

Summer is upon us, and while we are enjoying summer activities, it is also time to start thinking of the school year to come. Starting a new school year is always exciting and a little nerve-wracking. This is especially true when your child is diagnosed with celiac disease or non-celiac gluten sensitivity (also known as gluten sensitivity). Many parents are unsure what legal rights their child may have with regard to maintaining gluten-free status in school. It is important to understand your rights, and how to utilize them if needed. Section 504 of the Rehabilitation Act of 1973 is a federal anti-discrimination law that may be applicable to your child's circumstances. The following is for general informational purposes only. It is recommended that you speak with the 504 Coordinator at your child's school for further information about your specific situation.

# What legal rights does a gluten-free child have?

Although the law can sometimes seem daunting, it is important to understand how it affects the rights of children who need to be gluten-free. The Rehabilitation Act of 1973 is a federal law intended to prevent discrimination towards people with disabilities. The law applies to organizations and employers that receive financial assistance from any federal department

or agency. A school's participation in the National School Lunch Program is one example of its being a recipient of federal financial assistance, thus requiring it to comply with this anti-discrimination act. Section 504 of this act is specifically intended to ensure that qualified children who have disabilities have accommodation to receive a comparable education to that of their non-disabled peers. In an Amendment Act of 2008 (through the Americans with Disabilities Act), the term "disability" was enhanced to have a broad scope of protection. It notes that a "disability" can be a physical or mental impairment that substantially limits one or more major life activities. This includes eating and major bodily functions, including but not limited to, functions of the immune system, normal cell growth, digestive and bowel functions.

The U.S. Department of Education website notes that "(t)he Amendments Act... should be interpreted to allow for broad coverage. Students who, in the past, may not have been determined to have a disability ... may now in fact be found to have a disability under those laws." The definition of disability in this context has been expanded and could include children with gluten sensitivity, not only those with celiac disease. Due to the change, state and local agencies may need additional information about this adjustment in the regulation before being able to proceed with creating a 504 Plan for your

child. Further information can be found at "Questions and Answers on the ADA Amendments Act of 2008 for Students with Disabilities Attending Public Elementary and Secondary Schools." (See resource list at end of article.)

## How do I determine if my child qualifies for Section 504?

The most effective method of starting the process may be to visit your child's doctor. If your child is diagnosed by a medical doctor as having "a physical impairment that substantially limits that student in a major life activity," even if the child does not need educational assistance, you will have the option to request a 504 evaluation. The language of the law is broad, indicating that direct proof of physical impairment (such as medical tests or diagnostic procedures) is acceptable, but so is "regarding" a child as having a physical impairment, where hard physical proof may not be present.

#### Should we create a 504 Plan?

The process of creating a 504 Plan may be initiated by a parent or by the 504 Coordinator at the school, if the person in this position sees a child who needs assistance and believes that a 504 Plan may be applicable. A 504 Plan can be especially beneficial for young children, as it can follow them from year to year, and school to school. Aditionally, provisions for gluten-free classroom environments and activities may be included (gluten-free playdough, finger paints, etc.). In this manner, having a 504 Plan established will help the school faculty and administrators by providing a clear and detailed outline of provisions required to keep your child safe, and will hopefully prevent miscommunication and your child's inadvertent exposure to gluten.

Many public schools provide the opportunity for a glutenfree school lunch for children who need it, however this can vary from state to state, and school to school. If your child is older and able to take precautions during activities and events to avoid exposure to gluten, he or she may only need to be provided with a gluten-free school lunch and a 504 Plan may not be necessary.

### How do I begin to create a 504 Plan?

When first enquiring about accommodation for your child, contact the school principle or the school's 504 Coordinator: this could be a school nurse, counselor or other administrator. Most schools have a 504 Coordinator at the school itself, however if not, you will be referred to the coordinator for the district. This individual will be able to help you begin the process of determining if your child is eligible and if so, to create a 504 Plan. The American Celiac Disease Alliance collaborated with the Disability Rights Education and Defense Fund, Inc. to create an example 504 Document which can be found by clicking on the "For Families" tab at: www.americanceliac.org.



A team of professionals who are aware of the student's needs and can identify how their needs would have to be accommodated in the school environment will be assembled, generally by the 504 Coordinator. It may include the child's teacher, a member of the cafeteria staff, school nurse, a parent/guardian of the child, and anyone else who needs to be involved. This group will work together to determine what the data gathered (physician letters, other documents) will mean for the student and school, and the options available to assist the student. It may be helpful to provide a letter from your child's pediatrician, gastroenterologist or other licensed physician, which includes your child's diagnosis and an explanation of what that means in relation to gluten in foods, food preparation, foods allowed and not allowed.

Specific care during art and activities may be necessary if your child is younger or has other physical or mental disabilities that may prevent him or her from being able to avoid gluten when present in non-food environments. Gluten can be present in items such as finger-paint, glue, papier-mâché, play-dough, and pasta or cereal for art projects, to name a few. When creating a 504 Plan, it is important to include ways to keep



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your child safe even during non-food activities. For example it may be necessary to provide the child with an "allergen free" desk, or offer a hand washing station where the child is able to wash his or her hands after an activity.

School parties, field trips and other special events are regular occurrences in school. These are wonderful times to join with peers and socialize, but require a little special planning. Tactics to ensure your child has a gluten-free meal/environment should be included in the 504 Plan. Ask to coordinate with the teacher or lunch-room cook to find a gluten-free alternative for your child. Also, you can volunteer to bring safe food so that your child can participate in the event. Whether or not a child with celiac disease or gluten sensitivity shows symptoms, exposure to gluten is dangerous and damaging. It is important to make a clear and easy-to-follow action plan that the responsible adult (teacher, lunch room staff member) can follow if they believe the child has been exposed to gluten.

The easiest way to make sure your little one has safe food is to put it together at home. You can find recommendations for easy meal and snack ideas on the GIG website, www.gluten.net under the "Educational Bulletins" tab. Of course, when gluten-free foods are brought from home, prevention of cross-contamination during school eating occasions still must be considered.

### Where do I go from here?

Celiac disease is the only autoimmune disorder which is treatable with diet. While this is wonderful because progression of the disease can be prevented by being gluten-free, some people are still unaware of this fact. As research continues to investigate the physical implications of gluten sensitivity and other gluten-related disorders, it is important to make sure that all school faculty and staff understand the severity of these disorders. It may help to keep in mind that the gluten-free diet isn't just a diet, or a choice, it is a medical prescription for your child's health and it is as important as any medication that would be prescribed by a doctor.

Some people feel that this is a private matter and that school officials should only ever discuss it with the child, family or when dealing with food for the child. This may be especially important if your child is concerned about fitting in with his or her peers and doesn't want to be seen as "different" from them. The other option is to make your child's food restriction a topic for open discussion. One possibility at the start of the new school year, is to ask the teacher to take a half hour of class where all students and involved administrators sit together to discuss gluten-related disorders. Invite the whole class to talk about what the food sensitivity means for your child and ask them for their thoughts. By making it a topic of open conversation the stigma of having to eat "different" food may dissolve, allowing your child's need to eat gluten-free to become an accepted and unquestioned part of who they are. In this way other students and families can become part of your child's support group. This is a completely personal decision and you and your family are under no obligation to conceal or reveal your child's situation.

Gluten-related disorders, whether celiac disease or gluten sensitivity, are not rare. Over 3 million Americans are estimated to have celiac disease and many more may have gluten sensitivity. For more information about the specific rights and procedures at your child's school, please contact the 504 Coordinator at your child's school, since local, state, and federal policies may be different for your area and situation. No matter what, maintaining a positive attitude will help you and your child deal with the situation with as little stress and as much ease as possible. By working together with other families, teachers, and school administrators we can raise awareness, acceptance and understanding for the unique needs of everyone.

#### **Resources for further reading:**

- Accommodating Children with Special Dietary Needs in the School Nutrition Programs Guidance for School Food Service Staff (US Department of Agriculture Food and Nutrition Service): http://www.fns.usda.gov/cnd/Guidance/special\_ dietary\_needs.pdf.
- Americans with Disabilities Act (ADA): http://www.ada.gov
- Individuals with Disabilities Education Act (IDEA) (US Department of Education): http://idea.ed.gov
- Questions and Answers on the ADA Amendments Act of 2008 for Students with Disabilities Attending Public Elementary and Secondary Schools (OCR, January 2012):

http://www2.ed.gov/about/offices/list/ocr/letters/colleague-201109.html http://www2.ed.gov/about/offices/list/ocr/docs/dcl-504faq-201109.html

- Questions and Answers About the Lesley University
   Agreement and Potential Implications for Individuals with
   Food Allergies (DOJ, January 2013): http://www.ada.gov/q&a\_lesley\_university.htm
- Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs (Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, 2013): http://www.cdc.gov/healthyyouth/foodallergies/pdf/13\_243135\_A\_Food\_Allergy\_Web\_508.pdf
- A Parent and Educator Guide to Free Appropriate
   Public Education under Section 504 (Puget Sound
   Educational Service District): https://www.k12.wa.us/Equity/
   pubdocs/504ManualFinal.pdf
- FAQs about Section 504 and the Education of Children with Disabilities (U.S. Department of Education): http://www2.ed.gov/about/offices/list/ocr/504faq.html
- **OSPI Civil Rights Guidelines** (OSPI Equity & Civil Rights Office): http://www.k12.wa.us/equity/ProhibitingDiscrimination.
- Accommodation Special Dietary Needs Flowchart (OSPI Child Nutrition Department): http://www.k12.wa.us/childnutrition/programs/nslbp/pubdocs/AccommodatingSpecialDietaryNeedsFlowChartAndForms.pdf
- OSPI Guidelines for the Care of Students with Anaphylaxis (OSPI Health Services): https://www.k12.wa.us/healthservices/Publications/09-0009.aspx

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