child's school. Any school that receives federal funding must comply with Section 504 laws, or they may lose the federal funds. This act further prohibits programs and activities that receive federal financial assistance from discriminating against anyone with a disability. You do not need to wait until discrimination occurs to seek the protections of this law. Rather, initiating a 504 Plan is a very proactive step in advocating for your child's rights. This law requires schools to identify educational needs and, when necessary, develop a 504 Plan. A 504 Plan is a legal (written) document specifying what "reasonable" modifications and accommodations the school must provide for a student with a disability (generally put into place for a student with a medical disability such as diabetes). A child does not need to require special education to be protected; children with T1D are protected under this law.

Note on standardized testing

Under this law, high school students (and students in lower grades taking state tests) with T1D can receive special accommodations when taking standardized tests (e.g., PSAT, AP, NMSQT, SAT, and ACT). These accommodations usually include "stop the clock" breaks for blood-glucose testing, insulin administration, bathroom visits, or taking emergency glucose to treat low blood glucose. The organizations that administer the tests generally require that students have a 504 Plan on file before providing the accommodations. Students with T1D should request the following accommodations: "extra breaks," "extended breaks," and "breaks as needed" on the SAT, and "stop the clock breaks within sections" on the ACT. These accommodations are in addition to any additional testing time that may be granted for learning disabilities, attention deficit hyperactivity disorder, or other special needs.

Accommodations often take months to be approved, so it is a good idea to file for them early. It is especially important to have college entrance exam approvals in place well before the planned testing date. Since college entrance exams are in all likelihood the most important exam that students take throughout their high school careers, it is imperative that students with T1D receive the testing accommodations they need in order to do well on them. After all, the student's SAT and/or ACT scores will influence which colleges she is accepted into, and these outcomes can affect the path that her life will follow.

See Appendix II for more detailed information on precisely why and how to file the application for SAT and ACT accommodations.

Americans with Disabilities Act (ADA)

This law specifically prohibits all schools and day care centers—except those run by religious institutions—from discrimination against people with disabilities, including T1D. Its definition of disability is the same as in Section 504 (includes diabetes).

The laws within this act say that your child with T1D has the right to go to school, play a sport, join a club, and do everything else that kids without T1D do. It further states that public schools and other covered organizations must make “reasonable accommodations” for your child’s T1D.

Individuals with Disabilities Education Act (IDEA)

Many students with T1D do not qualify for IDEA protection, but it is important to know what it is in case you may qualify. This law covers children whose disability impairs their academic performance. It requires that such children be given a “free, appropriate public education.” Qualification depends on how T1D affects the student’s ability to learn. If a student qualifies, he has the right to develop an Individualized Education Program (IEP) with his school. An IEP is similar to a Section 504 but includes specific measures to address your child’s academic performance and needed special education and other related services.

State laws & policies

Even though federal laws already provide certain protections for children with disabilities, some states provide additional legal protections and/or issue policies to further support students with T1D in the school setting. States with such legislation and/or policies include those listed below. The following provides a brief summary of legislation and/or policies by state based on information available as of October, 2012. This listing is by no means exhaustive or comprehensive. Therefore, families are strongly encouraged to refer to the links listed below as well as other state-based resources for further information.

- **Arizona: Senate Bill 1229** (2008) School districts may adopt policies and procedures regarding diabetes care. Those policies shall include provisions that: permit students who are able to provide self-care to be allowed to do so; students may carry diabetes supplies; at least two nonmedical staff may be trained as diabetes care assistants and to

administer glucagon to treat severe hypoglycemia.

Source: azleg.gov/legtext/48leg/2r/bills/sb1229s.pdf

- **California: California Education Code 49414.5** (2005) Allows training of voluntary school personnel to administer emergency glucagon; permits students who are ably skilled to perform blood-glucose testing and to otherwise provide diabetes self-care in any location at any time.

Source: lawserver.com/law/state/california/codes/california_education_code_49414-5

- **Colorado: Colorado Board of Nursing 3 CCR 716-1, Chapter XIII (8)** (2007) An Individualized Healthcare Plan shall be established for each student with diabetes; trained nonmedical staff may administer insulin and glucagon and also assist with carb counting and blood-glucose monitoring.
- **Connecticut: House Bill 5348** (2012) School employees may volunteer to be trained to administer glucagon to students experiencing severe hypoglycemia.

Source: cga.ct.gov/2012/ACT/PA/2012PA-00198-R00HB-05348-PA.htm

Title 10 Education And Culture Chapter 170 Boards Of Education Connecticut General Statutes § 10-220j (2004) Students who are able to self-perform blood glucose testing and have a written physician’s order shall be permitted to do so at school.

Source: search.cga.state.ct.us/dtsearch_pub_statutes.html

- **Florida: Florida House Bill 747** (2010) Prohibits schools from sending students to a different school than the student might otherwise attend because the school does not have a full-time nurse or other trained personnel; students may provide self-care and transport supplies for all school related functions and during transport if authorized in writing by the parent and treating physician; the State Board of Education and Department of Health will create rules encouraging school districts to train school personnel in daily care and emergency treatment for students with diabetes; school districts and related entities will not be held liable for injuries resulting from a student who is transporting or using his/her diabetes supplies.

Source: [leg.state.fl.us/statutes/index.cfm?](http://leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=1000-1099/1006/Sections/1006.062.html)

[App_mode=Display_Statute&Search_String=&URL=1000-1099/1006/Sections/1006.062.html](http://leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=1000-1099/1006/Sections/1006.062.html)

- **Hawaii: Hawaii Statutes § 302A-1164** (2005) School staff may volunteer to be trained to administer glucagon. School staff may not be held liable for injury resulting from administration of glucagon unless administration of glucagon involved gross negligence, or gross/willful misconduct.

Source: capitol.hawaii.gov/hrs2006/Vol05_Ch0261-0319/HR-50302A/HRS_0302A-1164.HTM

- **Illinois: HB 6065, Care of Students with Diabetes Act** (2010) Parents shall submit a diabetes healthcare plan that includes treating physician's instructions; the plan shall be updated by the parents as needed, and shall include specific care instructions; a standardized record of blood-glucose levels and insulin dosing administered by school staff shall be maintained; delegated care aides shall perform duties to care for student based on his/her diabetes care plan; school principal will ensure compliance; all school staff will be trained in basics of diabetes care; delegated care aides shall be trained by a licensed healthcare professional to perform care duties; students may provide self-care if stated in his/her healthcare plan; students shall not be assigned to attend a specific school on the basis of diabetes; school staff shall not be liable for care except for willful or wanton misconduct.

Source: ilga.gov/legislation/fulltext.asp?DocName=09600HB6065&GA=96&SessionId=76&DocTypeId=HB&LegID=51897&DocNum=6065&GAID=10&Session=

- **Kentucky: Kentucky Statutes, Title 13, Chapter 158, § 158.838** (2005) Every school (public, private, or parochial) shall have at least one person on campus throughout the day who is trained to administer glucagon. Staff trained to administer glucagon will not be held liable unless action involved gross negligence or misconduct.

Source: statutes.laws.com/kentucky/158-00/838 and Kentucky Legislative Research Commission Report Student Health Services for Students with Chronic Conditions lrc.ky.gov/lrcpubs/RR374.pdf

- **Louisiana: Senate Bill 759** (2012) A diabetes management and treatment plan created by the treating physician shall be submitted for any student (public or private) who is seeking care of diabetes while at school; students who are capable of self-management shall be allowed to do so; if there is no school nurse available, unlicensed staff may be trained to serve as a diabetes care assistant who will be available to deliver care as per the student's management and treatment plan during the school day and school-related activities;

staff shall be immune from liability; training of staff shall be performed by the school nurse or a healthcare professional with expertise in diabetes.

Source: legis.la.gov/billdata/streamdocument.asp?did=812565

- **Massachusetts: General Laws of Massachusetts, Title 12, Chapter 71, § 54B** (2005) Students who are capable of self-care shall be permitted to do so and to be in possession of diabetes supplies.

Source: malegislature.gov/Laws/GeneralLaws/PartI/TitleXII/Chapter71/Section54b

- **Michigan: Michigan State Board of Education Model Policy on Diabetes Management in the School Setting** To view a copy, go to: michigan.gov/documents/mde/SBE_Model_Policy_on_the_Management_of_Diabetes_in_the_School_Setting_FINAL_11-8-11_370189_7.pdf

- **Montana: MCA § 20-5-412** (2004) Parents are permitted to designate a non-licensed school employee who willingly volunteers to be trained to administer glucagon; training must be provided by a healthcare professional or recognized expert in diabetic care selected by the parent/guardian.

Source: data.opi.mt.gov/bills/mca/20/5/20-5-412.htm

- **Nebraska: Nebraska Revised Statutes Annotated, Chapter 79, Article 2, (d) §79-225** (2008) An approved or accredited school, be it public, private or parochial, shall allow a student to self-manage his/her diabetes with written permission from the parent/guardian; the school and the parent/guardian, in partnership with the student's treating physician, shall develop a written diabetes medical management plan; the student shall be permitted to self-manage in any location at any time; if the student harms another individual with diabetes supplies, the student may be prohibited from possessing supplies and the parent/guardian shall be responsible for any costs associated with the injury.

Source: uniweb.legislature.ne.gov/laws/statutes.php?statute=79-225

- **New Jersey: NJA 267** (2009) If parent/guardian informs school of child's diagnosis of diabetes, school shall be required to develop an individualized healthcare plan and emergency plan; student shall be allowed full participation, and accommodations shall be provided for all school-sponsored activities; school nurse shall ensure that staff is appropriately trained in diabetes care; staff trained by the nurse may administer glucagon in an emergency if the nurse

is not available; a student who is deemed skilled shall be able to provide self-care; school bus drivers shall be trained in treatment of hypoglycemia and emergency protocols; school employees shall be not held liable if action is performed in good faith.

Source: njleg.state.nj.us/2008/Bills/A0500/267_R1.PDF

- **New York: NYS Department of Education Policies** (see below) Students with diabetes must be allowed to monitor blood-glucose level in any location at any time, and must receive assistance if needed; this care task may be performed by any staff person. Unlicensed personnel: may supervise a self-directed student in verifying insulin dosage; may be trained by a licensed healthcare professional to administer glucagon; perform blood-glucose monitoring.

Source: **NYS Dept. of Ed. Clarification on Insulin Pumps** (March 2012)

p12.nysed.gov/sss/schoolhealth/schoolhealthservices/insulin-pump.pdf

Source: **NYS Dept. of Ed. School Executive's Bulletin on Glucagon** (March 2004)

schoolhealthservicesny.com/uploads/Glucagon%20Memo%203-22-04.pdf

Source: **NYS Dept. of Ed. Blood Glucose Monitoring Memo** (January 2001)

p12.nysed.gov/sss/schoolhealth/schoolhealthservices/bloodglucosemonitoring.pdf

- **North Carolina: NC General Statutes § 115C-12, (31)** (2008, 2010) The State Board of Education shall adopt guidelines for the development and implementation of individual diabetes care plans (see source below for specific details) and shall take into account the American Diabetes Association's recommended guidelines for the care of children with diabetes and recent resolutions issued by the US Department of Education Office for Civil Rights involving complaints involving allegations of discrimination against students with diabetes; parents may submit a written request for the development of an individual diabetes care plan to be developed with involvement by the parents, treating physician, classroom teacher, student (if appropriate), and school nurse (if available); students who are able to self-manage shall be permitted to do so.

Source: ncleg.net/EnactedLegislation/Statutes/HTML/BySection/Chapter_115C/GS_115C-12.html

- **Oklahoma: Diabetes Management in Schools Act, HB 1051** (2007) A diabetes medical management plan shall be developed for any student seeking diabetes care at school or any related activity; a school nurse shall provide the care; if no nurse is available, the principal will make every effort to seek staff volunteers to assist the student with diabetes care; a school district shall not restrict the student's attendance to a particular school based on the presence of a school nurse; the school nurse or State Department of Health shall coordinate training of all aspects of diabetes care for designated staff; information about diabetes care shall be provided to school bus drivers; students who are able to provide self-care shall be permitted to do so in any location at school and have access to supplies; employees providing care shall be immune from civil liability unless performed with reckless or willful misconduct.

Source: sos.ok.gov/documents/legislation/51st/2007/1R/HB/1051.pdf

- **Oregon: Oregon Revised Statutes, Title 36, Chapter 433, § 433.800 to § 433.830** (2003) Nonmedical personnel are permitted to administer glucagon for emergency treatment of hypoglycemia; training shall be performed by a licensed healthcare professional; the volunteer trained to administer glucagon shall be immune from liability when acting in good faith except in those instances of wanton misconduct.

Source: leg.state.or.us/ors/433.html

- **Rhode Island: Rhode Island Code, Title 16, § 16-21-28.2** (2008) A parent may authorize nonlicensed personnel to be trained to administer emergency glucagon for those times when no school nurse is available; training shall be provided by a licensed healthcare professional; a school nurse shall not be required to provide training; a staff member may not be penalized for refusing to be trained, and school administrators shall allow staff to volunteer; school personnel will not be held liable unless there is evidence of gross negligence or willful misconduct.

Source: webserver.rilin.state.ri.us/Statutes/TITLE16/16-21/16-21-28.2.HTM

HOW WE MAKE PROGRESS

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Combine monitoring technology with insulin pumps to consistently provide the right amount of insulin—at the right time.



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Involves implanting new insulin-producing beta cells wrapped in a permeable protective barrier that releases insulin as required to reduce the need for injections, blood testing and carb counting.



Complications

JDRF funds studies that could lead to therapies to slow or stop kidney failure—which affects one-third of children and adults with T1D.



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RI State Department of Education Diabetes Care Management Policy: Each school district shall develop policies that allows students to self-manage diabetes care whenever possible; an individualized healthcare plan and emergency plan shall be developed by the school nurse in collaboration with the parent/guardian and student's healthcare provider, and student (if appropriate); students who are able to provide self-care shall be permitted to check blood-glucose level in any location at any time, carry supplies, have access to water and bathroom, at school or school-sponsored activities.

Source: thrivetri.org/documents/Diabetes%20Care%20Management.pdf

- **South Carolina: South Carolina Code of Laws, Title 59, Chapter 63, Article 1, § 59-63-80** (2005) Each school district shall adopt a policy requiring that students with special healthcare needs have individual healthcare plans; students who are deemed able shall be permitted to self-monitor and self-administer medication unless there is sufficient evidence that it would seriously jeopardize the safety of the student or others; students shall be permitted to carry supplies and medications.

Source: scstatehouse.gov/code/t59c063.php

- **Tennessee: Tennessee Code Annotated, Chapter 49-5-415** (2004) A medical management plan must be developed that lists the healthcare needs of the student at school; a student who is able to self-manage shall be permitted to do so in any location; nonlicensed personnel may volunteer to be trained to assist a student with diabetes care excluding insulin administration; all school nurses must have knowledge of diabetes care and the state guidelines; training of school personnel must be provided by a school nurse; all training must be conducted on an annual basis; a school nurse will provide care if available on site; a student shall not be forced to attend a different school than he might otherwise attend because of diabetes; sharps shall be disposed of consistent with the state's Tennessee Occupational Safety and Health Administration guidelines.

Source: tennessee.gov/tccy/tnchild/49/49-5-415.htm

- **Texas: Texas Statutes and Codes, Title 2, Subtitle H, Chapter 168, § 168.002-168.009** (2005) A diabetes management and treatment plan must be developed for each student by the parent/guardian and treating physician; the school principal shall seek nonlicensed staff members who

can be trained to assist in diabetes care, including admin of insulin and glucagon (see source below for specific details). If a school nurse is not available, nonlicensed trained staff shall provide care; at least one person will be available on campus to provide care; a student capable of self-care shall be permitted to do so in any location at any time and carry supplies; bus drivers shall be informed of emergency care instructions; students with diabetes may attend a school even if there are currently no personnel trained in diabetes care.

Source: statutes.legis.state.tx.us/Docs/HS/htm/HS.168.htm

- **Utah: Utah Code § 53A-11-603** (2006) A student's parents may provide signed permission authorizing staff to be trained to administer glucagon; once it is received by the school, the school shall train and allow at least two staff members to administer glucagon. Schools shall allow students and/or staff to possess glucagon so it can be accessed quickly in an emergency.

Source: le.utah.gov/code/TITLE53A/htm/53A11_060300.htm

Utah Administrative Code § R156-31b-701 (2008) A nurse may train unlicensed staff in the administration of glucagon; training shall occur at least once a year.

Source: rules.utah.gov/publicat/code/r156/r156-31b.htm#T32

Utah Administrative Code 156-31b-701a (2008) Students who are able to provide self-care shall be permitted to self-administer insulin. A nurse may train unlicensed staff to provide diabetes care, including how to administer insulin.

Source: rules.utah.gov/publicat/code/r156/r156-31b.htm#T32

- **Virginia: Code of Virginia Title 22.1, Chapter 14, Article 2, § 22.1-274(E)** In schools with at least 10 staff members, at least two staff members shall be trained to administer insulin and glucagon (and at least one staff person in schools with fewer than ten staff members).

Source: leg1.state.va.us/cgi-bin/legp504.exe?000+cod+22.1-274 and VA Department of Education Manual for Training Public School Employees in the Administration of Insulin and Glucagon doe.virginia.gov/support/health_medical/medication/manual_training_insulin-glucagon.pdf

- **Washington: Code of Washington, Title 28A, Chapter 28A.210, § 28A.210.330** (2005) A school shall provide individual health plans for students with diabetes; the school shall make exceptions necessary to accommodate the students' needs to eat whenever and wherever necessary, have easy, unrestricted access to water and bathroom use, have provisions made for parties at school when food is served, eat meals and snacks on time, and other necessary exceptions; a school employee may volunteer to be a parent-designated adult to provide care as needed and is trained by a healthcare professional or diabetes expert selected by the parents.

Source: apps.leg.wa.gov/RCW/default.aspx?cite=28A.210.330

- **West Virginia: Diabetes Care Plan Act, West Virginia Code Annotated, Chapter 18, Article 2K** (2006) The WV State Board of Education shall establish guidelines for the development and implementation of individual diabetes care plans that shall meet or exceed the American Diabetes Association's recommendations for the care of children with diabetes in the school and day care setting; the school nurse shall develop the plan with the child's parent/guardian and treating physician, teacher, student (if appropriate) and other relevant personnel; each county board of education shall make available information and staff development in order to appropriately support and assist students with diabetes.

Source: legis.state.wv.us/WVCODE/Code.cfm?chap=18&art=2K#02K

- **Wisconsin: Wisconsin Annotated Statutes, Chapter 118, § 118.29** (2001) Any school bus driver, school employee, or volunteer authorized by the school principal or school/district administrator, and likewise in any private school by the principal or school administrator, may administer (including via injection) a prescription drug to the student in compliance with the written instructions of a practitioner if the parents provide written consent; any school employee may administer glucagon provided it is also reported to an emergency medical service provider; any person who renders in good faith emergency care to a student is immune from civil liability.

Source: docs.legis.wisconsin.gov/statutes/statutes/118/29

The parent/school partnership continues

504 Plans are a way for you to hold the school accountable for meeting your child's needs while in the school's care. Remember, though, that this is a partnership you are building with your child's school, and all parties have a role in the 504 process. Below is general information regarding 504 Plans. For more detailed information on the 504 process and 504 Plans, please see Appendix III of this School Advisory Toolkit.

School's role in the 504 process

It is the responsibility of the school and its personnel to have an understanding of T1D and be trained in its management and in the treatment of T1D emergencies. Knowledgeable, trained school personnel are essential to a student's safety and physical well-being when dealing with immediate health risks of high or low blood-glucose level.

Furthermore, an individualized 504 Plan should be developed and signed by the school, the parent or guardian, and the child's T1D management care team. The 504 Plan should address the specific needs of the child and provide specific instructions related to the following:

- Times/places for blood-glucose monitoring, including accommodations for testing and treating
- Ensuring that staff members are trained in checking blood-glucose levels, recognizing and treating high- and low-blood-glucose symptoms, and administering both insulin and glucagon
- Allowing the student to eat whenever and wherever necessary, including eating lunch at an appropriate time and allowing enough time to finish eating
- Allowing extra trips to the bathroom or water fountain
- Ensuring the student's full participation in all sports, extracurricular activities, and field trips, with the necessary care and/or supervision
- Permitting extra absences for medical appointments and sick days when necessary, without penalty

Parent's role in the 504 process

In addition to submitting a formal request for a 504 Plan and a cover letter to the school, a parent or guardian is responsible for providing the school with the following:

- All materials and equipment necessary for T1D care tasks, including blood-glucose testing supplies and insulin administration (if needed). The parent is responsible for the maintenance of the equipment and must provide instructions to ensure the proper disposal of materials. A separate logbook should be kept at school for the staff or student to record blood-glucose-test results.
- Supplies to treat hypoglycemia, including a source of glucose and a glucagon emergency kit.
- Information about T1D.
- Emergency phone numbers for the parent and the student's diabetes doctor (and staff) so that the school can contact these individuals with T1D-related questions or during emergencies.
- Information about the student's meal and snack schedule. The parent should work with the school to coordinate this schedule with that of the rest of the class as much as possible. For young children, instructions should be given for when food is provided during school parties and other activities.

Legal Rights of the Child with T1D

If a school attempts to discriminate against your child with T1D or is unable or unwilling to commit to some agreement with the parents and child about how the child will be provided equal opportunity to participate in academic, extracurricular, or other school activities, then schools can be compelled by the legal system to provide these services.

It is suggested that the following steps be followed in such cases:

1. If the parents, school, and student cannot come to a mutual agreement about a 504 Plan or the parents suspect that the school isn't abiding by the agreement, the parents must request in writing that a 504 meeting take place. Prior to the meeting, the parent should review sample 504 Plans (see the Educate the Educator section) and prepare a list of modifications and accommodations they feel are appropriate. The parent has the right to bring a friend, advocate, or lawyer to the 504 meeting to assist in the discussion. Again, Appendix I and Appendix III of this School Advisory Toolkit contain detailed information about the laws that apply, the process for requesting a 504 Plan, and actions that can be taken when the parent feels that the school is not following the applicable laws.
2. On rare occasions, the student's academic performance may be so adversely affected by diabetes complications that he may need special education services. In such cases it is the parent's responsibility to formally request special education testing. Before this testing can take place, parents must give written permission to the school to administer these tests. The student must complete the testing and meet certain criteria to be eligible for special education services. If he/she is deemed eligible, an IEP is written, and certified special education teachers become involved in the education of the child.

If your child is denied a 504 Plan or you feel he has been discriminated against, please see Appendix I and Appendix III for more information on the legal rights of children with T1D.

Common 504 Plan Questions

Is a child with T1D automatically eligible for a 504 Plan?

The law does not provide any automatic eligibility for a 504 Plan. 504 eligibility is made on an individual basis. A team of people knowledgeable about the student must convene and determine eligibility. That being said, it would be highly unlikely that a student with T1D would not qualify for a 504 Plan. Several life functions are certainly impacted that would provide the basis for eligibility (e.g., “caring for oneself” and “learning” come quickly to mind). If a school has not suggested a 504 Plan, the parent should request, in writing, a 504 evaluation to take place. There are numerous sources (see Appendix III) that can help a parent with writing this request as well as provide information on what is to be considered by the team to determine eligibility.

Must the parent of a child with T1D be a part of the 504 team?

The law provides for the parent to be notified of the result of the 504 meeting/evaluation/discussion but does not specifically say a parent must be present at the meeting. However, the law does state that the 504 team is made up of persons knowledgeable about the student, which implies that if a parent is not allowed to attend, there may be cause for complaint and a hearing. It would be hard to argue that the parent is not a knowledgeable person about the child.

Must the 504 Plan be in writing?

The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that they are providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and violation of Section 504. As one of the representatives from the Department of Education Office for Civil Rights stated, “OCR would have no concept how a district/school would prove a 504 Plan exists and the accommodations being made without the Plan being in writing.”

Is there a requirement for an annual review of a 504 Plan?

The law does not require an annual review. It does require a “periodic” review. If the 504 Plan is well written and includes a requirement for any new teacher or staff member who will

be in contact with the child to be informed and trained, and nothing has changed in terms of the needs of the child, an annual review wouldn’t be necessary. This is one of those areas where parents can be sympathetic to school personnel time constraints. If the school is doing everything necessary and willingly trains the child’s teachers every year, and the 504 Plan already covers everything it needs to, then why make the school have an unnecessary meeting.

The law does require a “periodic” review. IDEA requires a review every three years, and that should also probably be the maximum time frame a 504 Plan should go without a formal review. There would also have to be a formal review at any time a change is needed in the 504 Plan to meet the needs of the child. It also may be necessary to have a review when the child goes to a new school in the same district (e.g., elementary to middle school building or middle school to high school building).

Must the school provide a nurse or other trained person to provide services for my child (e.g., give insulin, test blood glucose, give glucagon in an emergency)?

The law requires that *someone* who is trained should be in the school building at all times to provide needed services. The law does not require that this person is a school nurse. The school has the right to choose who is trained to provide this service. The parent has no legal right to choose a certified school nurse or other particular individual. The school can choose to have a health aide, a teacher, an administrator, or any other staff member trained to provide this service. The school cannot require the parent to be at school at any time to provide needed services. This should be written into the 504 Plan. Nurses or health aides get sick and are absent from school for any number of other reasons, so it is very important to include in the 504 Plan that staff members in addition to the nurse be trained to provide these services.

Some states have laws that state that only licensed staff members can give medication and/or injections. Again, it is up to the school to provide someone to be in the building at all times who can perform the needed services. If the school believes that only a licensed staff member can provide these services, then the school is obligated to provide a full-time licensed staff member to be at the school at all times.

Can the school say they will not qualify a child with T1D because the child is doing well academically and is socially responsible and personally independent?

Again, eligibility is not automatic for anyone, and a team with knowledge about the child must evaluate and determine eligibility. However, Section 504 protects all persons with a disability who:

1. Have a physical or mental impairment that substantially limits one or more major life activities;
2. Have a record of such an impairment; or
3. Are regarded as having such an impairment.

In number one, above, major life activities are defined as functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working. A strong argument could be made that students with T1D are substantially limited, especially when blood-glucose level is not normal, in caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, and learning. How can a school argue that when a student is in insulin shock, that this student's abilities in these areas are not substantially limited? A student in insulin shock cannot walk, speak, learn, or care for themselves. Learning would be substantially limited if a student with T1D missed field trips, missed instruction due to high blood glucose, missed class due to being in the nurse's office testing blood, etc. A child with T1D would also be eligible for a 504 Plan in numbers 2 and 3 above. Certainly a child with T1D has a record of an impairment AND would be regarded as having an impairment. In addition, the ADA Amendments that went into effect on January 1, 2008, now make it clear that even if a disabled student is doing well in school, the student is still eligible for a 504 Plan and the needed accommodations and modifications.

There are certainly other arguments that can be made that a student with T1D, who is doing well, is still eligible for a 504 Plan. Things do change and learning may be substantially impacted by changes in blood glucose due to a growth spurt, early adolescence (hormones), etc. School or teacher rules may prevent snacks in the classroom, which would need a 504 Plan to provide for an exception to this rule. School rules may prevent blood testing to occur in the classroom and again, a 504 Plan would be needed to provide for an exception to this rule.

A school that will not provide a 504 Plan because a student with T1D is "doing well" is setting itself up for great trouble—it is a lawsuit against the school district waiting to happen. The school should set up a 504 Plan with training for teachers and procedures for handling a child with T1D's ongoing needs, as well as procedures for emergencies and a written plan demonstrating that the school is providing full access to school activities and learning opportunities.

Can the school prevent my child with T1D from wearing a diabetes ID bracelet?

Unless a school has a "no jewelry of any kind" rule (which VERY few schools have), a student should be able to wear an ID bracelet. If it's written into the 504 Plan, the child should be able to wear it, no matter what the school rule. On occasion, there may be a legitimate safety reasons for a particular teacher or coach to ask the child to temporarily remove the ID bracelet (e.g., a shop class where power tools are being used and where a bracelet may be dangerous; a sport with a lot of physical contact where another child may be injured by the ID bracelet).

What is the difference between IDEA and Section 504? What should I be requesting for my child with T1D?

IDEA is an education act (and sometimes known as Special Education), and Section 504 is a Civil Rights Act. In practical terms, the vast majority of students with T1D will fall under the Section 504 umbrella, which is to prohibit discrimination on the basis of a disability. Most students with T1D will have no reason to be involved in the world of IDEA. There are only two reasons a diabetic student might be eligible for IDEA:

- The impact of T1D is so great that the student's learning is severely impacted (which might qualify the diabetic child for special education services under the other health-impaired category), or
- The diabetic child has an additional disability (most likely not related in any way with T1D) that demands an IEP, e.g., mental retardation, autism, emotional disturbance, learning disability, etc.

What should I do to be sure that my child with T1D has accommodations available for ACT/SAT tests and state standardized tests?

Accommodations for state standardized tests should be listed in a student's 504 Plan. For the ACT test, there is a form to complete, which is available at act.org/aap/disab/opt1.html. Note that one of the requirements is to “enclose written documentation from your school describing in detail the accommodations you normally receive in school.” Some high schools may require a 504 Plan stating these accommodations before they would provide them to ACT. Note that another requirement is to provide “the name and phone number of a school official familiar with your current testing accommodations.” It would be a good idea to meet with the child's counselor a few months before the test will be given to make sure that the counselor (or another identified school staff member) is able to respond if contacted by ACT.

The SAT has similar requirements, such as:

- Have documentation on file at your school that supports the need for requested accommodations and meets the Guidelines for Documentation, and
- Receive and use the requested accommodations, due to the disability, for school-based tests.

For further information on the SAT test, go to collegeboard.com/ssd/student/index.html

For detailed information on SAT and ACT testing, please see Appendix II of this School Advisory Toolkit

Where do I go when I believe that the school is discriminating against my child with T1D and not providing the appropriate services?

Step 1: Try one more time at the school level. Try to have a one-on-one, heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable.

Step 2: In almost all school systems, there is a special education coordinator or someone who is charged with managing Section 504 issues. Again, be nice, be respectful, be understanding of school limitations, and have your list of items that are on your non-negotiable list.

Step 3: Contact the school superintendent with the same attitude and issues as above.

Step 4: Obtain the services of an attorney and file for a due-process hearing.

Step 5: Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your nonnegotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

Step 6: Contact the regional office of the Department of Education Office for Civil Rights for your state. Contact information is available at ed.gov/about/offices/list/ocr/addresses.html. Based on the advice of this agency, filing a formal complaint may be the next step.

See Appendix I and Appendix III for more detailed information on options for what to do when a parent believes the school is not following applicable laws.

Do private schools have to provide the same services as public schools?

1. If the private school does not receive federal funding, then the 504 Act does NOT apply. Therefore, the school would not have to consider or provide a 504 Plan. If a private school DOES receive federal funding, then it must provide the same services as public schools.
2. The ADA applies to all schools EXCEPT those run by religious institutions. If a private school is run by a religious institution, then the parent is pretty much at the whim of what the school is willing to do, and the parent/child have little recourse. If the private school is NOT run by a religious institution, then ADA applies and the school is prohibited from discriminating against people with disabilities, including diabetes. “Reasonable accommodations” must be provided.

See Appendix I for more information on the laws that apply in various situations to a student with T1D.

References for Those Who Desire More Information

A great deal of information about schools and students with T1D is available, including sample 504 Plans, checklists for school personnel, details on the law and schools, information for teachers and other school personnel, help for parents, help for the child with T1D, etc. The following list is just a sampling of such resources:

- Helping the Student with Diabetes Succeed: A Guide for School Personnel. This guide was produced by the National Diabetes Education Program and is a joint program of the National Institutes of Health and the Centers for Disease Control and Prevention and more than 200 other partner organizations. It is available at **ndep.nih.gov**
- JDRE:
jdrf.org/index.cfm?page_id=103439
- Children with Diabetes:
childrenwithdiabetes.com
- American Diabetes Association:
diabetes.org

T1D in the Day-Care Setting and in the College Years

- T1D in the day-care setting
- T1D in the college years
- For the student: going away from home
- Letter to the roommate



T1D in the Day-Care Setting

First and foremost, remember that the laws just discussed in the previous sections apply to the parent with a child in day care as much as they do for a school-age child. Day-care centers (with the exception of religious affiliations) cannot legally deny your child access to their services because of diabetes. Many day-care centers receive federal funding through Head Start or other child development government programs. Under these laws, diabetes is considered a disability, and it is illegal for day-care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with diabetes.

Remember, all of the information in the previous sections of this guide also applies to the parent with a child in day care. See Appendix I for more information on disability laws and the day-care setting.

The parent/guardian and the child's T1D doctor should develop an individualized plan for the child's day care; the plan should address the specific needs of the child and provide specific instructions for each of the following:

1. Blood-glucose monitoring, including the frequency and circumstances requiring blood-glucose checks.
2. Insulin administration (if necessary), including doses/injection times prescribed for specific blood-glucose values, and the storage of insulin.
3. Meals and snacks, including food content, amounts, and timing.
4. Symptoms and treatment of hypoglycemia (low blood glucose), including the administration of glucagon if recommended by the student's healthcare provider.
5. Symptoms and treatment of hyperglycemia (high blood glucose).
6. Checking for ketones and appropriate actions to take for abnormal ketone levels, if requested by the student's healthcare provider.

Do day-care centers have to take my child with T1D?

Based on the ADA and Section 504 of the Rehabilitation Act of 1973, it is illegal for schools and/or day-care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with disabilities. The exception is child-care centers that are run by religious entities. So almost all day-care centers are covered.

- Children with disabilities must have an equal opportunity to participate in the child-care center's programs and services. This means that if a day-care center is full, a child with T1D must be put on the list for openings. It does not mean that the child with T1D must be taken ahead of other applicants.
- Centers have to make reasonable modifications to their policies and practices to integrate children, parents, and guardians with disabilities into their programs unless doing so would constitute a fundamental alteration of the nature of the child-care program. Children with diabetes can usually be integrated into a child-care program without fundamentally altering it, so they should not be excluded from the program on the basis of their diabetes.
- Centers must provide appropriate training to one or more employees and provide for the administration of insulin, glucagon, and blood testing and provide access to snacks and other appropriate food.
- The child's parents are responsible for providing insulin, glucagon, blood-testing equipment, training, and food necessary for the child's care.

A special note: the Department of Justice has settlement agreements with KinderCare, La Petite Academy, and others that address the issue of admitting children with T1D to their child-care centers. See Appendix I for more information on disability laws and day-care centers.

T1D in the College Years

It is important for parents to be aware that things change a bit at the college level. At the elementary and secondary levels, the school district is responsible for identifying, evaluating, and providing the appropriate services for students with diabetes. Colleges and universities, on the other hand, have no responsibility to identify diabetes or any other disabilities. It is the student's responsibility to make his disability known and to request special accommodations. Once the student or parents have done that, the college should be willing to fulfill the requirements of Section 504.

One of the benefits of a student's declaring his T1D to the university disability office is that it will help protect the student from receiving a poor grade due to excessive absences or missed work due to T1D-related illnesses. Most professors will be more apt to allow the student extra time to complete assignments or to help with missed work due to absences that result from T1D.

As parents, you may want to inquire about special accommodations while exploring colleges with your teen in order to help guide his decision based on his specific needs. Once your teen is accepted to the college and you begin the enrollment process, housing applications, etc., you can work with a disabilities coordinator to complete the necessary paperwork. If your teen is living on campus, it is suggested that you put in writing any desired accommodations and the need for nutritional data from food services.

Regarding confidentiality: most colleges will request that parents indicate on a special signed form who needs to know about the student's disability. In most cases, the dean of students, the accommodations coordinator, food services, the resident assistant (R.A.), and professors need to know. That form does not give them consent to discuss your student's health issues with other parents, students, or outside personnel who have no need to know why certain accommodations are being made.

Alcohol and T1D

It is no secret that many students consume alcohol during their college years. It is very difficult to control blood glucose in the presence of alcohol, and the presence of alcohol can impair the judgment needed to detect and treat hypoglycemia. Because of the possibility that some students will choose to drink while at school, we have included some important information about the effects of alcohol on the body.

Moderate alcohol usually causes the blood-glucose level to rise. If you choose to drink alcohol, it is best to do so only occasionally and when your T1D and blood glucose are well controlled. One drink of alcohol should be counted as two fat exchanges, and regular beer also counts as an extra one-starch exchange.

While a moderate amount of alcohol can cause blood-glucose level to rise, excess alcohol can actually decrease your blood-glucose level by preventing the liver from adding glucose to the bloodstream sometimes causing it to drop to a dangerous level. Alcohol can also interfere with insulin efficiency, increase triglyceride levels, increase blood pressure, and cause flushing, nausea, increased heart rate, confusion, and slurred speech.

The following are a few ways for people with T1D to drink more responsibly if they choose to drink:

- Do not drink more than two alcoholic drinks in a 24-hour period. (One alcoholic drink = 5 oz. glass of wine, 1½ oz. "shot" of liquor, or 12 oz. beer).
- Drink alcohol only with food.
- Drink slowly.
- Avoid "glucosey" mixed drinks, sweet wines, or cordials.
- Mix liquor with water or alternate between glasses of water and alcoholic beverages.

Warning: glucagon shots may be less effective in treating severe low blood glucose caused by drinking because of the effect of alcohol on the liver.

For the Student: Going Away from Home

Going away to college can be scary, especially if it's your first real foray into working with T1D professionals on your own. Your medical care team is critical to your physical well-being as well as your success in college, so invest time up front in finding good medical professionals to work with. When you visit colleges, be sure to visit their health centers. Make an appointment to meet with representatives there regarding available T1D care. Interview the doctors, nurses, and educators.

Your parents will most likely be very helpful to you in completing this process. Don't feel you have to rely on the school health center if better healthcare is available elsewhere in the area. You may want to ask your pediatrician for recommendations of endocrinologists in the area.

Discuss health insurance coverage with your parents before you leave home. You should know what your options are, how to handle emergency situations, and what your insurance requires.

More tips for college:

- Request a meeting with your parents and the R.A. to go over emergency procedures. Offer to give the R.A. a glucagon kit to use in case you have severe low blood glucose.
- Have a small refrigerator in your room for supplies and snacks. You may want to buy it yourself instead of sharing the expense with a roommate so you won't feel guilty taking up so much of the space. Let friends know that snacks in the refrigerator are necessary for you, and ask them not to help themselves without asking first.
- Whatever you take for insulin reactions, have your parents buy it in bulk. That way, you won't think twice about sticking a handful into whatever bag or coat you grab.
- When you go to a party, make sure that someone you know will be there—someone who knows you have T1D and knows what to do in case of a reaction.
- If you don't have relatives or friends nearby, have your parents network through their friends to find someone who can act as a local emergency contact if needed.
- Make the decision to ALWAYS wear a Medic Alert bracelet. There are many different styles available these days.
- Photocopy insurance and prescription cards, in case your wallet is lost or stolen. Your parents should keep a copy. Keep another in your dorm room.
- Have two blood-glucose meters, in case one malfunctions, and extra batteries.
- Make sure you have a safe system for discarding needles and strips.
- Keep a three-month inventory of supplies. Be sure to check periodically and call home before you start to run low. As a safeguard against running out of insulin, make sure your prescriptions are on file at a local pharmacy.
- Thank your roommate ahead of time for providing support. An occasional card or small gift works wonders.
- Give your roommate a "dear roommate" letter explaining T1D and what your needs are.

Letter to the Roommate

When you head off to school, you don't need to tell everyone you have T1D, but some key people need to know: health services, of course; your roommate; the RA; and a few close friends. Here is a sample letter to a new college roommate, provided by a JDRF volunteer whose daughter has T1D; it can also be adapted for the RA.

Dear Roommate:

I am letting you and a few other people around me know that I have type 1 diabetes (T1D). Please understand that I do not want or need to be treated differently because of my T1D, but there are some things I'd like you to know about the condition.

Usually my T1D is under control, but sometimes my blood glucose gets too low or too high, which can endanger my health. To keep that from happening, I have to do certain things, like test my blood glucose and (wear an insulin pump/give myself insulin shots). It may help you to understand if I first tell you a little about T1D.

First of all, please know that T1D is not contagious. When a person eats a meal, the food is broken down into different substances, is absorbed, and enters the bloodstream. One of these substances is glucose, a glucose. The body cannot function without glucose. In turn, the body cannot use glucose without insulin, which is produced by the pancreas. My pancreas, like that of other people with T1D, doesn't produce insulin, so I have to take insulin shots every day. It's mainly insulin, exercise, food, and stress that cause my blood glucose to go up or down.

I do not expect you to have to take care of me, but I do sometimes have low blood glucose or an insulin reaction, which might confuse or scare you if you don't understand what's happening. During a reaction, for no apparent reason, you may notice any of these symptoms coming on suddenly:

I usually know when my glucose is getting low and can avoid a reaction, but not always. If the low blood glucose persists too long, I may seem sleepy and withdrawn. At these times, I need to drink a glucose drink or eat something from my "low blood glucose food stash" right away. I may not be able to get it myself, so I would appreciate your help, even if I resist. If you don't feel comfortable with that, please call the RA or health services to help me.

Once I have some glucose, I should seem much better within 10 to 15 minutes. If not, try giving me more food and call one of my contacts listed below. Low blood glucose can be life threatening to me, so my food stash is like my "medicine" and needs to be kept separate from the food we can share. Finally—and hopefully this will never happen—if you ever find me unconscious, anytime, including after partying, or if I am sleeping longer than usual and you cannot wake me, I am probably in serious danger. Please call 911.

If you feel uncomfortable about being around the shots and finger pricks, or keeping an eye open for emergencies, I'm happy to talk with you about it. My T1D is totally familiar to me but I realize it may take a little time and experience for you to adjust. Believe it or not, in spite of all the challenges that come with T1D, I am able to lead a pretty "normal" everyday life. Most people won't even know that I have T1D unless I tell them. I'm sure you have lots of questions, so let's set a time to talk.

Thanks,

(Signature)

You may also want to include a list of emergency contacts for low-blood-glucose situations.

About JDRF

- Research funding facts



About JDRF

Dedicated to finding a cure

JDRF is the worldwide leader in funding research to cure T1D, an autoimmune disease that strikes children and adults suddenly and lasts a lifetime. JDRF sets the global agenda for T1D research and is the largest charitable funder of and advocate for T1D science worldwide.

JDRF's mission has been constant since it was founded four decades ago: to find a cure for T1D and its complications through the support of research. Until a cure is found, JDRF is also committed to working tirelessly to develop new and better treatments to improve the lives of people who have T1D and keep them as healthy as possible.

Today, people with T1D rely on insulin to manage the disease. But insulin is not a cure, nor does it prevent the possibility of the disease's devastating effects, which can include kidney failure, blindness, heart disease, stroke, amputation, and pregnancy complications. JDRF is dedicated to finding a cure for T1D and removing the burdens and threats that the disease carries.

A global leader in T1D research

JDRF funding and leadership is associated with most major scientific breakthroughs in T1D research to date. The foundation remains a global leader in driving T1D science forward by funding more T1D research than any other charity. JDRF directed more than \$110 million to such research in FY2012, bringing its total research funding to more than \$1.7 billion since its founding in 1970. To ensure that it supports science with the greatest potential to produce results as soon as possible, JDRF has established a research review process that involves leading scientists from around the world, as well as lay reviewers who either have T1D themselves or have family members with the disease.

Moving discoveries from bench to bedside

JDRF is a leading catalyst for translating research advances into new treatments that can improve the lives of people with T1D in the near term—and ultimately lead to a cure. In recent years, JDRF has driven a major increase in the number of new drugs and devices being evaluated in human clinical trials, funding more than 50 such trials in FY2011. JDRF has also helped spark new interest in T1D science from biotechnology and major pharmaceutical companies; they will be crucial partners in bringing new therapies and cures to market.

JDRF research encompasses multiple areas, with the goal of discovering and developing new drugs and devices to cure, treat, and prevent T1D. Areas of focus include developing immune therapies, replacing and regenerating beta cells, achieving tight glucose control, and preventing complications.

Efficiently organized for successful results

JDRF is structured on a business-world model that efficiently and effectively directs resources to research aimed at finding a cure and developing new treatments as soon as possible. More than 80 percent of JDRF's expenditures directly support research and research-related education. Because of its unwavering focus on its mission to find a cure, JDRF annually receives top rankings from independent sources that rate charitable giving. JDRF leverages its impact by partnering with academic institutions, governments, biotechnology and pharmaceutical companies, other disease organizations and foundations, and people with T1D.

A backbone of dedicated and active volunteers

JDRF was founded in 1970 by parents of children with T1D. Today, volunteers at JDRF's more than 100 locations worldwide remain the driving force behind the foundation's success in advancing research toward a cure. Because of their personal connection to T1D, JDRF's volunteers have a passionate and unrelenting commitment to the JDRF mission.

Research Funding Facts

JDRF is the largest charitable supporter of T1D research. The goal of JDRF research is to improve the lives of all people affected by T1D by accelerating progress on the most promising opportunities for curing, better treating, and preventing T1D. JDRF collaborates with a wide spectrum of partners who share this goal.

- Since its founding in 1970 by parents of children with T1D, JDRF has funded more than \$1.7 billion in research.
- More than 80 percent of JDRF's expenditures directly support research and research-related education.

JDRF's research goals

JDRF is committed to aggressively following the most promising paths to cure, better treat, and prevent T1D. We are targeting our resources on science that seeks to:

- Arrest the immune attack on the insulin-producing beta cells
- Restore or replace beta cell function
- Better control blood-glucose levels
- Protect people from—or reverse—complications

Therapeutic areas

JDRF targets its research funding in five therapeutic areas:

Beta cell therapies

This area aims to find ways to restore the body's ability to make insulin through the:

- Regeneration of insulin-producing beta cells (i.e., triggering the body to regrow beta cells); and
- Replacement of the beta cells lost to T1D

JDRF is prioritizing regeneration because of its potential to restore beta cell function in the largest number of people living with T1D.

Immune therapies

This area focuses on ways to stop the immune-system attack on the body's insulin-producing beta cells that causes T1D. Within this area, JDRF is prioritizing antigen-specific therapies that would reverse the immune attack in T1D without suppressing the entire immune system.

Glucose control

This area seeks to identify ways to dramatically improve blood-glucose control while avoiding dangerous highs and lows in people at all stages of T1D. JDRF is prioritizing the development of a closed-loop artificial pancreas system, a device combining a glucose monitor and insulin pump, to enable people to achieve tight blood-glucose control and reduce their risk of complications. JDRF is also prioritizing the development of novel insulins that are glucose-responsive, faster-acting, easier to use, and more effective.

Complications therapies

This area focuses on ways to free people from the devastating long-term complications that can accompany diabetes, including diseases of the eyes, nerves, and kidneys. JDRF is prioritizing research in complications protection, or new approaches to assess risk and block complications from developing and progressing.

Prevention of T1D

This area seeks to prevent T1D from occurring in those most susceptible. JDRF is focused on both primary prevention (of beta cell autoimmunity) and secondary prevention (of onset of insulin dependence) of the disease. Prevention of T1D represents a “cure” for those at risk of developing the disease, and in fact, will likely represent the most cost-effective cure, and is the only approach in the short-term to impact the incidence and prevalence of the disease.

Resources/References



Below is a listing of published government materials and other information sources containing additional information about the topics covered in this guide.

Helping the Child with Diabetes Succeed: A Guide for School Personnel issued by the National Diabetes Education Program and endorsed by JDRF and many other organizations.

ndep.nih.gov/publications/PublicationDetail.aspx?PubId=97&redirect=true#main

Sample 504 Plan and Individualized

Healthcare Plan issued by the Disability Rights Education & Defense Fund (in collaboration with the ADA). These are extremely thorough and comprehensive plans that can be tailored to meet a child's individual needs.

dredf.org/504/504-plan-2004.pdf

Protecting Students with Disabilities issued by the U.S. Department of Education's Office for Civil Rights (OCR). Written in a frequently asked questions format.

ed.gov/about/offices/list/ocr/504faq.html

Legal Text of Section 504 of the Rehabilitation Act of 1973 posted on the OCR website.

ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html

Legal Text of Americans with Disabilities Act of 1990 posted on the OCR website.

ed.gov/policy/rights/reg/ocr/edlite-28cfr35.html#S101 or this pamphlet version at ed.gov/about/offices/list/ocr/docs/hq9805.html

The Civil Rights of Students with Hidden Disabilities issued by the OCR and posted on its website.

ed.gov/about/offices/list/ocr/docs/hq5269.html

What is "Free, Appropriate Public Education"? issued by OCR.

ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

Listing of U.S. Department of Education's OCR Regional Offices

ed.gov/about/reports/annual/ocr/annrpt2004/report_pg22.html

OCR Listing of Parental Advocacy Resources

ed.gov/parents/needs/rights/ocr/parents2.html

OCR Online Grievance of Non-Compliance/Discrimination Complaint Form

ed.gov/about/offices/list/ocr/complaintintro.html

Diabetes and the School Setting, American School Health Association.

Health In Action: ashaweb.org

Diabetes Management in the School Setting

A Resource Guide for School Health Nurses
National Association of School Nurses.

nasn.org/portals/0/positions/2012psdiabetes.pdf

Diabetes Ready Reference Guide for Health Professionals, Pathophysiology of Diabetes & Sick Day Rules Ballard, AM American Diabetes Association.

Sample Section 504 Plan, Disability Rights Education and Defense Fund.

dredf.org/504/504-plan-2004.pdf

The Americans with Disabilities Act, U.S. Department of Education, Office for Civil Rights.

www2.ed.gov/about/offices/list/ocr/docs/hq9805.html

How to file a Discrimination Complaint with the Office for Civil Rights, U.S. Department of Education, Office for Civil Rights.

www2.ed.gov/about/offices/list/ocr/docs/howto.html

Legal Rights of Students with Diabetes, James Rapp, Arent Shereen, Brian Dimmick, Brystal Jackson.

diabetes.org/assets/pdfs/know-your-rights/for-lawyers/education/legal-rights-of-students-with-diabetes-2009.pdf

Care of Children and Adolescents with Type 1

Diabetes, Diabetes Care Journal.

care.diabetesjournals.org/content/28/1/186

Sample 504 Plan by Age and Insulin Therapy,

Children with Diabetes.

childrenwithdiabetes.com/504/

College Entrance Exams, Children with T1D.

Sample Collection of Letters & Forms for SAT

and ACT accommodations.

childrenwithdiabetes.com/504/

Type 1 Diabetes in College, JDRF

jdrf.org/index.cfm?page_id=103581

Diabetes and the Law: La diabetes y la legislacion,

American Diabetes Association.

diabetes.org/espanol/diabetes-y-la-legislacion.jsp

Diabetes at School, Children with Diabetes.

childrenwithdiabetes.com/d_0q_000.htm

Appendix I: Laws That Apply to Children with T1D

- What laws apply to what settings?
- The three laws
- What to do when there is a problem



What Laws Apply to What Settings?

Setting	Section 504	ADA	IDEA
Public school	Yes (if receiving federal funding) No (if not receiving federal funding)	Yes	Yes , if the student qualifies for special education or related services.
Private school	Yes (if receiving federal funding) No (if not receiving federal funding)	Yes	Yes . If the local school district determines that the child is eligible for IDEA, then the local school district must provide a proportionate share of equitable services. ¹
Religious operated school	No	No	Yes . If the local school district determines that the child is eligible for IDEA, then the local school district must provide a proportionate share of equitable services. ¹
Private day care	Yes (if receiving federal funding) No (if not receiving federal funding)	Yes	If the private day care provides only day care services, the answer is no . If the private day care is providing elementary education, then IDEA will apply if the child qualifies.
Religious operated day care	No	No	No

- Section 504 refers to Section 504 of the Rehabilitation Act of 1973
- ADA refers to the Americans with Disabilities Act of 1990, and the ADA Amendments Act of 2008 (passed 9/25/08, effective 1/1/09)
- IDEA refers to the Individuals with Disabilities Education Act (enacted in 1990, reauthorized in 1997), and the IDEA Improvement Act of 2004.

¹ Under IDEA, children with disabilities who attend private schools do not have an individual entitlement to services they would receive if they were enrolled in a public school. Instead, the *local school district* (also known as the *local educational agency*, or LEA) is required to spend a proportionate amount of IDEA funds to provide equitable services to these children.

Disclaimer: This chart and the remaining contents of this Appendix are not intended to be legal advice and should not be construed as such. They are, rather, a general guideline of the laws that apply to most schools and child care centers. A family would be well advised to look into the particular circumstances of their school if they encounter a problem, and consider consulting an attorney for specific legal advice.

The Three Laws

1. Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act of 2008,
2. Section 504 of the Rehabilitation Act of 1973 (Section 504)
3. Individuals with Disabilities Education Act (IDEA)

Law #1—ADA (Americans with Disabilities Act)

The ADA is an antidiscrimination law and applies to all public entities (including public schools, private school, day-care centers, etc.) except those operated by a religious entity. The purposes of the ADA that apply to *individuals with T1D* are, “(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities” and “(2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.”

The ADA also states that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. This means *children with T1D (or other disability)* must be given an equal opportunity to participate at school and cannot be excluded from any equal access academic programs or school-sponsored extracurricular activities, field trips, etc.

Schools and other public entities (e.g., day-care centers) are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided—or is an undue hardship (*meaning an action requiring significant difficulty or expense*).

ADA defines the term disability as follows:

“The term ‘disability’ means, with respect to an individual

(A) a physical or mental impairment that substantially limits one or more of the major life activities* of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such impairment....”

*The ADAAA (ADA Amendments Act of 2008) adds to the ADA a definition of “major life activity” that includes, but is not limited to, “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating and working.” The ADAAA also defines a “major life activity” to include “major bodily functions,” which include, but are not limited to, “functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions.”

Newly passed amendments to ADA went into effect on January 1, 2009. Sections of the newly passed amendments state that, 1] major life activities now specifically include the “endocrine system,” 2] mitigating measures such as the use of medicine, medical supplies, or medical equipment shall not be considered in determining whether the person is disabled. In other words, a person with diabetes who uses insulin and/or an insulin pump (or other device) to reduce the impact of her disease is still considered disabled and protected by the law. 3] “emphasizes that the definition of ‘disability’ should be interpreted broadly.” These newly passed amendments help to clarify that people with diabetes are covered under ADA (and Section 504, as well). For more detailed information on the ADA amendments that went into effect on January 1, 2009, go to ed.gov/policy/rights/guid/ocr/disability.html.

Eligibility

There is no formal process (no strict due-process procedure) for a person/student with T1D to follow to be declared as, “eligible” as a disabled person under ADA. However, if a problem occurs in a school setting and a child with diabetes is not receiving appropriate services, a family should try to educate school personnel and negotiate with school personnel to obtain the necessary services. If these measures fail, a complaint can be filed alleging discrimination under ADA.

Questions about ADA?

The U.S. Department of Justice answers questions about the ADA and provides free publications by mail and fax through its ADA Information Line [800-514-0301 (voice) 800-514-0383 (TDD)] and on its ADA Home Page on the internet at ada.gov/. The ADA Information Line provides answers to general and technical questions, on Monday through Friday from 10:00 a.m. until 6:00 p.m. except Thursdays, when the hours are from 1:00 p.m. until 6:00 p.m. (Eastern Time). You may also order regulations and other free materials for mail delivery 24 hours a day. ADA Information by Fax provides many ADA publications that can be sent directly to your fax machine. To order, call the ADA Information Line at any time and follow the fax-back system directions.

Law #2—Section 504 of the Rehabilitation Act of 1973

Section 504 is also an antidiscrimination law. The purpose of this law is to “eliminate discrimination on the basis of handicap in any program or activity *receiving Federal financial assistance*.” This would include public or private schools that accept federal funding. The law requires that, for an eligible student, a free and appropriate public education must be provided. An educational program must be provided that is equal to that provided for non-disabled peers. Related aids and healthcare services must be provided, the program must be provided in the least restrictive manner, and reasonable accommodations must be provided. Students are required to have the same educational opportunities as nondisabled students, including participation in field trips and extra-curricular activities. The law provides that a school evaluate and determine whether the student is eligible, document the findings, and periodically reevaluate the student’s eligibility.

Note: The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that it is providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and a violation of Section 504. As one of the representatives from the Department of Education Office for Civil Rights (OCR) stated, “OCR would have no concept how a district/school would prove a 504 Plan exists and the accommodations being made without the Plan being in writing.”

Section 504 also applies to day-care programs.

“A recipient ... that provides preschool education or day care or adult education may not, on the basis of handicap, exclude qualified handicapped persons and shall take into account the needs of such persons in determining the aid, benefits, or services to be provided.”

Eligibility

A process exists for a student to be declared eligible under Section 504 and for a 504 Plan to be developed that formally and legally describes what accommodations a child with a disability will receive. Section 504 eligibility is not automatic but is made on an *individual* basis. A team of people knowledgeable about the student must convene and determine eligibility. Although there is nothing in the law that *specifically* requires parents to be invited to this meeting, parents are certainly knowledgeable about the child, and it would be logical to assume that they *should* be invited to the meeting. Parents should be sure to make themselves available for this meeting, as the meeting can go forth if parents are invited but do not attend. Since Section 504 uses the same definition of disability as does ADA, eligibility for Section 504 and a 504 Plan should be the result. The 504 eligibility process doesn’t require the student to take or pass any particular test to be found eligible. However, the student’s academic record and teacher recommendations are among the sources to be considered by the team.

Note: Health plans are not a substitute for a 504 Plan. A 504 Plan provides a framework for the overall accommodations/modifications that a child with T1D needs in the school setting. A health plan gives specifics of what to do when a health issue arises. For example, a 504 Plan gives the right to attend a field trip or to not take a test with high blood glucose, while the health plan covers the particulars of how many carbohydrates are to be eaten for lunch, how many units of insulin are to be given at what time, what to do in a medical emergency, etc.

Note: It is of utmost importance that a request to initiate a meeting to determine eligibility for 504, to request modifications to an existing plan, to document grievances of noncompliance, expressions of gratitude, etc. be in *written* form!

Questions about Section 504?

Information on Section 504 is located on the internet at ed.gov/about/offices/list/ocr/docs/placpub.html. The OCR in the U.S. Department of Education enforces Section 504 of the Rehabilitation Act of 1973 in programs and activities that receive assistance from ED. OCR also enforces Title II of the ADA, which is applicable to state and local governments.

Law #3—IDEA (Individuals with Disabilities Education Act)

IDEA is a law that governs how states and public agencies provide early intervention, special education, and related services. IDEA requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. If a child is determined to be eligible, IDEA requires public school systems to develop an appropriate IEP for the child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student. Specialized services are then provided for a student by specially trained/certified special education staff.

IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be reviewed at least annually. The team includes the child's teacher; the parents; the child, subject to certain limited exceptions if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion.

Eligibility

For children with diabetes attending a public school, the school district is required to determine eligibility for IDEA, if requested to do so. For children with diabetes attending a private school (including a religious school), the *local school district* is also required to identify and evaluate these children to determine whether they are eligible for IDEA. The process involves obtaining parental consent for testing to take place, testing for a variety of potential disabilities including: processing difficulties, emotional disabilities, and other potential disabilities, as well as IQ testing. Eligibility is determined by the team, which looks at significant discrepancies between abilities and performance as well as other factors that significantly impact a student's ability to learn. IDEA is an education act (and sometimes known as Special Education), and Section 504 is a civil rights act. In practical terms, the vast majority of T1D students will fall under the Section 504 umbrella, the primary purpose of which is to prohibit discrimination on the basis of a disability. Most T1D students will have no reason to be involved in the world of IDEA. There are only two reasons a student with T1D might be eligible for IDEA. 1] the impact of diabetes is so great that the student's learning is severely impacted (which might qualify the child with T1D for special education services under the *other health* impaired category); or 2] the T1D child has an additional disability (most likely not related in any way with T1D) that demands an IEP, e.g., learning disability, mental retardation, autism, emotional disturbance, etc. If it is determined that a child with T1D is eligible for an IEP, then this IEP would include all necessary modifications, and a 504 Plan would not be necessary.

Questions about IDEA

Information on IDEA is on the internet at idea.ed.gov.

What to Do When There Is a Problem

Most schools are cooperative and do a fine job of addressing and meeting the needs of a student who has T1D. When there is a problem, follow these steps.

Note: Most schools have teachers, administrators, nurses, etc. who love children and will do whatever they can to make any child successful—including a child with T1D. Most schools do a good job most of the time and make a good-faith effort to provide the needed accommodations/modifications necessary and will happily provide a 504 Plan and the services necessary for the child to actively participate in all of the school activities. However, parents are strongly encouraged, just in case there is school resistance, to document everything. Put in a request for 504 Plan, a request for modifications to an existing plan, any grievances for noncompliance, any expressions of gratitude in writing; document the dates of meetings, who attended the meetings, what was decided in the meetings, etc. Parents should receive and keep copies of any paperwork generated from these meetings.

Step 1: Try one more time at the school level. Try to have a one-on-one, heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable. Remember that the goal is to obtain assistance and the accommodations/modifications needed for your child to be successful. If the school is making a good-faith effort to provide for the needs of your child and a problem still occurs, be a good parent and help out. After helping out, work with school personnel to come to a mutual understanding and agreement on how to address similar issues in the future.

Step 2: Section 504 law requires a recipient (a school) that employs 15 or more persons to designate at least one person to coordinate its efforts to comply with the law. In most school districts (but not all), this is the special education director/coordinator. This administrator is usually more knowledgeable about Section 504, ADA, and IDEA laws and is more likely to work to solve the problem. Contact this person. Again, be nice, be respectful, be understanding of school limitations, and have a list of items that are on your nonnegotiable list. Appeal to this person's understanding of the laws. (Note: School administrators in this position are sometimes pushed very hard by their supervisors to keep spending to a minimum. In

most situations, the accommodations and services needed by students with diabetes do not cost money. Work with these people to show them that what is being requested is reasonable and will not be costly in any significant way.)

Step 3: Contact the school superintendent with the same attitude and issues as above.

Step 4: Section 504 law requires a recipient that employs 15 or more persons to adopt grievance procedures that incorporate appropriate due-process standards and that provide for the prompt and equitable resolution of complaints. Put in writing a request for a due-process hearing. Address the request to the principal of the school and copy the coordinator for Section 504 (described in Step 2), and the superintendent of schools (and your attorney if you have one at this point).

Step 5: Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your nonnegotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

Step 6: Obtain the services of an attorney and file for a due-process hearing AND/OR

Contact the regional office of the Department of Education Office for Civil Rights for your state. A list showing regional offices of the Department of Education Office for Civil Rights is available at ed.gov/about/offices/list/ocr/addresses.html. Other information concerning filing a complaint can be found on the internet at ed.gov/about/offices/list/ocr/index.html. Based on the advice of this agency, filing a formal complaint may be the next step.

Appendix II: Accommodations for Standardized Testing

- Why should a student with T1D request accommodations for standardized tests?
- How and when a student with T1D should request accommodations for national standardized exams
- The SAT exam
- The ACT exam
- Sample physician's letter



Why Should a Student with T1D Request Accommodations for Standardized Tests?

A student with T1D is eligible to request accommodations when taking standardized tests, including the PSAT, NMSQT, AP, and SAT, which are administered by the College Board, and the ACT college entrance exam, which is administered by ACT, Inc. The request for accommodations must be filed many months in advance of your planned testing date, since it often takes up to five months for complete and proper accommodation approval to be granted.

Sometimes the testing firms do not initially grant all of the accommodations requested. In this case, it may be necessary to go back to the College Board or ACT and ask them to reprocess the request. The most common reason this problem occurs is that the proper forms or paperwork were not filled out when making the request. The biggest problem seems to be the lack of a specific line on the accommodation request forms for “breaks as needed” on the SAT and “stop the clock breaks within sections” on the ACT. It is important to know how to phrase this accommodation request in order for it to be granted. Please remember that if a student with T1D is denied the requested accommodation, the problem can be solved with a call to the testing board to see what is needed in order to meet the student’s requirements.

When applying for accommodations for standardized tests, it is important to work with school personnel; they can offer invaluable assistance in securing the medical and learning accommodations that the student with T1D needs to succeed academically. It is also important to remember, however, that school personnel are not doctors and cannot possibly be aware of all of the medical issues that a student with T1D deals with on a daily basis. It is therefore up to the parents and student to make sure that the proper accommodations are applied for and that all of them are approved.

Students with T1D know that stress often causes high blood glucose. Stress produces adrenaline, and adrenaline produces glucose. Therefore, in addition to dealing with the emotional stress that most students experience when preparing to take their college entrance exams, students with T1D must deal with the physical and mental toll that abnormal blood-glucose patterns take on their minds and bodies.

During a standardized exam, the student with T1D may have to correct blood-glucose imbalances with either food or insulin, and she may need to be allotted additional time while waiting for the necessary correction to take effect. The student may need to test her blood glucose, have snacks during the exam, or take additional bathroom breaks. Having the proper accommodations in place will allow the extra time needed to handle all of the above without taking time away from the actual exam.

In order to address T1D-related problems that can occur during exams, the student with T1D needs to have “extra breaks” (five minutes long), “extended breaks” (10 minutes long), and most importantly, “breaks as needed” (which are granted as requested by the student, even if in the middle of a test section) for College Board exams, and “stop the clock breaks within sections” for the ACT exam. Please be aware that these accommodations are **in addition to any accommodations that may be granted for learning disabilities, ADHD, or any other special needs**. This will usually entail the student taking the test alone in a nonstandard room with a separate proctor who is paid for by the College Board (SAT) or ACT, Inc.

Generally, the College Board and ACT, Inc. will try to do whatever is medically necessary to accommodate the student and grant whatever accommodations the student with T1D normally receives in school as per his or her Section 504 Plan or IEP. It is important to note, however, that approval by one testing organization does not guarantee approval by the other. The Section 504 Plan or IEP must be current and must have been approved within the prior 12 months. However, it is possible to have accommodations granted without having a formal 504 Plan or IEP in place—for example, when a student is newly diagnosed with T1D or when she is “homeschooled.” Since T1D is a chronic illness, all that should be needed in order to receive the proper accommodations is a statement from the student’s endocrinologist—on the physician’s letterhead and signed by the physician—stating that the student has T1D, giving the date of diagnosis, and outlining the needed accommodations. The statement must spell out the “functional limitations” of the student as follows: it must state that the student requires “extra breaks,” “extended breaks,” and “breaks as needed” (or “stop the clock breaks within sections” in the case of ACT) during testing time so that she may test her blood-glucose level, take extra bathroom breaks, and bring a glucometer into the testing room, along with insulin for

hyperglycemia and snacks for hypoglycemia. The letter should also state that the student may need to begin a test portion late or that she may need to wait to complete a test portion for either the blood glucose to rise if too low, or for the insulin to work if the blood glucose is too high. The physician's statement is also needed when submitting the application through the student's SSD (Services for Students with Disabilities) coordinator.

It's important to request these accommodations, since it would be a shame for a student with T1D to try to complete her exam while dealing with either very high or very low blood-glucose. These problems may affect the student's ability to think or see clearly and lead to poor test results, causing the student to choose to void her test scores and possibly missing college application deadlines. Accommodations need to be in place in order to prevent this from happening.

Another important thing to know is that if a student with T1D is having a really bad blood-glucose day or is sick on their test date, it is possible to postpone taking the exam—as long as the exam is rescheduled for within four calendar days of the original test date. It is also possible to delay the starting time of the exam on the original, scheduled date as long as a “supervisor irregularity report” is submitted by the testing center along with the completed test. These problems do pose a bit of difficulty if the student was scheduled to have his or her own proctor, but sometimes these unavoidable circumstances do occur.

How and When a Student with T1D Should Request Accommodations for National Standardized Exams

When requesting disability accommodations for the first time, whether for medical or learning disabilities, the student with T1D needs to register for the College Board exams (SAT) or the ACT exam via mail (note: schools—but not parents or students—may now make requests for accommodations online to the College Board). If the student chooses to take the test again, she may make subsequent registrations with accommodations online using her SSD eligibility code, which can be found on the student's eligibility letter of approval. It is a good idea to register for the College Board exams as soon as the student enters ninth grade so that she may use the accommodations on the PSAT, NMSQT, AP, and SAT exams. Once approved by the College Board, the eligibility form needs to be submitted only once, as long as the student's school verifies annually that the student continues to receive accommodations on school tests.

If the student does not want or need accommodations for the PSAT, NMSQT, or AP exams, she should apply for the SAT college entrance exam accommodations at least five months in advance of her planned testing date. **An important point to note when planning to take college entrance exams with accommodations is that it takes a month or so longer to receive the student's test scores than for exams taken without accommodations; therefore the student should schedule her test date with this delay in mind,** especially if it is near the application deadline for the college of her choice.

College Board Services for Students with Disabilities

P.O. Box 6226

Princeton, NJ 08541-6226

Phone: 609-771-7137

Fax: 609-771-7944

The SAT Exam

When a student with T1D requests accommodations for the SAT exam, the student and his parent need to complete the “Student Eligibility Form for Accommodations on College Board Test Based on Disability” and the “Consent Form for Request for Accommodations.” These forms must be sent with your physician’s statement to the student’s SSD coordinator for submission to the College Board. On the application for accommodations, it is imperative that the “Accommodation” section be filled out by checking “extended breaks” and “extra breaks” and by writing in “breaks as needed” in the “Other” section. Additional items to write in under the “Other” section include: juice, water, and snacks in the testing room; extra bathroom breaks; and glucometer and insulin pump or pen in the testing room. **It is the “breaks as needed” accommodation that will give the student the ability to “stop the clock” during the exam if he needs to do so in order to wait for his blood glucose to rise or fall as needed.** For more information, visit professionals.collegeboard.com/testing/ssd/accommodations/breaks.

In order to register and request the necessary SAT accommodations, the student and his parents should first review the application process online at professionals.collegeboard.com/testing/ssd/application. Go to the link on applying for accommodations to see a sample of the application and instructions.

A sample of the Student Eligibility Form and instructions can be found online at professionals.collegeboard.com/testing/ssd/application/apply/eligibility and

collegeboard.com/prod_downloads/ssd/eligibility_form_instructions.pdf.

Both the student and the parent must also complete the “Consent Form for Request for Accommodations” at

collegeboard.com/prod_downloads/ssd/Consent_Form.pdf.

In all likelihood, the student with T1D will be considered a “school-based” tester, and his exam will be mailed under separate cover to the student’s SSD coordinator, who will make accommodation arrangements for the exam. If the student’s high school is not a test center, then his SSD coordinator must either make arrangements to accommodate the student at his school or at another location.

Having a separate proctor is the only way that the student will be able to “stop the clock.” Proctors cannot stop the clock for a large group of students taking the exam. A week before the exam is to take place, it is a good idea to contact the student’s school to make certain that he will indeed be testing in a room by himself and not grouped with numerous other students receiving different accommodations, which could prove to be very distracting for all of the students receiving separate accommodations.

Since these are national standardized exams, there are very strict guidelines regarding time allotted when administering the exams. **Remember, the accommodations must be explicitly spelled out on the student’s “Accommodation Approval Letter” or he will not receive them. Make sure the student’s SAT approval letter lists “breaks as needed” as part of the accommodations.**

ACT, Inc. Special Testing Department
301 ACT Drive
P.O. Box 4028
Iowa City, IA 52243-4028
Phone: 319-337-1332

The ACT Exam

When a student with T1D requests accommodations for taking the ACT college entrance exam, the student and his parents must complete the “ACT Request for Special Testing” application. The SSD coordinator will submit this form along with a copy of the student’s physician statement. The statement must be prepared on the endocrinologist’s letterhead and be signed by the physician. It must state that the student has T1D, give the date of diagnosis, and list the accommodations needed. It must spell out the student’s “functional limitations” by stating that he requires “stop the clock breaks within sections” during testing time so that the student may test his blood-glucose level, take extra bathroom breaks, bring a glucometer into the testing room along with insulin for hyperglycemia, and bring snacks for hypoglycemia. The letter should also state that the student may need to begin a test portion late or that he may need to wait to complete a test portion for the blood glucose to rise if too low, or for the insulin to work if the blood glucose is too high.

When accommodations for T1D issues are the only accommodations being requested, the “ACT Request for Special Testing” form must be completed by the student, parents, and SSD coordinator. The “Time Requested” option that must be chosen is “standard time on each test; authorization to test over multiple days.”

The student must also complete the “Other Accommodations Requested” question and fill in that he needs “stop the clock breaks within sections,” “extra breaks,” “extended breaks,” and “extra bathroom breaks.” The student must also request that he be allowed to bring the following into the testing room: a glucometer, an insulin pen or pump, and snacks including water and juice. This is the only option that truly accommodates “stop the clock breaks within sections”—which will allow the student experiencing a serious blood-glucose imbalance during the exam to wait as long as needed for his blood glucose to rise if it is too low or for the insulin to work if blood glucose is too high.

In the event the student also needs extra testing time for learning disabilities, ADHD, or other special needs in addition to accommodations for his T1D, the option for “extended time on each test; authorization to test over multiple days” should be checked. When the student receives his Accommodation Approval Letter, make sure that “stop the clock breaks within sections” has been granted. For more information, visit act.org/aap/pdf/spectest.pdf.

A NOTE TO EDUCATORS ABOUT ACT ACCOMMODATIONS: Please be aware that students do not want to take the exam over multiple days any more than you want to take multiple days to proctor the exam. At present, “standard time on each test; authorization to test over multiple days” on the ACT application is the only option available that will accommodate “stop the clock breaks within sections” for a long-enough period of time to allow the student with T1D to correct serious blood-glucose imbalances. “Extended time on each test; authorization to test over multiple days” is the only option that the ACT has available that will accommodate “stop the clock breaks within sections” to correct serious blood-glucose imbalances AND give the student with learning disabilities, ADHD, or other special needs extra testing time. “Center Testing #1; Standard Time National Testing” will allow a student with T1D to have snacks while testing, but it will group the student with other students who have varying disabilities and who may not be on the same schedule as the student with T1D. This option may also not allow enough time for blood-glucose corrections to take place and can prove to be very distracting for the student taking the exam. As with the SAT, receipt of test results taken with disability accommodations will be delayed by four to six weeks, especially if the ACT plus Writing has been taken. For more information, go to act.org/aap/disab/opt1.html.

Please be aware that the guidelines for the College Board and ACT, Inc. testing accommodations can be used across the United States since these exams are national standardized exams. Students, please also keep in mind that these accommodations are available to you because of your disability; you should not hesitate to use them.

Sample Physician's Letter

Dr. Alicia Romanzani
Pediatric Endocrinology
123 Main Street
Anytown, USA 12345
Phone: 123-456-7890

Physician License #:

June 1, 2010

To Whom It May Concern:

John Smith is a young man under my care for T1D, diagnosed February 17, 2000. He is managed with an insulin pump and requires the following considerations during his SAT or ACT testing:

- He may need to begin a test portion late or need to wait to complete a test portion for either the blood glucose to rise (if too low) or insulin to work (if too high).
- He may require “extra breaks,” “extended breaks,” and “breaks as needed” and “stop the clock breaks within sections” during testing to monitor his blood-glucose levels or to have a snack and fluids to manage hypoglycemia. He will need to take an insulin pen or pump and his glucometer into the testing room in addition to snacks, juice, and water. He may require extra bathroom breaks as well.

Should you require any additional information, please do not hesitate to contact this office.

Sincerely,

Dr. Alicia Romanzani

Appendix III: All You Ever Wanted to Know about 504 Plans

- Document everything
- Research 504 Plans and prepare a draft 504 Plan for your child
- Consult with the child's physician and prepare a medical/health plan
- Write a letter requesting a meeting for the purpose of establishing eligibility for a 504 Plan as well as writing and approving the 504 Plan
- At the 504 meeting
- What to do if things don't go well
- 504 Plans and kindergarten
- Sample letter to request a 504 meeting
- Sample letter to request a due-process hearing
- Section 504 provides



The process of requesting and obtaining a 504 Plan from your child's school can seem daunting and complex. In most situations, schools are receptive and more than willing to assist a child with T1D and her parents through the 504 Plan procedures. In really good schools, a simple phone call can get the process under way, although administrators may ask that you put your request for a meeting in writing for their records. Unfortunately, some schools or school districts resist doing 504 Plans under the mistaken notion that doing so may cost the school a good deal of money or that the 504 Plan will be an enormous amount of work that they just don't want to do. Thankfully, these schools are few in number, but when it's your child who attends one, the process can become emotionally and physically draining. Whether your child attends a helpful and caring school or one of those schools that doesn't quite measure up (from now on referred to as the "reluctant" school), the information below, in a step-by-step format, will assist you in understanding what you need to do in order to end up with a 504 Plan that meets the needs of your child.

Of course, it's always nice when you have the time to take all of these steps in order, but that doesn't always work in real life. So if your child is diagnosed with T1D in the middle of the school year and you have to skip a step or two to get the process rolling, don't worry. The information below is a guide, not a mandate. The goal is to end up with a 504 Plan that allows your child to receive the modifications and accommodations she needs to be successful in the school setting. If you implement the steps below out of order but end up with the same positive result, good for you and your child's school!

Step 1—Document Everything

It's vitally important, especially in dealing with a reluctant school, to document everything. This means that each time you call the school, you should write down the date and time of the phone call, the name of the person to whom you spoke, and what was discussed and/or decided. You should also keep a copy of all emails, letters, or other documents that you send to or receive from the school. If problems arise during the school day in the treatment of your child, you should also write down as much detail as you know concerning the incident. If your school is doing a great job, you should write down good things the school is doing for your child. It never hurts to refer to these specific items when thanking school personnel as a group or thanking an individual school staff member.

Step 2—Research 504 Plans and Prepare a Draft 504 Plan for Your Child

Sample 504 Plans are readily available. This appendix contains many ideas about what to include in a 504 Plan. In addition, the JDRF website (jdrf.org) has other sample 504 Plans. Entering "sample 504 Plans" into an internet search engine provides numerous examples of 504 Plans. No matter where you find them, most 504 Plans focus on requesting accommodations and/or modifications in the following areas.

1. Blood-testing issues (when and where)
2. Classroom accommodations (extra time, homework modifications, etc.)
3. Rule accommodations (can carry a backpack, eat in classroom, etc.)
4. Training (who is trained, substitute teacher procedures, etc.)
5. Communication (among parents, doctor, nurse, teachers, etc.)
6. Safety/care issues
7. Legal issues

After researching all the potential accommodations and modifications and choosing which ones pertain to your individual child and her grade, age, and maturity, it is wise to draft a 504 Plan specific to your child to share with the school. Group your requests under topics 1 to 7 listed above to make your requests clear and easily understood.

Step 3—Consult with the Child's Physician and Prepare a Medical/Health Plan

A medical/health Plan provides the school the needed medical information about how to treat the T1D child. It is **not** a substitute for a 504 Plan! The 504 Plan should have an item listed that says, "Follow the medical/health plan supplied by [doctor's name]."

Step 4—Write a Letter Requesting a Meeting for the Purpose of Establishing Eligibility for a 504 Plan as Well as Writing and Approving the 504 Plan

1. Address the letter to the principal of the school with copies to 1] the district 504 coordinator (usually, but not always, the special education director), 2] the child's counselor/social worker, if applicable, 3] the district superintendent, 4] the district school nurse, and 5] the school nurse/health aide, if applicable. If your child is mature enough, communicate that your child will be attending the meeting with you.
2. Keep a copy of the letter.
3. Include in the letter a request for all appropriate personnel who are knowledgeable about your child to attend the meeting and that it is your expectation that the meeting will take place within a certain time period after receipt of the letter (about 10 days is appropriate).
4. Include in the letter a thank you for what the child's school has done for your child in the past and your willingness to work with the school to provide the best services for your child in the future.
5. Include with the letter a copy of the medical/health plan from the child's doctor as well as the draft 504 Plan you have written, including the list of accommodations and modifications you are requesting.
6. If possible, include a hard copy of the JDRF School Advisory Toolkit—either an original available from the JDRF local chapter or a copy. If a hard copy is not available, include in the letter the link to the JDRF website where a copy can be requested.

At the end of this Appendix III section, you will find a sample letter for requesting a 504 Conference Meeting. If the school is one of those “reluctant” schools or has been “putting you off,” you might consider sending the letter certified with a receipt. Keep this receipt with your other documentation.

Step 5—At the 504 Meeting

Although it may not be desirable or necessary at the very first meeting, you always have the right to take someone with you to a 504 meeting. If both parents can attend, that is best. A neighbor or someone else to softly touch your arm to calm you if you start getting emotional is a good thing. An advocate or attorney might be wise at future meetings if things do not go well. *It is highly recommended that you never surprise school personnel by showing up, unannounced, with an advocate or an attorney.* Especially with an attorney, there is a good chance that your meeting will be cancelled until such time as the school can reschedule the meeting with its own attorney present. Letting the school know, up front, who will be attending the meeting with you is polite, respectful, and demonstrates your willingness to openly communicate and work with the school cooperatively.

It never hurts to bring some cookies or healthy snacks to the first meeting as a thank you and ice breaker. It also never hurts to verbally thank those in attendance for what they have done and what they will be doing in the future for the safety and well-being of your child. Acknowledge that caring for your child with T1D will take some time and effort, but assure them that you are there to cooperate and assist when necessary.

During the meeting, try to remain calm and carefully *listen to and consider* what school personnel are saying. Although you know your child best in many respects, school personnel may have quite valid and workable suggestions as to the best way to handle particular issues or situations. If you don't agree, say so, but understand that school personnel know better than you how things work at school and their ideas on how to modify or accommodate your child's needs may be even better than what you requested.

Go through all of your requested accommodations and modifications—adjusting them when the school makes a better suggestion with which you agree. At the end, if you are happy, sign the 504 Plan and get a copy! If you are not happy, don't sign anything and say you will give some thought to what to do next. If the meeting is not completed due to lack of time, make sure another date is scheduled as soon as possible to conclude the meeting.

504 law fine points to remember

1. Based on the new definition of disabled in the *ADA Amendments Act of 2008*, there is now no doubt that a child with T1D is eligible for a 504 Plan. (Section 504 uses the definition of disabled in the ADA.) If school officials tell you a 504 Plan is not necessary or they won't do one, they need to be educated as to the laws that apply to a disabled child.
2. Remember, Section 504 doesn't apply to *religion-sponsored* private schools.
3. Again, health plans are not a substitute for a 504 Plan. A 504 Plan provides a framework for the overall accommodations/modifications that a child with T1D needs in the school setting. A health plan gives specifics of what to do when a health issue arises. For example, a 504 Plan gives the right to attend a field trip or not to take a test when your child has high blood glucose, while the health plan covers the particulars of how many carbohydrates are to be eaten for lunch and how many units of insulin are to be given and at what time.
4. The 504 law requires **reasonable** accommodations/modifications. What is reasonable is up to interpretation. If you can't work things out with the school, don't sign anything and consider legal procedures to obtain what you believe to be reasonable.

What to Do if Things Don't Go Well

It's always good to try one more time to ask for a meeting with the principal and/or 504 coordinator and/or superintendent to nicely work things out. Calmly explain why you believe what you are asking for is reasonable. Don't bring in lots of peripheral issues. Just specifically list each accommodation or modification that you believe to be reasonable but the school refuses to do. Check with other school systems to see if they offer what you are requesting. If they do, you can explain to your school that if it's reasonable for another school to do what you are requesting, it must be a reasonable request. *In addition, call the Federal Department of Education Office for Civil Rights and check with someone at that office to see if he believes what you are requesting is reasonable. If he agrees with you, write down the person's name and direct phone number and communicate to the school that you have checked with the experts and that the experts agree with your definition of reasonable. With this information in hand, try nicely one*

more time to get what you need. (Remember—document all of these conversations!) If you are still stymied in your request, you will need to move on to other methods of obtaining the necessary services for your child.

Below you will find three methods for obtaining the 504 Plan you believe is appropriate for your child. You can proceed with any one of these, or you can implement more than one or all three at the same time. In each case, thorough and detailed documentation will be invaluable to you.

1. The easiest method and one that will cost you no money is to contact and make a complaint to your state department of education.

Try not to be emotional during the conversation. Share what you know about Section 504 law. Explain the *specific* topics of concern and the specific accommodations and modifications that are still at issue and explain why you think they are reasonable. Share the process you used to try to obtain an appropriate 504 Plan. Ask what the state department of education can and is willing to do for you. Ask if the person would like copies of any of your documentation. Ask about what they will be doing and when they might get back to you. Let them know how long this process has already taken and the urgency of the 504 Plan to be adopted so that training, medical emergency procedures, and academic accommodations and modifications can be put into place so that your child receives the education she deserves under the law. This method of enlisting the assistance of your state board of education is the most likely method (although not guaranteed) to obtain a quick response from the school.

2. The second method is to formally request a *due-process hearing*.

This request should be in written form and sent certified mail with return receipt. (A sample due-process hearing request letter is provided at the end of this Appendix III of the *School Advisory Toolkit*.) Requesting a due-process hearing is a legal right you have based on Section 504 law. The actual due-process hearing costs are paid for by the school system. However, you may incur expenses if you wish to have an attorney who specializes in special education law assist you in writing the due-process hearing request letter and/or in representing you at the hearing. (A court, at its discretion, may require the school district to pay a reasonable attorney's fee if the due-process hearing finds in the parents' favor.) It is not required

that you be represented by an attorney, but it is probably a wise choice at this point in the process. A due-process hearing consists of an independent party hearing both your side and the school's side of the issues and then rendering a decision. The due-process hearing officer effectively acts as a "judge" who listens to both sides and then makes a decision based on his/her interpretation of the applicable laws.

- a. Address the letter requesting a due-process hearing to the principal of the school with copies to 1] the district 504 coordinator (usually, but not always, the special education director), and 2] the district superintendent. (Keep a copy of the letter!)
 - b. Consider listing the specific areas of disagreement and your reasoning as to why the accommodations and modifications you are requesting and the school is denying are reasonable.
 - c. Request that the due-process hearing be held as expeditiously as possible.
 - d. Request to be kept informed and up to date as to the progress of scheduling the due-process hearing.
 - e. Consider hiring an attorney to represent you at the due-process hearing as well as assisting you in writing the letter requesting the due-process hearing.
 - f. Bring all documentation with you to the due-process hearing to share with the due-process hearing officer. This would include:
 - All letters sent by you to the school
 - All letters received by you from the school
 - Documentation of all phone calls to and from the school with the topics of conversation of these calls and the results, if any, of the calls
 - Copies of any paperwork you received at any of the meetings with school personnel
 - Documentation of any issues you have had with the school, including any times that you felt your child was denied access to programs or was put in an unsafe position or treated poorly.
3. The third method is to file a discrimination complaint with the Federal Department of Education Office for Civil Rights.

- At the time of the printing of this document, the following is the correct contact information for this office.
- ADA specialists are available Monday through Friday from 9:30 a.m. until 5:30 p.m. (Eastern Time) except on Thursday, when the hours are 12:30 p.m. until 5:30 p.m.
- Spanish language service is also available.
- For general ADA information, answers to specific technical questions, free ADA materials, or information about filing a complaint, call: 800-514-0301 (voice) or 800-514-0383 (TTY).

Although filing an antidiscrimination complaint with the Department of Education Office for Civil Rights may be the strongest and most compelling legal recourse you have, it is not necessarily a short process, and you should know that it may take some time for the process to come to conclusion. Of course, just knowing that a parent is actually going forward and filing a civil rights complaint sometimes immediately prompts a school to reconsider its stance. No school wants to be involved in a civil-rights complaint.

504 Plans and Kindergarten: Sending Your T1D Child to School for the *First Time*

Your child is ready for kindergarten next year. Normally this is an exciting and happy time ... but your child has T1D. So, in addition to the excitement, you also have some anxiety about how this is all going to work. This section provides you with some information that should reduce your anxiety and just leave the feelings of excitement and joy that come with sending your child to school for the first time.

Your planning should begin about six months before your child begins kindergarten. Somewhere around the beginning of March of the school year *before* your child will be going to school, you'll want to contact the school and set up two meetings. The first meeting is an informal introductory meeting to share information about your T1D child. The second meeting is an official 504 Plan eligibility conference for the purpose of writing the 504 Plan. You should respectfully request that participants in the first meeting include the principal, the district nurse, the school nurse or health aide (if applicable), and the school counselor or social worker (if applicable).

At the first introductory meeting

1. Bring treats! This always helps a meeting begin on a friendly note.
2. Introduce yourself.
3. Communicate your concerns and fears.
4. Express your confidence in school staff to provide for the safety of your child and calm your concerns and fears.
5. Communicate your willingness to work cooperatively with the school.
6. Talk about how you can assist during the day, and communicate any limitations to your assistance (e.g., work schedule).
7. Acknowledge that you understand that school officials are taking on additional responsibility in taking care of your child—and that you appreciate their work!
8. Bring/provide information about your child and his T1D.
9. Provide information about diabetes (e.g., *School Advisory Toolkit*).
10. Point out important sections of the *School Advisory Toolkit*, including Appendix I on the applicable laws. (This lets school staff know, in a nice way, that you are aware of your legal rights.)
11. Formally request a 504 Plan eligibility conference meeting—verbally and in writing. (See previous section on 504 Plans).
12. Bring a first draft of your requested 504 Plan (see previous section on 504 Plans).
13. Assure school personnel that the accommodations and modifications you are requesting do not cost much, if any, money. (They usually don't if T1D is the only issue.)
14. Ask what additional information school personnel would like you to bring to the 504 meeting.
15. Request that school personnel who are able to make decisions concerning the 504 Plan be present at the meeting.
16. Talk to the principal about a teacher for your child. Ask if the principal is willing to assign your child to that teacher before the 504 conference so the teacher can attend the meeting.
17. Set a date for the 504 eligibility conference meeting.
18. Thank school staff for spending time with you!!!

Before the 504 eligibility conference meeting, read the previous section on 504 Plans and meetings.

Sample Letter to Request a 504 Meeting

[Name of Parent]

[Address]

[City/State/Zip]

[Date]

To: [Principal of School]

CC: [District School Nurse] [School Nurse/Health Aide, if applicable] [District 504 Coordinator/Special Education Coordinator] [Child's Social Worker/Counselor, if applicable]

Please consider this letter a formal request to convene a 504 Conference Meeting for the purpose of determining 504 eligibility for my child, [child's full name], as well as the writing of a 504 Plan with reasonable modifications and accommodations for [child's first name]. The reason for this request is that [Child's first name] has been diagnosed with T1D (type 1 diabetes). Based on information I have received concerning Section 504 law, I have no doubt that [child's name] will qualify for a 504 Plan. I request that all appropriate personnel who are knowledgeable about [child's first name] attend the 504 meeting, including [his/her] teacher. I also request that school personnel who have the authority to make decisions concerning the approval of a 504 Plan be in attendance at this meeting. Since I feel that [child's first name] is mature enough to contribute to this meeting, [he/she] will be attending the meeting with me. {Include this last sentence only if the T1D child is mature enough to attend.} I know that scheduling a meeting with this number of school staff can be challenging, so I am willing to be as flexible with my schedule as possible to accommodate school staff. Due to the potential for a medical emergency, it is of utmost importance that we begin this process as quickly as possible. Therefore, I respectfully request that this meeting be scheduled within the next 10 days if at all possible.

I want to say up front that I am grateful for all that [name of school] has done for [child's first name] in the past and acknowledge that the diagnosis of T1D will add to the school's responsibilities. I appreciate the extra time school personnel will put into this 504 Plan meeting and the extra care that all of you will provide for [child's first name] in the future. I assure you that I will do everything I can to make your job as easy as possible and that I will fulfill, to the best of my ability, any parental responsibilities that come with having a T1D child at your school.

With this letter, I have provided a copy of the JDRF publication, the *School Advisory Toolkit*. {Or provide the link to the *School Advisory Toolkit*, which is jdrf.org/index.cfm?page_id=108007.} Although I hope you will be able to read all of this publication before our meeting, I'd like to specifically direct you to Appendix I of the *School Advisory Toolkit*, which has information on all of the laws that apply to a T1D child in a school setting. {If possible, also include with this letter any health information provided by your child's physician concerning how the school should deal with your child. Also, if possible, include a list of items you would like to see included in the 504 Plan.}

Again, thank you for your assistance in scheduling the 504 Plan meeting, and I look forward to hearing from you soon about the scheduled date and time.

Sincerely,

[Parent Name]

Sample Letter to Request a Due-Process Hearing

[Name of Parent]

[Address]

[City/State/Zip]

[Date]

To: [Principal of School]

CC: [District 504 Coordinator/Special Education Coordinator] [School Superintendent]

Please consider this letter a formal request for a due-process hearing for my child, [child's full name]. The reason for this request is that I believe my child is being denied reasonable accommodations and modifications based on [his/her] diagnosis of T1D (type 1 diabetes). As defined in the American Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008, I believe T1D qualifies as a disability and therefore, Section 504 of the Rehabilitation Act of 1973, and as amended in 1974, applies.

I have met with [Name of School] personnel on a number of occasions in an attempt to qualify my child for a 504 Plan and write and sign a 504 Plan. Although I have made great effort to explain why I believe accommodations and modifications that I have requested for my child are reasonable, school personnel have not agreed. Attached to this letter are the specific issues and areas of disagreement.

Due to the potential for a medical emergency, as well as the fact that I believe my child is being discriminated against according to ADA and Section 504 laws, it is of utmost importance that this due-process hearing be scheduled as expeditiously as possible. I respectfully request that I be kept informed and up-to-date as to the progress of the scheduling of the due-process hearing.

[You may want to include a paragraph here communicating to the principal what other actions you have taken or plan to take regarding the disagreements. These could include contacting the state department of education and/or filing a complaint with the Department of Education Office for Civil Rights.]

With this letter, I have provided to you a copy of the JDRF publication, the *School Advisory Toolkit*. {Or provide the link to the *School Advisory Toolkit*, which is jdrf.org/index.cfm?page_id=108007.} Although I hope you will be able to read the entire publication before our meeting, I'd like to specifically direct you to Appendix I of the *School Advisory Toolkit*, which has information on all of the laws that apply to a T1D child in a school setting.

Thank you for your assistance in scheduling the requested due-process hearing, and I look forward to hearing from you shortly about the scheduled date and time.

Sincerely,

[Parent Name]

Section 504 Provides:

“No otherwise qualified individual with a disability in the United States, as defined in section 705 (20) shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.”

Below is a copy of the regulations issued by the Department of Education Office for Civil Rights that pertain and apply to preschools, elementary schools, and secondary education schools. (Section 504 does not apply to schools run by religious organizations.)

TITLE 34 EDUCATION

SUBTITLE B—REGULATIONS OF THE OFFICES OF THE DEPARTMENT OF EDUCATION

CHAPTER I—OFFICE FOR CIVIL RIGHTS, DEPARTMENT OF EDUCATION

PART 104—NONDISCRIMINATION ON THE BASIS OF HANDICAP IN PROGRAMS OR ACTIVITIES RECEIVING FEDERAL FINANCIAL ASSISTANCE

Subpart D—Preschool, Elementary, and Secondary Education

104.31 Application of this subpart

104.32 Location and notification

104.33 Free appropriate public education

104.34 Educational setting

104.35 Evaluation and placement

104.36 Procedural safeguards

104.37 Nonacademic services

104.38 Preschool and adult education

104.39 Private education

104.31 Application of this subpart

Subpart D applies to preschool, elementary, secondary, and adult education programs or activities that receive federal financial assistance and to recipients that operate, or that receive federal financial assistance for the operation of, such programs or activities.

104.32 Location and notification

A recipient that operates a public elementary or secondary education program or activity shall annually:

- (a) Undertake to identify and locate every qualified handicapped person residing in the recipient's jurisdiction who is not receiving a public education; and
- (b) Take appropriate steps to notify handicapped persons and their parents or guardians of the recipient's duty under this subpart.

104.33 Free appropriate public education

(a) *General.* A recipient that operates a public elementary or secondary education program or activity shall provide a free appropriate public education to each qualified handicapped person who is in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap.

(b) *Appropriate education.* (1) For the purpose of this subpart, the provision of an appropriate education is the provision of regular or special education and related aids and services that (i) are designed to meet individual educational needs of handicapped persons as adequately as the needs of nonhandicapped persons are met and (ii) are based upon adherence to procedures that satisfy the requirements of 104.34, 104.35, and 104.36.

(2) Implementation of an Individualized Education Program developed in accordance with the Education of the Handicapped Act is one means of meeting the standard established in paragraph (b)(1)(i) of this section.

(3) A recipient may place a handicapped person or refer such a person for aid, benefits, or services other than those that it operates or provides as its means of carrying out the requirements of this subpart. If so, the recipient remains responsible for ensuring that the requirements of this subpart are met with respect to any handicapped person so placed or referred.

(c) *Free education*—(1) *General*. For the purpose of this section, the provision of a free education is the provision of educational and related services without cost to the handicapped person or to his or her parents or guardian, except for those fees that are imposed on non-handicapped persons or their parents or guardian. It may consist either of the provision of free services or, if a recipient places a handicapped person or refers such person for aid, benefits, or services not operated or provided by the recipient as its means of carrying out the requirements of this subpart, of payment for the costs of the aid, benefits, or services. Funds available from any public or private agency may be used to meet the requirements of this subpart. Nothing in this section shall be construed to relieve an insurer or similar third party from an otherwise valid obligation to provide or pay for services provided to a handicapped person.

(2) *Transportation*. If a recipient places a handicapped person or refers such person for aid, benefits, or services not operated or provided by the recipient as its means of carrying out the requirements of this subpart, the recipient shall ensure that adequate transportation to and from the aid, benefits, or services is provided at no greater cost than would be incurred by the person or his or her parents or guardian if the person were placed in the aid, benefits, or services operated by the recipient.

(3) *Residential placement*. If a public or private residential placement is necessary to provide a free appropriate public education to a handicapped person because of his or her handicap, the placement, including non-medical care and room and board, shall be provided at no cost to the person or his or her parents or guardian.

(4) *Placement of handicapped persons by parents*. If a recipient has made available, in conformance with the requirements of this section and 104.34, a free appropriate public education to a handicapped person and the person's parents or guardian choose to place the person in a private school, the recipient is not required to pay for the person's education in the private school. Disagreements between a parent or guardian and a recipient regarding whether the recipient has made a free appropriate public education available or otherwise regarding the question of financial responsibility are subject to the due-process procedures of 104.36.

(d) *Compliance*. A recipient may not exclude any qualified handicapped person from a public elementary or secondary education after the effective date of this part. A recipient that is not, on the effective date of this regulation, in full compliance with the other requirements of the preceding paragraphs of this section shall meet such requirements at the earliest practicable time and in no event later than September 1, 1978.

104.34 Educational setting

(a) *Academic setting*. A recipient to which this subpart applies shall educate, or shall provide for the education of, each qualified handicapped person in its jurisdiction with persons who are not handicapped to the maximum extent appropriate to the needs of the handicapped person. A recipient shall place a handicapped person in the regular educational environment operated by the recipient unless it is demonstrated by the recipient that the education of the person in the regular environment with the use of supplementary aids and services cannot be achieved satisfactorily. Whenever a recipient places a person in a setting other than the regular educational environment pursuant to this paragraph, it shall take into account the proximity of the alternate setting to the person's home.

(b) *Nonacademic settings*. In providing or arranging for the provision of nonacademic and extracurricular services and activities, including meals, recess periods, and the services and activities set forth in 104.37(a)(2), a recipient shall ensure that handicapped persons participate with nonhandicapped persons in such activities and services to the maximum extent appropriate to the needs of the handicapped person in question.

(c) *Comparable facilities*. If a recipient, in compliance with paragraph (a) of this section, operates a facility that is identifiable as being for handicapped persons, the recipient shall ensure that the facility and the services and activities provided therein are comparable to the other facilities, services, and activities of the recipient.

104.35 Evaluation and placement

(a) *Preplacement evaluation*. A recipient that operates a public elementary or secondary education program or activity shall conduct an evaluation in accordance with the requirements of paragraph (b) of this section of any person who, because of handicap, needs or is believed to need special education or related services before taking any action with respect to the

initial placement of the person in regular or special education and any subsequent significant change in placement.

(b) *Evaluation procedures.* A recipient to which this subpart applies shall establish standards and procedures for the evaluation and placement of persons who, because of handicap, need or are believed to need special education or related services that ensure that:

- (1) Tests and other evaluation materials have been validated for the specific purpose for which they are used and are administered by trained personnel in conformance with the instructions provided by their producer;
- (2) Tests and other evaluation materials include those tailored to assess specific areas of educational need and not merely those which are designed to provide a single general intelligence quotient; and
- (3) Tests are selected and administered so as best to ensure that, when a test is administered to a student with impaired sensory, manual, or speaking skills, the test results accurately reflect the student's aptitude or achievement level or whatever other factor the test purports to measure, rather than reflecting the student's impaired sensory, manual, or speaking skills (except where those skills are the factors that the test purports to measure).

(c) *Placement procedures.* In interpreting evaluation data and in making placement decisions, a recipient shall (1) draw upon information from a variety of sources, including aptitude and achievement tests, teacher recommendations, physical condition, social or cultural background, and adaptive behavior, (2) establish procedures to ensure that information obtained from all such sources is documented and carefully considered, (3) ensure that the placement decision is made by a group of persons, including persons knowledgeable about the child, the meaning of the evaluation data, and the placement options, and (4) ensure that the placement decision is made in conformity with 104.34.

(d) *Reevaluation.* A recipient to which this section applies shall establish procedures, in accordance with paragraph (b) of this section, for periodic reevaluation of students who have been provided special education and related services. A reevaluation procedure consistent with the Education for the Handicapped Act is one means of meeting this requirement.

104.36 Procedural safeguards

A recipient that operates a public elementary or secondary education program or activity shall establish and implement, with respect to actions regarding the identification, evaluation, or educational placement of persons who, because of handicap, need or are believed to need special instruction or related services, a system of procedural safeguards that includes notice, an opportunity for the parents or guardian of the person to examine relevant records, an impartial hearing with opportunity for participation by the person's parents or guardian and representation by counsel, and a review procedure. Compliance with the procedural safeguards of section 615 of the Education of the Handicapped Act is one means of meeting this requirement.

104.37 Nonacademic services

(a) *General.* (1) A recipient to which this subpart applies shall provide nonacademic and extracurricular services and activities in such manner as is necessary to afford handicapped students an equal opportunity for participation in such services and activities.

(2) Nonacademic and extracurricular services and activities may include counseling services, physical recreational athletics, transportation, health services, recreational activities, special interest groups or clubs sponsored by the recipients, referrals to agencies that provide assistance to handicapped persons, and employment of students, including both employment by the recipient and assistance in making available outside employment.

(b) *Counseling services.* A recipient to which this subpart applies that provides personal, academic, or vocational counseling, guidance, or placement services to its students shall provide these services without discrimination on the basis of handicap. The recipient shall ensure that qualified handicapped students are not counseled toward more restrictive career objectives than are nonhandicapped students with similar interests and abilities.

(c) *Physical education and athletics.* (1) In providing physical education courses and athletics and similar aid, benefits, or services to any of its students, a recipient to which this subpart applies may not discriminate on the basis of handicap. A recipient that offers physical education courses or that operates or sponsors interscholastic, club, or intramural athletics shall provide to qualified handicapped students an equal opportunity for participation.

(2) A recipient may offer to handicapped students physical education and athletic activities that are separate or different from those offered to nonhandicapped students only if separation or differentiation is consistent with the requirements of 104.34 and only if no qualified handicapped student is denied the opportunity to compete for teams or to participate in courses that are not separate or different.

104.38 Preschool and adult education

A recipient to which this subpart applies that provides preschool education or day care or adult education may not, on the basis of handicap, exclude qualified handicapped persons and shall take into account the needs of such persons in determining the aid, benefits, or services to be provided.

104.39 Private education

(a) A recipient that provides private elementary or secondary education may not, on the basis of handicap, exclude a qualified handicapped person if the person can, with minor adjustments, be provided an appropriate education, as defined in 104.33(b)(1), within that recipient's program or activity.

(b) A recipient to which this section applies may not charge more for the provision of an appropriate education to handicapped persons than to nonhandicapped persons except to the extent that any additional charge is justified by a substantial increase in cost to the recipient.

(c) A recipient to which this section applies that provides special education shall do so in accordance with the provisions of 104.35 and 104.36. Each recipient to which this section applies is subject to the provisions of 104.34, 104.37, and 104.38.

**For more information on finding your
local JDRF chapter, please visit
jdrf.org/locations.**

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About JDRF

JDRF is the leading global organization funding type 1 diabetes (T1D) research. JDRF's goal is to progressively remove the impact of T1D from people's lives until we achieve a world without T1D. JDRF collaborates with a wide spectrum of partners and is the only organization with the scientific resources, regulatory influence, and a working plan to better treat, prevent, and eventually cure T1D. As the largest charitable supporter of T1D research, JDRF is currently sponsoring \$568 million in scientific research in 17 countries.

For more information, please visit jdrf.org.

