

# **Handbook for Children with Special Food and Nutrition Needs**



**National Food Service Management Institute**  
The University of Mississippi

Item Number ET69-06

2006

#### Disclaimer

The information provided in this publication is the result of independent research produced by NFSMI and is not necessarily in accordance with U.S. Department of Agriculture Food and Nutrition Service (FNS) policy. FNS is the federal agency responsible for all federal domestic child nutrition programs including the National School Lunch Program, the Child and Adult Care Food Program, and the Summer Food Service Program. Individuals are encouraged to contact their local child nutrition program sponsor and/or their Child Nutrition State Agency should there appear to be a conflict with the information contained herein, and any State or Federal policy that governs the associated child nutrition program. For more information on the Federal child nutrition programs please visit [www.fns.usda.gov/cnd](http://www.fns.usda.gov/cnd).

This project has been funded at least in part with Federal funds from the U.S. Department of Agriculture, Food and Nutrition Service through an agreement with the National Food Service Management Institute at The University of Mississippi. The contents of this publication do not necessarily reflect the views or policies of the U.S. Department of Agriculture, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. government.

The University of Mississippi is an EEO/Title VI/Title IX/Section 504/ADA/ADEA Employer.

In accordance with Federal law and U.S. Department of Agriculture policy, this institution is prohibited from discriminating on the basis of race, color national origin, sex, age, or disability.

To file a complaint of discrimination, write USDA, Director, Office of Civil Rights; Room, 326-W, Whitten Building, 1400 Independence Avenue, SW, Washington, DC 20250-9410 or call (202) 720-5964 (voice and TDD). USDA is an equal opportunity provider and employer.”

© 2006, National Food Service Management Institute, The University of Mississippi

Except as provided below, you may freely use the text and information contained in this document for non-profit or educational use providing the following credit is included:

#### Suggested Reference Citation:

National Food Service Management Institute. (2006). *Handbook for Children with Special Food and Nutrition Needs*. University, MS: Author.

The photographs and images in this document may be owned by third parties and used by the University of Mississippi under a licensing agreement. The University cannot, therefore, grant permission to use these images. For more information, please contact [nfsmi@olemiss.edu](mailto:nfsmi@olemiss.edu).

**National Food Service Management Institute  
The University of Mississippi**

***Building the Future Through Child Nutrition***

The National Food Service Management Institute (NFSMI) was authorized by Congress in 1989 and established in 1990 at The University of Mississippi in Oxford. The Institute operates under a grant agreement with the United States Department of Agriculture, Food and Nutrition Service.

**PURPOSE**

The purpose of NFSMI is to improve the operation of Child Nutrition Programs through research, education and training, and information dissemination. The Administrative Offices and Divisions of Technology Transfer and Education and Training are located in Oxford. The Division of Applied Research is located at The University of Southern Mississippi in Hattiesburg.

**MISSION**

The mission of the NFSMI is to provide information and services that promote the continuous improvement of Child Nutrition Programs.

**VISION**

The vision of the NFSMI is to be the leader in providing education, research, and resources to promote excellence in Child Nutrition Programs.

**CONTACT INFORMATION**

**Headquarters**

The University of Mississippi  
Phone: 800-321-3054  
Fax: 800-321-3061  
[www.nfsmi.org](http://www.nfsmi.org)

**Education and Training Division**

**Technology Transfer Division**

The University of Mississippi  
6 Jeanette Phillips Drive  
P.O. Drawer 188  
University, MS 38677-0188

**Applied Research Division**

The University of Southern Mississippi  
118 College Drive #10077  
Hattiesburg, MS 39406-0001  
Phone: 601-266-5773  
Fax: 888-262-9631

## **Acknowledgments**

### **WRITTEN AND DEVELOPED BY**

Harriet H. Cloud, MS, RD, FADA  
Owner, Nutrition Matters  
Professor Emeritus, Department of  
Nutrition Sciences  
University of Alabama  
Birmingham, AL

Anne Bomba, PhD, Associate Professor  
Teresa Carithers, PhD, RD, LD,  
Associate Professor and Chair  
Diane Tidwell, PhD, RD, LD,  
Associate Professor  
Department of Family and Consumer Sciences  
The University of Mississippi Oxford, MS

### **GRAPHIC DESIGN BY**

Vicki Howe  
National Food Service Management Institute

### **TASK FORCE MEMBERS**

Sincere appreciation is expressed to the following people who  
contributed their time and expertise to plan and review these materials.

Diana Cunningham, RD, LD  
Chief Clinical Dietitian  
North Mississippi Regional Center  
Oxford, MS

Darlene Hoar, MS, RD, LD  
Director, Project RUN Early  
Intervention Program  
North Mississippi Regional Center  
Oxford, MS

Linda B. Godfrey, MS, RD, SFNS, LD  
Child Nutrition Program Director, Retired  
School Nutrition Consultant and Trainer  
Vestavia Hills, AL

Beth King, PhD  
Director of Technology Transfer, Retired  
National Food Service Management  
Institute

Virginia Webb, MS, RD  
Director of Education and Training  
National Food Service Management Institute

### **NFSMI PROJECT COORDINATOR**

Ensley Howell, MS, RD, LD

### **NFSMI EXECUTIVE DIRECTOR**

Charlotte B. Oakley, PhD, RD, FADA

---

## **Table of Contents**

Introduction.....	3
Regulations and School Food Service .....	7
Disabilities Defined .....	7
Individuals with Disabilities Education Act (IDEA).....	8
Diet Prescription .....	9
The Role of School Food Service .....	10
Description of Selected Disabilities.....	15
Autism.....	15
Cerebral Palsy .....	16
Epilepsy or Seizure Disorder .....	17
Muscular Dystrophy .....	18
Mental Retardation .....	18
Down Syndrome .....	18
Prader Willi (PW) Syndrome.....	19
Spina Bifida .....	20
Cystic Fibrosis .....	21
Rett Syndrome .....	22
Metabolic Diseases .....	26
Diabetes .....	26
Inborn Errors of Metabolism (IEM) .....	27
One Diet Does Not Fit All.....	29
Diets May Need Adjustments .....	29
Need for Consultants .....	29
How To Handle Mistakes .....	31
Food Allergies and Food Sensitivities .....	35
Common Food Allergens.....	35
Foods that commonly contain the “Big Eight” allergens and should be avoided.....	35
Symptoms of Food Allergy.....	36
Gastrointestinal symptoms associated with food allergy.....	37
Cutaneous, or skin, symptoms associated with food allergy .....	37
Respiratory symptoms associated with food allergy .....	37
Anaphylaxis .....	37
Managing Food Allergies in Children .....	38
Monitoring for an allergic reaction .....	39
Food Intolerance .....	40
Celiac Disease.....	41
Treatment Strategies .....	41

## *Table of Contents*

---

Issues Impacting Nutrition and Special Dietary Orders .....	45
Energy Needs .....	45
Overweight.....	45
Underweight.....	47
Feeding Problems .....	48
Oral-Motor Problems.....	49
Modification of Food Texture.....	50
Positioning Problems .....	50
Behavioral Issues .....	51
Self-feeding.....	51
Tube Feedings.....	52
Special Formulas and Special Medical Foods .....	55
The Purchase of Special Formulas and Special Medical Foods .....	55
Fluids and Fiber .....	56
Intervention Strategies and the Team Approach.....	61
Environmental Considerations.....	65
Dining Environment .....	65
Scheduling .....	65
Space.....	65
Location .....	66
Lighting.....	66
Dealing with Distractibility .....	66
Food Safety Issues .....	69
Glossary .....	73
Reference List .....	77
Resources .....	85
Appendices.....	89
Appendix 1: Diet Prescription for Meals at School.....	91
Appendix 2: Foods to Avoid when Casein is omitted .....	92
Appendix 3: Gluten Free Foods by Food Groups.....	93
Appendix 4: The National Dysphagia Diet (NDD) .....	96



# **Introduction**





## **Introduction**

An amazing number of children with developmental disabilities and special health care needs are entering pre-schools, elementary schools, and high schools every year. It is estimated that 17% of children less than 18 years of age have some type of developmental disability. Other surveys report that 3-4 million Americans have a developmental disability and another 3 million have milder forms of cognitive disorders or mental retardation (American Dietetic Association, 2004). Congress first addressed this concern in the Rehabilitation Act of 1973. Since 1975 these children have been served in the public school system under the Education of the Handicapped Act later called the Individuals with Disabilities Education Act (IDEA). IDEA requires that a free and appropriate public education be provided for children with disabilities, ages 3 through 21. A third act, Americans with Disabilities Act, was passed providing a comprehensive law, which broadens and extends civil rights protections for Americans with disabilities. Many of the children and adolescents served under this law have health problems that require nutrition intervention and benefit greatly by modification of the school breakfast and lunch.

The purpose of this handbook is to

1. identify the developmental disabilities and other health care needs to be served by school food service, and
2. provide information related to the type of intervention indicated.

The handbook will also include a discussion of the regulations requiring the school's participation and training needs of the food service workers. This manual should not be considered "all inclusive" but it will address many conditions most frequently encountered in

the school environment. Additional resources are given for investigating conditions that may not be presented.



# **Regulations and School Food Service**





## **Regulations and School Food Service**

When the Rehabilitation Act of 1973 was passed and children with developmental disabilities began entering school, the use of the school food service program by these children presented a number of questions and challenges. School personnel were concerned with how much it would cost, how menus would be written to prepare dietary modifications, and how to accommodate the needs of individual children.

Today three federal legislative acts mandate that school food service will serve children with special dietary needs. These are the Rehabilitation Act of 1973, Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA). In addition, the USDA came forth with nondiscrimination regulations (7CFR 15 b) as well as regulations which govern the National School Lunch Program and School Breakfast Program. These regulations make it clear that substitutions to the regular meal must be made for children unable to eat school meals because of their disabilities when a licensed physician certifies the need. Guidance for schools is based on USDA Food and Nutrition Service Instruction 783-2, Revision 2, Meal Substitutions for Medical or Other Dietary Reasons.

### **Disabilities Defined**

A person with a disability is a person who has a physical or mental impairment, which substantially limits one or more of the major life activities, has a record of such impairment, or is regarded as having such as impairment (USDA Food and Nutrition Service, 2001).

Diseases or conditions, which cause physical or mental impairment, include the following:

- Orthopedic, visual, speech, and hearing impairments

- Cerebral palsy
- Epilepsy
- Muscular dystrophy
- Multiple sclerosis
- Cancer
- Heart disease
- Metabolic diseases (such as diabetes or inborn errors of metabolism)
- Severe food allergy
- Mental retardation
- Emotional illness
- Drug addiction and alcoholism
- Specific learning disabilities
- HIV disease
- Tuberculosis

There are additional conditions not listed such as spina bifida and Prader-Willi syndrome since they limit one or more major life activities.

### **Individuals with Disabilities Education Act (IDEA)**

IDEA recognizes the following disability categories that establish a child's need for special education and related services. This is included in Part B of the Act. IDEA includes the following as meeting the term disability:

- Autism
- Deaf-blindness
- Deafness or other hearing impairments
- Mental retardation
- Orthopedic impairments
- Other health impairments due to chronic or acute health problems such as asthma, diabetes, nephritis, sickle cell anemia, heart condition, epilepsy, rheumatic fever, hemophilia, leukemia, and lead poisoning
- Emotional disturbance
- Specific learning disabilities
- Traumatic brain injury
- Speech or language impairment
- Visual impairment
- Multiple disabilities

Attention deficit disorder (ADD) or attention deficit hyperactivity (ADHD) may be included in one of the above categories, as will many other disorders. Under IDEA, an Individualized Education Program (IEP) is required and must include problems and goals that should include a nutritional problem, if one exists. Some states supplement the IEP with a written statement specifically designed to address a student's nutritional needs (USDA Food and Nutrition Service, 2001).

### **Diet Prescription**

The following text is taken from the United States Department of Agriculture Food and Nutrition Service document, *Accommodating Children with Special Dietary Needs in the School Nutrition Programs: Guidance for School Food Service (2001)*.

#### **Physician's Statement for Children with Disabilities**

USDA regulations 7 CFR Part 15b require substitutions or modifications in school meals for children whose disabilities restrict their diets. A child with a disability must be provided substitutions in foods when that need is supported by a statement signed by a licensed physician. The physician's statement must identify:

- the child's disability;
- an explanation of why the disability restricts the child's diet;
- the major life activity affected by the disability;
- the food or foods to be omitted from the child's diet, and the food or choice of foods that must be substituted.

[Page 5]

#### **Medical Statement for Children with Special Dietary Needs**

Each special dietary request must be supported by a statement, which explains the food substitution that is requested. It must be signed by a recognized medical authority.

The medical statement must include:

- an identification of the medical or other special dietary condition which restricts the child's diet;
- the food or foods to be omitted from the child's diet; and
- the food or choice of foods to be substituted.

[Page 6]

## **The Role of School Food Service**

The following text is taken from the United States Department of Agriculture Food and Nutrition Service document, *Accommodating Children with Special Dietary Needs in the School Nutrition Programs: Guidance for School Food Service (2001)*.

### **III. SCHOOL ISSUES**

The school food service, like the other programs in the school, is responsible for ensuring that its benefits (meals) are made available to all children, including children with disabilities. This raises questions in a number of areas:

A. What are the responsibilities of the school food service?

#### **A. SCHOOL FOOD SERVICE RESPONSIBILITIES**

- School food service staff must make food substitutions or modifications for students with disabilities.
- Substitutions or modifications for children with disabilities must be based on a prescription written by a licensed physician.
- The school food service is encouraged, but not required, to provide food substitutions or modifications for children without disabilities with medically certified special dietary needs who are unable to eat regular meals as prepared.
- Substitutions for children without disabilities, with medically certified special dietary needs must be based on a statement by a recognized medical authority.
- Under no circumstances are school food service staff to revise or change a diet prescription or medical order.
- For USDA's basic guidelines on meal substitutions and accessibility, see FNS Instruction 783-2, Revision 2, *Meal Substitutions for Medical or Other Special Dietary Reasons*, in **Appendix A**.  
[Page 7]
- It is important that all recommendations for accommodations or changes to existing diet orders be documented in writing to protect the school and minimize misunderstandings. Schools should retain copies of special, non-meal pattern diets on file for reviews.
- The diet orders do not need to be renewed on a yearly basis; however schools are encouraged to ensure that the diet orders reflect the current dietary needs of the child.

### **Providing Special Meals to Children with Disabilities**

The school food service is required to offer special meals, at no additional cost, to children whose disability restricts their diet as defined in USDA's nondiscrimination regulations, 7 CFR Part 15b.

- If a child's IEP includes a nutrition component, the school should ensure that school food service managers are involved early on in decisions regarding special meals or modifications.
- The school food service is not required to provide meal services to children with disabilities when the meal service is not normally available to the general student body, unless a meal service is required under the child's IEP.

For example, if a school breakfast program is not offered, the school food service is not required to provide breakfast to the child with a disability, unless this is specified in the child's IEP. However, if a student is receiving special education and has an IEP, and the IEP indicates that the child needs to be served breakfast at school, then the school is required to provide this meal to the child and may choose to have the school food service handle the responsibility. This is discussed in more detail in *Section V*, under Situation 2.

### **Menu Modifications for Children with Disabilities**

Children with disabilities who require changes to the basic meal (such as special supplements or substitutions) are required to provide documentation with accompanying instructions from a licensed physician.

[Page 8]

This is required to ensure that the modified meal is reimbursable, and to ensure that any meal modifications meet nutrition standards which are medically appropriate for the child.

### **Texture Modifications for Children with Disabilities**

For children with disabilities who only require modifications in texture (such as chopped, ground or pureed foods), a licensed physician's written instructions indicating the appropriate food texture is recommended, but not required.

However, the State agency or school food authority may apply stricter guidelines, and require that the school keep on file a licensed physician's statement concerning needed modifications in food texture.

- In order to minimize the chance of misunderstandings, it is recommended that the school food service, at a minimum, maintain written instructions or guidance from a licensed physician regarding the texture modifications to be made. For children receiving special education, the texture modification should be included in the IEP.

- School food service staff must follow the instructions that have been prescribed by the licensed physician.

**Serving the Special Dietary Needs of Children Without Disabilities**

Children without disabilities, but with special dietary needs requiring food substitutions or modifications, may request that the school food service meet their special nutrition needs.

- The school food authority will decide these situations on a case-by-case basis. Documentation with accompanying information must be provided by a recognized medical authority.
- While school food authorities are encouraged to consult with recognized medical authorities, where appropriate, schools are not required to make modifications to meals based on food choices of a family or child regarding a healthful diet.

[Pages 7-9]

Additionally, it is the goal of the school nutrition program to provide healthful meals for all children, which are based on established nutrition standards and consistent with the *Dietary Guidelines for Americans*.

It is also important to note that it is not the responsibility of the school food service to determine what foods may be substituted in special diets. The physician or recognized medical authority should provide specific instructions for the school food service to follow.

USDA strongly recommends that the school food service department work with students, teacher(s), school nurse, dietitian, parent(s), and the child's physician in a team approach to address meeting the needs of children with disabilities who are unable to consume the school meal as prepared because of their disability.



# **Description of Selected Disabilities**





## **Description of Selected Disabilities**

There are a number of disabilities or conditions that cause physical or mental impairment and may result in a nutritional problem, which requires a modification of the usual school breakfast or lunch. The condition may affect the energy needs of the child, the actual ingredient content of many of the foods normally served, how the food is prepared, or the texture of the food served such as regular, chopped, blended, or pureed.

When a diet prescription is written, it will generally contain a diagnosis or description of the condition. The diagnosis or condition description is important because it will help the food service director and the staff to understand why the menu change is needed (See Appendix 1).

### **Autism**

Autism is a part of the Autism Spectrum or group of disorders. Generally it is identified when a child has many behavioral problems such as not connecting with children or adults, often refusing to establish eye contact, not talking to others, and is very limited in their food intake. There are clinics that treat these children with a special meal plan that omits all foods that contain gluten, a product of wheat and some other cereals, and casein, the protein component of milk (Cornish, 2002). Although results have not been universally beneficial, many physicians prescribe the diet. The types of foods to avoid are listed in Appendices 1 and 2. There are other types of autistic disorders which are listed under Autism Spectrum disorders, but their treatment is very similar to the one just described (Fugassi, Stevens & Ekvall, 2003).

## **Cerebral Palsy**

Cerebral Palsy (CP) is a disorder where there has been an injury to the developing brain early in life. Frequently it is the result of a premature birth or other problems associated with pregnancy such as blood type incompatibility or placental insufficiency. It is estimated that its occurrence is two per 1000 live births. Some of the signs and symptoms of CP include increased motor tone and abnormal motor patterns and postures. Some children with CP have low muscle tone. They require early treatment by speech therapists, physical therapists, and occupational therapists to work with motor development that involves the ability to crawl, walk, talk, and develop oral motor feeding skills. Although CP is primarily a motor disability, it can be accompanied by mental retardation and learning disabilities.

From infancy on, many children with CP have difficulty gaining weight, receiving adequate nutrition due to feeding problems such as difficulties with sucking, chewing and swallowing normally, and later feeding themselves. This can contribute to an inability to gain weight and grow adequately in length or height. Often speech is delayed or difficult to understand. Walking may be difficult or the child may not be able to walk. Any of the nutrition problems listed in the medical prescription could be included in the IEP (Fung et al., 2002).

**What to expect in the Diet Prescription:**

1. Increased calories
2. Texture changes—could be chopped, pureed, or blended
3. Special utensils for self-feeding
4. Positioning (correct positioning often improves the child's chewing and swallowing ability)
5. Thickened liquids

## **Epilepsy or Seizure Disorder**

Epilepsy (or seizure disorder) has multiple causes involving the brain. The seizures that occur are sudden episodes of abnormal behavior which result from what is described as “firings” within the brain. The behavior may be mild with rolling or blinking of the eyes or may be very obvious with the child falling to the floor in generalized seizures.

Seizures can be caused by a metabolic problem such as hypoglycemia (low blood sugar) or poor control of diabetes with excess insulin administration. Seizures can also occur when there are abnormalities involving the electrolytes of the body such as sodium and potassium. Most children who have been diagnosed with a seizure disorder are treated with medications called anticonvulsants. These medications help to prevent or reduce the occurrence of a seizure. These medications may also contribute to constipation problems. Some children are placed on diet plans called ketogenic diets which are very high in fat and low in carbohydrates (Vining, 2002). These diets require special planning by a dietitian following the children in a clinical program and must be followed rigidly to produce optimal results.

### What to expect in the Diet Prescription

1. The child with epilepsy or seizures may have a low calorie diet order due to excessive weight gain prompted by an anticonvulsant medication. (Some seizure medications may cause weight loss.)
2. A ketogenic diet (requires input from the dietitian following the child)
3. Instructions to address feeding problems

## **Muscular Dystrophy**

There are many forms of muscular dystrophy (MD). They are referred to as a group of genetic disorders characterized by progressive weakness and degeneration of the skeletal muscles that control movement. Some of the forms of MD are congenital or present at birth, while others are identified in adolescence. The three most common are Duchenne, facioscapulohumeral, and myotonic. Duchenne primarily affects boys, and as the disease progresses, the boys will be unable to walk and will require a respirator to breathe. There is no specific treatment for any of the forms of muscular dystrophy, but providing adequate nutrition is very important. As the disease progresses, feeding and the ability to chew and swallow may be difficult.

### What to expect in the Diet Prescription

1. Feeding problems
2. Need for special utensils
3. Texture modification for chewing and swallowing problems
4. Increased calories

## **Mental Retardation**

Often mental retardation is caused by conditions called syndromes. Syndromes are defined as a set of characteristics which occur together. Two of the most common are Down syndrome and Prader-Willi syndrome.

**Down Syndrome** is a disorder of the chromosomes. The normal genetic pattern of chromosomes is when each individual has 23 pairs in each cell or a total of 46 chromosomes.

The individual with Down syndrome will have an extra chromosome on the 21<sup>st</sup> chromosome and is sometimes called Trisomy 21. The incidence of Trisomy 21 or Down syndrome is 1 in 600 live births. The infant may be born with a heart defect, and it is common for the infant to have slanted eyes, flattened nose, low set ears, and low muscle tone. Many infants with Down syndrome develop slowly related to cognitive and motor skills, crawling, and walking (Blackman, 1990).

These children often have feeding problems due to a weak “suck” and are slow to cut their teeth. Their growth may be slower, and they are often shorter than other classmates. Nutrition problems are individualized, but their most frequent problem when school age, is the potential to be overweight (Rubin, Timmer, Chioine, Braddock & McGuire, 1998). As pre-schoolers, chewing and swallowing may be a problem, resulting in difficulty changing to cup drinking and eating “table” foods.

What to expect in the Diet Prescription

1. Low calories for the child who is overweight
2. Texture modification for chewing and swallowing problems
3. Self-feeding devices

**Prader Willi (PW) Syndrome** involves the 15<sup>th</sup> chromosome. Although PW is less frequent than Down syndrome, it is now identified shortly after birth and appears with characteristics similar to Down syndrome. The PW infant has very low muscle tone, difficulty in sucking and swallowing, and may have failure to thrive. Later in the preschool period, most children with PW have an overwhelming appetite and lack the ability to know

when they are full. As a result, limiting their intake and the availability of food is extremely important (Schoeller, Livitsky, Bandini, Dietz, & Walozak, 1988). In the past, these individuals became extremely obese and difficult to manage. Even with better diagnostic techniques, there continue to be children who are not diagnosed early and are identified once obesity and unusual food consumption patterns become more evident. Under current treatment with controlled food intake, increased activity, and use of growth hormone, the PW child's health picture is greatly improved. However, their appetite remains the same and supervision is required to control the food consumed. Individuals with PW require regular physical activity, which can be difficult due to the low muscle tone, and they may require a calorie restricted plan.

What to Expect in a Diet Prescription

1. Decreased calories
2. Supervision to prevent food seeking (Environmental controls are essential because children with PW cannot control this continual urge to obtain additional food.)

### **Spina Bifida**

Spina bifida is the term frequently used to describe various forms of a neural tube defect. Other terms are myelomeningocele, meningocele, and spina bifida occulta. These children are born with a lesion in the spinal column. In normal development the spine is formed with a spinal cord making a column along the back surrounded by a membrane and the bones of the spine. In spina bifida, the formation is incomplete and a sac is formed in the back. The spinal cord grows into this sac, and the spinal nerves are not properly connected to the spinal cord and the brain. This can result in many problems related to walking and

elimination since both the urinary tract and the intestinal tract can be involved. In addition there can be a problem with the accumulation of the spinal fluid in the head causing a condition called hydrocephalus. Surgical repair or closure of the lesion occurs shortly after birth, and if needed, a shunt is placed in the head to drain off excess fluid, usually into the abdominal cavity (Ekvall & Cerniglia, 2005).

Children with spina bifida encounter many health problems. These include urinary tract infections, constipation, frequent infections involving the shunt, obesity, and feeding problems related to swallowing. Since 1995, folic acid has been used to supplement the dietary intake of women of childbearing age, and its use has resulted in a 20% decrease in the incidence of spina bifida.

#### What to Expect in the Diet Prescription

1. Possible low calorie meal plan
2. Extra fluids including cranberry juice (Overweight children may require low-calorie cranberry juice; be certain that the cranberry juice blend contains at least 27-30% cranberry juice.)
3. Increased fiber
4. Texture modification

### **Cystic Fibrosis**

Cystic fibrosis (CF) is a serious disorder of childhood characterized by the production of increased amounts of mucus, progressive lung disease, and impaired absorption of fat and protein. The child with cystic fibrosis has frequent respiratory symptoms such as coughing

and wheezing and may require frequent hospitalization and medications. CF is an inherited disorder with both parents as carriers and has an incidence of 1 in 2000 births (Luder, 2005).

Treatment for cystic fibrosis consists of taking enzymes which improve the absorption of proteins and fats. In addition, the child with CF may have lactose intolerance which requires the elimination of milk and milk products. Lack of weight gain is frequently a problem along with limited growth and vitamin and mineral deficiencies (Borowitz, Baker, & Stallings, 2002).

What to Expect in the Diet Prescription

1. Increased calories
2. Lactose free or reduced-lactose food choices
3. Increased protein

### **Rett Syndrome**

Rett syndrome (RS) is a neuron developmental disorder primarily involving girls. Rett syndrome is a genetic disorder, characterized by a period of apparently normal development followed by the arrest of developmental skills. There are problems with growth starting with a deceleration of head growth after five months of age until 4 years of age. One of the most identifiable symptoms is the loss of purposeful hand use and wringing of the hands, along with impaired language and psychomotor retardation (Isaacs, Murdock, Lane, & Percy, 2003).

Many RS children have problems with chewing and swallowing that leads to reduced intake, reflux, and major problems with constipation. They may require increased fiber in

the diet, special feeding devices, and occasionally tube feeding. Routine monitoring of their nutritional status throughout the life span is essential.

Refer to Table 1 for a summary of the most frequently occurring disabilities requiring prescriptions for special meals.

**Table 1. Frequently occurring disabilities**

<b>SYNDROME/DISABILITY</b>	<b>Altered Growth Underweight Obesity</b>	<b>Altered Energy Need</b>	<b>Constipation / Diarrhea</b>	<b>Feeding Problems</b>	<b>Others</b>
<p><b>Cerebral Palsy</b> A disorder of muscle control or coordination resulting from injury to the brain during its early (fetal, perinatal, and early childhood) development. There may be associated problems with intellectual, visual, or other functions</p>	Underweight	Increased calories, failure to thrive	Constipation	Oral / Motor Problems, inability to self-feed, Swallowing incoordination	Central nervous system involvement, Orthopedic problems, Positioning problems
<p><b>Down Syndrome (a genetic disorder)</b> Results from an extra #21 chromosome causing development problems such as congenital heart disease, mental retardation, small stature, and decreased muscle tone</p>	Overweight, short stature	Caloric need lower than normal	Constipation	Poor suck in infancy, Difficulty transitioning to textured foods	Gum disease, increased risk of heart disease
<p><b>Prader-Willi Syndrome ( a genetic disorder)</b> A disorder characterized by a lack of internal controls including uncontrollable eating habits and inability to distinguish hunger from appetite, severe obesity, poorly developed genitalia, and moderate to severe mental retardation</p>	Overweight, short stature, low muscle tone	Calorie need lower than normal. Failure to thrive in infancy	Constipation	Weak suck in infancy; Requires a food-controlled environment	Risk of Diabetes Mellitus, PICA (a craving for unusual or inedible items; this can be life-threatening)

**Table 1. Frequently occurring disabilities, continued**

<b>SYNDROME/DISABILITY</b>	<b>Altered Growth Underweight Obesity</b>	<b>Altered Energy Need</b>	<b>Constipation / Diarrhea</b>	<b>Feeding Problems</b>	<b>Others</b>
<p><b>Autism</b></p> <p>Classified as a type of pervasive developmental disorder; diagnostic criteria include communication problems, ritualistic behaviors, and inappropriate social interaction</p>				<p>Refusal to eat many foods with texture</p> <p>Very selective in foods to accept</p> <p>Possible gluten or casein intolerance</p>	<p>Medication/ Nutrient interaction</p>
<p><b>Cystic Fibrosis (CF)</b></p> <p>An inherited disorder of the exocrine glands, primarily the pancreas, pulmonary system, and sweat glands characterized by abnormally thick luminal secretions</p>		<p>Need for increased nutrient intake; May need increased calories;</p> <p>Decrease of nutrients related to pancreatic insufficiency and chronic pulmonary infection</p>			<p>Increase in secondary illnesses</p> <ul style="list-style-type: none"> <li>* Diabetes</li> <li>* Liver Disease</li> <li>* Osteoporosis</li> </ul>
<p><b>Spina Bifida</b> (Myelomeningocele)</p> <p>Results from a midline defect of the skin, spinal column, and spinal cord. Characterized by hydrocephalus, mental retardation, and lack of muscular control</p>	<p>Obesity</p>	<p>Altered energy needs based on short stature and limited mobility</p>	<p>Constipation</p>	<p>Swallowing problems caused by the Arnold Chiari malformation of the brain.</p>	<p>Urinary tract infections;</p> <p>Increased risk of pressure ulcers due to lack of feeling in lower body</p>

## **Metabolic Diseases**

### **Diabetes**

Diabetes is a disorder in which the body is unable to produce or respond to insulin. Insulin is the substance produced and secreted by the pancreas, and enables the body to properly use sugar in the form of glucose, an essential source of energy for the body. There are two types of diabetes: Type 1 and Type 2. Type 1 is insulin dependent and requires insulin injections. Type 2 is usually treated with a diet and oral medication (American Dietetic Association, 2000).

Early symptoms include excessive hunger and thirst, excessive urination, weight loss, and fatigue. This may be a very common disorder facing school nutrition directors, due to the increasing existence of childhood obesity.

The American Diabetes Association encourages effective school management programs. Effective diet management at school promotes a better learning environment, reduces student absences and classroom disruptions, and helps assure an effective response to diabetes-related emergencies. Treatment includes dietary management with a diet limiting simple sugars and fats and providing adequate amounts of complex carbohydrates and proteins for growth and development. The diet should be designed to provide adequate calories for the child's age, sex, activity level, and growth rate. A physician's order is required to implement dietary modifications. The order from the physician should include a copy of the child's diet. It is also helpful if the family or physician provides guidance to the school on the child's target blood glucose range, insulin schedule, testing times, and instructions for managing various situations (i.e., low blood sugar) (American Dietetic Association, 2006).

### **Inborn Errors of Metabolism (IEM)**

Inborn errors of metabolism (IEM) are disorders in which individuals have missing or defective enzymes necessary to metabolize the food they eat. Food that is not broken down properly may produce chemicals that can build up in various parts of the body and cause medical problems that can be mild or very serious (Seashore & Wappner, 1999). The treatment for many IEMs usually includes some type of diet changes and may require special formula or supplements and/or medically modified foods. These diet changes can be very different (even for individuals with the same disease) and relate both to the individual IEM and how mildly or seriously affected an individual is.

Inborn errors of metabolism such as phenylketonuria, galactosemia, arginosuccinicaciduria, glutaric aciduria, and others are types of metabolic diseases in which the child or adolescent is unable to normally utilize the nutrients in regular meals. For example, a child with phenylketonuria is unable to break down the protein sources he eats to amino acids and then to smaller parts of the amino acids. This is because the child is unable to secrete sufficient enzymes from the liver that breaks down protein. For that reason, if the individual eats more protein foods than the body can process, high levels of phenylalanine occur in the blood, go into the brain, and cause mental retardation. If the diet is managed properly and the blood content of phenylalanine is controlled at an appropriate level, the child can grow, function, and learn normally (March of Dimes, 2006). In galactosemia, children are unable to use the carbohydrate found in milk products and some other foods, due to an absent or defective enzyme. Reading labels is critical to successful diet implementation for these individuals.

IEMs have traditionally been considered rare diseases that would seldom be encountered in local schools. There are now new technologies available to states that have led to expanded screening and diagnosis of many of these diseases in newborns. Early detection and diet intervention help individuals function normally as long as their diet is consistently maintained. Because of increased screening and successful treatment, we are now seeing more of these children in our schools.

It is helpful for school personnel to be aware of which IEMs are included in newborn screening in their individual state. This allows resources to be more readily available for these conditions. However, it is important to remember that IEMs may be diagnosed without required screening, and children with diagnosed conditions may relocate and require services from states that may not screen for their diagnosis. Thus, it is very helpful for school food service directors to know how to track appropriate IEM resources and be able to seek specialized consultation quickly. The National Newborn Screening and Genetics Resource Center (NNSGRC) maintains an updated report that provides tables identifying which diagnoses are screened for in the United States (US). This report may be accessed at the following Web site: <http://genes-r-us.uthscsa.edu/nbsdisorders.pdf> (The National Newborn Screening and Genetics Resource, 2006). This link will provide a chart of which diseases are screened by each state. Understanding the uniqueness of managing the diets of children with IEMs will help food service personnel provide more optimal assistance.

### **One Diet Does Not Fit All**

Because there is significant variation in disease presentation, different individuals with the same IEM may be mildly affected while others are severely affected. Different levels of restriction may be required even for individuals with the same diagnosis. Although there are general management protocols developed for managing the diets for individuals with IEMs, most diets must be individualized. Guidelines given to the schools (including portions to be served) must be followed without exception. Measurement of even foods allowed is critical since consuming too much of what is considered an “allowed” food can produce medical problems. Special training and monitoring of food service personnel is important to assure continued adherence to established protocols. Strict adherence to the diet prescription enables the physician to make appropriate recommendations for diet adjustments when needed.

### **Diets May Need Adjustments**

Diets for individuals with IEMs may require adjustments because of growth, illness, or changes in blood levels of monitored nutrients. This makes strict reliance on the initial “medical authorization” almost impossible and requires a system that allows for routine diet adjustments.

### **Need for Consultants**

Some individuals with IEMs require use of special products or services. These products may require special vendors as well as unique preparation techniques. Although some may be essential (i.e., metabolic formulas), others may be optional or require selective use (i.e., low protein products). Because of the complexity of IEM diets, school food service personnel may find it helpful to seek consultation services from nutrition or genetic

specialists, especially when diets are first implemented. These communications can help determine which products are being funded through other sources, which products will add variety and which products may be helpful, but too costly for a local school to invest in. Parents of children with IEMs are trained to manage their child's diet and should provide the school with the appropriate "medical authorization" and guidance. It is critical for the families and the food service personnel to have an understanding regarding the communication of the child's diet information. How severely a child is affected, their age and developmental stage, as well as the socioeconomic needs of each family may dictate whether the family requests only minor accommodations or complete meal modifications. For this reason, it may be more difficult for families to give the school a simple "allowed or not allowed" list as with other types of diets. Because adherence to and monitoring of daily intake is critical for these individuals, families are sometimes apprehensive and may be overly protective. For unique situations, it is advisable for the school to have access to a consultant or specialist. Such a consultant can function as an advocate and resource for the school and assist with determining what would be reasonable and unreasonable requests.

An optimal communication approach requires the school to communicate with the family about the normal menu offerings and allow the family to provide a modified menu that indicates which items the child can have and specific portions of each food specified. Schools are always advised to maintain documentation of all requests or guidance received from parents in the event that questions or mishaps occur.

### **How To Handle Mistakes**

If a mistake occurs, it is always in the best interest of the child and the school, for information regarding the mistake to be communicated immediately to the parents. This is important for several reasons. First of all, it will allow the child to receive emergency care if needed (although this is seldom required). Secondly, knowledge of inappropriate consumption will allow the parents to adjust the remaining intake for the day and actually prevent an adverse rise or fall of blood levels. Thirdly, knowledge of inappropriate consumption will provide an explanation of an unusual blood level and allow specialists to make more appropriate diet adjustments.





# **Food Allergies and Food Sensitivities**





## **Food Allergies and Food Sensitivities**

Food allergy, which is also called food sensitivity, is an adverse reaction to a food that involves the immune system. The immune system produces antibodies in response to the consumption of specific components of food, which are called allergens, and a physiologic reaction ensues that can be fatal. Approximately 6–8% of children suffer from food allergy during their first three years of life and about 4% of the American population is affected with food allergies. Food intolerances, such as lactose intolerance, do not affect the immune system but may have symptoms similar to food allergy.

### **Common Food Allergens**

The Food and Drug Administration (FDA) has identified eight major food allergens. A food allergy is caused by a reaction to a food protein. The food industry sometimes uses these proteins to make food taste better and have longer shelf life, which means that there are hidden allergens in many processed foods. It is important to check food labels for allergy warnings. The terminology “major food allergen” is defined by FDA as one of the following foods or a food ingredient that contains protein derived from one of these foods.

- Crustacean shellfish, such as crab, lobster, shrimp
- Egg
- Fish such as bass, cod, flounder
- Milk
- Peanuts
- Soybeans
- Tree nuts, such as almonds, pecans, walnuts
- Wheat

### **Foods that commonly contain the “Big Eight” allergens and should be avoided:**

- **Shellfish** — clams, crab, crawfish (crayfish—commonly dissected in biology classes), lobster, mollusks, mussels, oysters, scallops, snails, shrimp, seafood flavorings

- **Egg** – egg, egg substitutes, macaroni, mayonnaise, meringue
- **Milk** – butter, buttermilk, cheese, cream (including whipped), cottage cheese, custard, ice cream, sherbet, nougat (found in many candy bars), pudding, sour cream, yogurt, ingredients containing casein, lactose, or whey on food labels
- **Peanut** – peanuts, peanut oil, ground nuts, mixed nuts, nut pieces, peanut butter, chocolate candies, candy bars, and ice cream may contain peanuts; **READ LABELS CAREFULLY!**
- **Soy** – tofu, miso, soy sauce, tamari sauce
- **Tree nut** – almonds, brazil nuts, cashews, chestnuts, hickory nuts, macadamia nuts, almond paste or extract, nougat, nut butters, pecans, pesto, pine nuts, pistachios, walnuts, other nut extracts
- **Wheat** – bran, bread crumbs, crackers, flour (including whole wheat, enriched, all-purpose, cake, and graham flours), gluten, granola or granola bars, macaroni, spaghetti and other pastas, soy sauce, starch, modified food starch, hydrolyzed vegetable protein

### **Symptoms of Food Allergy**

Wide ranges of symptoms have been reported in allergic reactions. Gastrointestinal symptoms occur most frequently, followed by symptoms involving the skin and respiratory system. Respiratory symptoms occur frequently in individuals with peanut and tree nut allergy, while wheat allergy usually triggers GI symptoms. Especially sensitive peanut allergies can trigger symptoms without the individual actually consuming peanuts; in these cases, simply inhaling airborne particles from nearby peanuts can trigger a severe response. Soy allergy usually triggers skin and respiratory response. An allergic reaction can involve any combination of symptoms from any of the three categories. For most people, an allergic reaction to a particular food is uncomfortable, but for some people, a food reaction can be frightening and even dangerous. The most severe allergic reaction is anaphylaxis (Mayo Clinic, 2006).

### **Three main categories of symptoms:**

- Gastrointestinal (GI) – affecting the stomach, small intestine, and large intestine
- Cutaneous – affecting the skin
- Respiratory – affecting the throat, lungs, and breathing

**Gastrointestinal symptoms associated with food allergy:**

- Abdominal pain (stomach cramps)
- Nausea
- Vomiting
- Diarrhea
- Gastrointestinal bleeding

**Cutaneous, or skin, symptoms associated with food allergy:**

- Skin inflammation (swelling)
- Rash (change of color, usually red)
- Itching of any body part
- The following skin conditions can occur:
  - Hives – patches of skin become red, swollen (bumpy), and itchy
  - Eczema – large areas of skin become dry, hot, itchy, and red

**Respiratory symptoms associated with food allergy:**

- Runny or stuffy nose
- Itching of the nose, roof of mouth, throat, eyes, and ears
- Swelling or watering of the eyes
- Sneezing
- Asthma – narrowing or blocking of the air passages characterized by:
  - Difficulty breathing or swallowing
  - Shortness of breath
  - Wheezing and repetitive coughing

**Anaphylaxis**

Anaphylaxis (anaphylactic shock) is a sudden, severe allergic reaction that involves a person's whole body and can result in death. Symptoms can begin anywhere from five minutes to one hour after exposure to the allergen. Individuals who have experienced anaphylaxis have an increased chance of experiencing it again, so it is important for these individuals to carry medicine (an injection of epinephrine) and strictly avoid the foods that cause allergic reactions. Epinephrine is a hormone administered by injection to counteract anaphylactic shock by opening the airways and maintaining heartbeat and blood pressure (National Institutes of Health, 2006). Anaphylactic reactions to food occur in children and

adolescents, and the failure to recognize the severity of the reactions and to administer epinephrine promptly increases the risk of a fatal outcome (Sampson, Mendelson, & Rosen, 1992).

**Signs of anaphylaxis include any or all of the above allergic symptoms as well as:**

- Confusion
- Rapid or weak pulse
- Blue skin
- Slurred speech
- Loss of consciousness (fainting)

### **Managing Food Allergies in Children**

The FDA 2005 Food Code recommends that the person in charge of a food service operation should be able to identify major food allergens and describe symptoms identified with food allergy (FDA, 2006). A policy should be established for each school on how to handle food allergies. The Food Allergy and Anaphylaxis Network (2006) states that a written emergency action plan signed by the child's physician should be available for all at-risk children to ensure quick treatment of an allergic reaction. Parents, children, and school staff should work together in developing individualized action plans for each child with food allergy or food hypersensitivity. Managing food allergies begins with prevention.

#### **In the kitchen:**

- **Know which foods to avoid.** Read food labels to identify potential allergy-causing ingredients. Request lists of foods to avoid from the parents of children with food allergies and post these lists where they are visible.
- **Keep the kitchen organized to avoid cross-contamination.** Designate an area in the kitchen for preparing allergy-free meals. Sometimes allergic reactions are triggered by cross-contamination during cooking. The use of separate utensils during cooking, preparing, and serving of food can help to avoid cross-contamination. Cross-contamination can occur when allergen-containing ingredients are transferred to allergy-free food by hands, food-contact surfaces, sponges, cloth towels, and utensils.

- **Clean.** Thoroughly clean the surfaces and utensils involved in the preparation of foods with potentially harmful ingredients, especially if these surfaces and utensils will also be used to prepare allergy-free meals.

**Outside the kitchen:**

- Communicate with students and parents. Identify the students with food allergies. Work with the families to develop the best plan for handling the allergy. Ask questions whenever needed.
- Develop a plan. Come up with a way to identify students with food allergies as they move through the cafeteria line. Young children especially cannot be relied upon to alert food service staff to an allergy. A written plan is necessary to avoid accidental allergic reactions.
- Work as a team. Involve parents, siblings, and teachers in the management of a child's food allergy. Older siblings can be especially helpful in monitoring a young child's food intake in the cafeteria.
- Don't leave the responsibility to the child. It is important to stay involved during mealtimes. Monitor the child as he or she moves through the cafeteria line, eats, and prepares to return to class. Symptoms of allergic reaction can occur immediately or up to several hours after mealtime.

**Monitoring for an allergic reaction:**

- Know the signs and symptoms.
- Less obvious signs include putting hands in mouth, pulling or scratching tongue, voice becoming hoarse or squeaky
- Be aware of phrases a child might use to describe an allergic reaction, such as
  - Mouth, tongue, and/or lips: "burning," "tingling," "hot," "feel funny," and "itchy."
  - Throat: "closing up," "feels thick," and "feels tight" "has something stuck in it"
  - Ears: "itchy," and "like something's crawling in them"

Remember, since food allergy reactions can occur anywhere on school property, teachers, administrators, staff, and food service personnel should become aware and

knowledgeable about food allergies, symptoms, and specific food allergies known to occur in children attending the school. When working with food, always read food labels on everything.

### **Food Intolerance**

Food intolerance is an adverse reaction to a food and is caused by toxic, pharmacologic, metabolic, or idiosyncratic reactions to a food or chemical substances in food that does not involve the body's immune system. Symptoms caused by food intolerances include gastrointestinal, cutaneous, and respiratory problems and are often similar to those caused by food allergy.

The most common food intolerance is lactose, which is the sugar in milk. Unlike milk allergy, which is an allergic response to a protein in milk, milk intolerance does not involve production of antibodies by the immune system. However, the symptoms of milk or lactose intolerance can be quite uncomfortable and painful for children. Common symptoms of lactose intolerance include gastrointestinal cramping and pain, bloating, nausea, gas, and diarrhea. Children who are lactose intolerant should not be forced to drink milk. Lactose-free milk and over-the-counter enzyme therapy are available.

Other food intolerances include certain food additives such as preservatives, flavor enhancers such as monosodium glutamate (MSG), coloring agents such as tartrazine (FD&C No. 5), and sulfites in foods. It is estimated that 1% of people are intolerant to sulfite and about 5% of those are asthmatic. Sulfite is used in many foods to prevent browning, control microbial growth and spoilage, and modify the texture of food. Sulfite reactions are very individualized and vary with each person.

## **Celiac Disease**

Celiac disease is a genetically-based autoimmune disease characterized by sensitivity to gluten, a protein found in wheat, barley, and rye (American Dietetic Association, 2007; American Dietetic Association, 2009). When a person with celiac disease eats gluten, it causes an immune system reaction resulting in damage to the tissues of the small intestine (American Dietetic Association, 2007; American Dietetic Association, 2009; Thompson, 2008). When the small intestine is damaged, it may be unable to properly absorb nutrients.

Malabsorption may lead to a variety of gastrointestinal symptoms and medical conditions. The signs and symptoms of celiac disease vary greatly and in children may include diarrhea, constipation, abdominal pain, abdominal bloating, dental enamel defects, delayed growth, and delayed puberty (National Digestive Diseases Information Clearinghouse, 2008).

## **Treatment Strategies**

The only treatment for celiac disease is a gluten-free diet (American Dietetic Association, 2007; American Dietetic Association, 2009). A gluten-free diet does not include protein from the grains wheat, barley, rye, and hybrids of these grains, such as triticale (a cross between wheat and rye) (American Dietetic Association, 2007; American Dietetic Association, 2009).

These grains are found in a wide variety of foods, including flour, bread, bread products (for example, pizza crust), pasta products, breakfast cereals, cookies, cake, crackers, and pretzels. Gluten ingredients also may be found in many other processed foods, including soup, hot dogs, and gravy (Thompson, 2006).

Because gluten may be found in so many processed foods, labels must be read very carefully. If a food product is not labeled gluten free, the ingredients list (and in the case of wheat the “Contains” statement) must be read for wheat, barley, rye, oats not labeled gluten free (oats may be contaminated with gluten), malt (this ingredient is made from barley), and brewer’s yeast (this ingredient may be contaminated with gluten) (American Dietetic Association, 2009; Thompson, 2010). If the food product is a meat product (for example, hot dog, sausage patty), poultry product (for example, seasoned chicken), or egg product (for example, liquid eggs), the ingredients list also should be read for modified food starch, dextrin, and words that mean flour\* (American Dietetic Association, 2009; Thompson, 2010).

There are many grains that can be included in a gluten-free diet, including the very familiar grains corn and rice and the less familiar grains millet, sorghum, teff, wild rice, buckwheat, quinoa, and amaranth (American Dietetic Association, 2007; American Dietetic Association, 2009; Thompson, 2008; Thompson 2010). These grains are used in specially-made gluten-free breads, pastas, and snack foods that are labeled gluten free.

In addition to reading food labels, it is very important to make sure that gluten-free food does not become contaminated with wheat, barley, or rye while being stored, prepared, or served. Steps that should be taken to prevent cross-contamination include storing gluten-free foods away from gluten containing foods, preparing gluten-free food in a separate sanitized area of the kitchen using clean food preparation tools, and using separate clean utensils when serving gluten-free foods.

\*Allergen labeling is voluntary for foods regulated by the United States Department of Agriculture. Unlike FDA-regulated foods, meat products, poultry products, and egg products may include ingredients that contain wheat protein and this might not be declared on the food label.

Please see Lesson 5: Managing Celiac Disease in *Meeting Children’s Special Food and Nutrition Needs in Child Nutrition Programs* for more detailed information. This lesson is available at: [www.nfsmi.org](http://www.nfsmi.org)



# **Issues Impacting Nutrition and Special Dietary Orders**





## **Issues Impacting Nutrition and Special Dietary Orders**

There are many nutrition problems which occur with the conditions discussed in this handbook. The most common nutrition problems include:

- Energy needs which may be lower than normal leading to overweight, or higher than normal leading to underweight or failure to thrive.
- Feeding problems related to difficulty in chewing and swallowing or increased or decreased muscle tone.
- Altered nutrient needs such as carbohydrates, amino acids, protein, fiber, gluten and casein, and others.

### **Energy Needs**

#### **Overweight**

Children with Down syndrome, Prader-Willi syndrome, and spina bifida often require meals lower in energy value than other children because of limited mobility and low muscle tone. Two important factors are involved in the management of weight problems for all children: (1) determining the energy level required for the individual child and (2) increasing the activity level. School food service will be the contributor of an appropriate meal pattern but not the activity level of the child. If weight management for the child with a developmental disability is necessary, it should be a part of the IEP, which will involve the parents, teachers, therapists, and the school food service director. The School Meal Prescription (Exhibit 1) is attached and should be filled out to indicate a particular energy value (Alabama Department of Education, 1999).

**Table 2: Intervention strategies for reducing calories in school lunch and breakfast.**

- Select meats, fish, and poultry low in fat
- Limit preparation to baking and broiling; omit frying
- Limit the serving size
- Emphasize salads and vegetables
- Replace high sugar desserts with fruit
- Provide skim or low fat milk

**Table 3. Modification of the Regular Menu—Lunch**

<b>Menu</b>	<b>Low calorie</b>	<b>High calorie</b>	<b>Chopped</b>	<b>Ground</b>	<b>Pureed</b>
Hamburger	no change	add cheese	served with noodles	ground, with cream soup added	puree with beef or tomato soup
Buns	no change	add margarine	cut into quarters	substitute noodles	soup or mashed potatoes
French Fries	baked French fries	no change	mashed potatoes	mashed potatoes	mashed potatoes
Broccoli	no change	no change, add margarine or cheese	chopped and cooked	mashed	blended with cream soup
Canned Peaches	sugar free canned peaches	no change	cut into small pieces	chopped and mashed	pureed with juice
Milk	1 %	whole	whole	whole	whole

## **Underweight**

Children with cerebral palsy, extreme prematurity, Rett's syndrome, or pulmonary disease may be in the group who tend to be thin, and have a greater inability to gain weight. Their diet prescription may read high calorie or specify a definite number of calories. These children often have poor appetites or like only a few foods. They may tire easily while eating and just stop. It is usually not effective to increase the calories for these children with large or double portions. The key is to increase calories by adding fats, oils, sugars, or thickeners such as cereal or commercial supplements to the food without increasing the serving size. Some of the foods that can be added to increase calories are listed in Table 4.

If the child requires a supplemental beverage, the school is required to provide that beverage unless the parent is enrolled in a supplemental program such as Medicaid. An additional consideration for the child who is underweight and has a picky appetite is to make sure that they eat where distractibility is low. This may mean a corner of the cafeteria (Alabama Department of Education, 1999). Refer to Table 3, for a sample menu modified for increasing calories. Table 4 shows ways to increase calories.

**Table 4. Ways to Increase Calories**

<b>Food</b>	<b>Calories</b>	<b>Suggested Use</b>
Cheese	75-120/oz	Add to creamy foods
Infant cereal	15 calories/T	Add to fruits, soups, cereal
Eggs, cooked	75/egg	Baked goods, meat loaf and puddings
Evaporated Milk	40 calories/oz	Beverages, soups, cereals, puddings
Powdered Milk	25 calories /T	Soups, mashed potatoes, cream sauces, puddings.
Peanut Butter* (peanut butter may be a choking risk for children with swallowing disorders)	87 calories/T	With crackers or bread
Margarine	100 calories/T	Add to meats, hot cereal, vegetables or bread
Vegetable Oil	110 calories/T	Soups, casseroles, vegetables, gravies
Baby Food Meat	100-150 cal/jar	Mix with cream soups, thin mashed potatoes, soups
Commercial Nutrition Supplements	30 cal per oz	Serve as beverage
Graham Crackers/Vanilla Wafers	20-30 calories each	Snack

From *Meeting Their Needs*, by the USDA/FNS, 1993 with permission

### **Feeding Problems**

What is a feeding problem? A feeding problem is defined as the inability to consume adequate food or liquid due to a neuromuscular disturbance, behavioral problems, or both, which alter intake. The conditions associated with impaired feeding include prematurity; cardiopulmonary compromise; defects of the oral cavity and oropharynx; defects of the larynx, trachea and esophagus; neurologic defects; and neuromuscular disease. The feeding problems associated with the conditions described usually start in infancy and if treated in Early Intervention Programs from birth to three may be non-existent by the time the child

starts school. Unfortunately, many of these conditions are present in the school age child and require feeding intervention by therapists and modification of food intake (Cloud, Ekvall, & Hicks, 2005).

Feeding problems are usually classified as oral-motor, positioning, self-feeding, or behavioral. The oral-motor problems involve sucking, swallowing, and chewing. Positioning problems may include the inability to sit in a regular chair, inability to hold up the head, and lack of stability of the trunk. Self-feeding problems usually include the inability to hold feeding utensils or a cup. Behavioral problems include refusal to eat, distractibility during mealtime, crying, throwing food on the floor, and extreme selectiveness about foods.

### **Oral-Motor Problems**

For the child with any of the oral motor problems (sucking, swallowing, or chewing) changes in food textures are commonly needed. The school nutrition program is the best provider of nutritious foods modified in texture. Participation in the school nutrition program is preferred over food sent from the home or food blended by the teacher in the classroom. Food safety is extremely important in all aspects of food service and may not be appropriately followed in the classroom.

Textures are modified to make eating safe for the child and to stimulate feeding development. Close communication with the teacher or therapist working on the feeding problem is important because various textures may be requested. Some children have increased sensitivity to food texture, so being consistent each day in preparing ground or blended foods is important.

Some foods such as mashed potatoes, oatmeal, pudding, and some soups do not require special preparation for a child who has difficulty with chewing. Preparation of meats and other foods that are difficult to chew may be ordered as part of the physician's instructions and clarified by the speech therapist, occupational therapist, registered dietitian, or parent.

### **Modification of Food Texture**

- **Chopped** – Food is chopped by cutting it into bite-sized pieces with a food chopper, knife, food processor, or French knife.
- **Ground** – Food should be soft or small enough to swallow with little or no chewing. The food is ground using a food processor or blender.
- **Pureed** – Food has a smooth texture similar to pudding. The food should not be runny. The food is pureed in a food processor or blender. In order to puree many foods, a small amount of liquid has to be added to avoid dryness and to make it smooth (American Dietetic Association, 2002). The National Dysphagia diet is now available and can be applied for children with oral-motor problems. It consists of three levels and could possibly be ordered for the child in school (See Appendix 4).

Students with swallowing problems may require thickened beverages which are usually requested by the speech or occupational therapist or the physician. Generally the therapist will add the powdered thickener to the beverage unless specific instructions are given to the teacher. There are a number of commercial products used to thicken beverages and a variety of pre-thickened beverages are also available (See Resources section of this handbook.)

### **Positioning Problems**

Assessment of positioning problems is usually completed by the physical therapist or occupational therapist and includes observation of head control, trunk control, foot stability, placement of the hip and pelvis, shoulder girdle, knee flexion, and sitting base. Appropriate

positioning varies depending on the problem identified and could include reclining on the stomach, lying on the side, sitting, or standing. Children fed in this position would rarely be fed in the cafeteria. However, children fed in a wheel chair designed especially for their problem would require a table that accommodates the wheel chair. Proper positioning improves visual control by the child, increases food intake since the child may better see the food being offered, and enhances the ability to self-feed (American Dietetic Association, 2003).

### **Behavioral Issues**

Behavioral issues may include distractibility during the mealtime and difficulty in completing a meal, refusal to eat, spitting out food, or knocking food utensils on the floor. Although behavioral intervention is the role of the teacher or therapist, food service provides a great service by working with the therapist in providing small servings, limiting the number of foods served, or finding the ideal placement of the child in the school cafeteria. Behavioral issues should be a part of the Individualized Education Program (IEP), and the IEP meeting should include the School Food Service Director.

### **Self-feeding**

Children with muscle control problems such as cerebral palsy have difficulty in holding a spoon or fork for self-feeding. There are many devices available for use with these children; however, the child needs training in how to use these devices. The training is usually provided by the therapist or teacher. Provision of this equipment and the washing and sanitizing of the equipment is the responsibility of the Child Nutrition Program. In some schools the Special Education Program will provide the special utensils. Some individuals

will require adaptive utensils, cups, or plates (for example: built-up handled utensils, cups with handles, cut-away cups, high-sided plates, scoop plates, etc.).

### **Tube Feedings**

Tube feedings are frequently ordered for the child with a severe feeding problem that has not improved with the usual oral-motor intervention or if the child cannot swallow without getting food or liquid into the lungs. Often the child who is tube fed is severely underweight, and the child is unable to gain weight with oral feedings. Giving the tube feeding is the responsibility of a nurse or therapist assigned by the school. The provision of the formula is the responsibility of either the parent or the school. If refrigeration of the formula is needed, it is the responsibility of the school to provide adequate refrigeration. [Note: Un-opened formulas are usually not refrigerated. Refrigeration could change the viscosity (stickiness or gumminess) and thereby decrease tolerance of the formula.]



# **Special Formulas and Special Medical Foods**





## **Special Formulas and Special Medical Foods**

At times, the school may need to supplement the usual IEM diet by providing some specially modified products. This will help to expand the offerings available to a child. This can range from ordering special formulas to food products that have been modified for specific diagnoses. At times, this is beneficial to decrease the boredom that can occur when an individual must consume a very restricted diet throughout life. When good relationships exist between the family and the school, families also may provide some items. It is advantageous for the school to have a supply of what is traditionally referred to as “free foods”. These are foods that do not contain restricted ingredients, and family members can provide a list. “Free foods” are very helpful if a child refuses the diet the family has requested and can be used for snacks or special events that may occur without enough warning for food service personnel to contact a parent for additional guidance.

### **The Purchasing of Special Formulas and Special Medical Foods**

The cost of these specially formulated foods is borne by the School Nutrition Program. Generally the family will provide a special formula for a disorder such as PKU or other inborn errors of metabolism. Schools may not charge children with disabilities or with certified special dietary needs who require food substitutions or modification more than they charge other children for program meals or snacks (USDA Food and Nutrition Service, 2001).

A potential funding source for children with special needs is Individuals with Disabilities Education Act (IDEA), which provides money to the states for students who need special education and related services. Services which can be funded under IDEA

include purchase of special foods, supplements or feeding equipment, services of a registered dietitian or nutrition professional, and services of the special education teacher, occupational therapist, or other health professional in feeding the child or developing feeding skills (United States Department of Agriculture-Food and Nutrition Service, 2001).

Medicaid is another resource for funding special dietary supplements, eating devices, and nutritional consultation as medically necessary. The Medicaid program varies from state to state in the type and amount of services it will provide.

### **Fluids and Fiber**

Fluid and fiber content of the school meals are usually identical to the recommendations for the general population. Children with disabilities and special health care needs often have problems with adequate fluid consumption and with fiber consumption. As a result, constipation may be a severe problem for some children, necessitating extra fluids and fiber. Table 5 lists the recommended amount of fluid and fiber based on the Dietary Reference Intake.

**Table 5. Recommended amount of fluid and fiber for children and adolescents.**

<b>Recommendations by Weight</b>	<b>Fluid Recommendation</b>	<b>Fiber Recommendations by age in grams</b>
< 10 kg	80-120 ml/kg	4-8 yrs — 25 g
> 10 kg	1000 ml + 50 ml for each kg > 10 kg — 6-8 cups	9-13 yrs male—31 g
> 20 kg	1500 ml + 20 ml/kg for each kg > 20 kg	9-13 yrs female—26 g
		14-18 yrs male—38 g
		14-18 yrs female—26 g

**Fluid**

Adapted from Isaacs, JS. *Fluid and Bowel problems*. Chapter in Lucas BL, Feucht SA, Greiger LE, editors, 2004. *Children with special health care needs: Nutrition care handbook*. Pediatric Nutrition Practice group and Dietetics in Developmental and Psychiatric Disorders, American Dietetic Association.

**Fiber**

Adapted from Dietary reference intake, Appendix 1-2. in Ekvall, S.W., and Ekvall, VK. , 2<sup>nd</sup> ed. 2005. *Pediatric Nutrition in Chronic Diseases and Developmental Disorders, Prevention, Assessment and Treatment*.





# **Intervention Strategies and the Team Approach**





## **Intervention Strategies and the Team Approach**

Nutrition problems that involve the student with disabilities or special needs are better served when various disciplines work together in a team approach. A team approach will aid in assuring quality food service and acceptance of that food service. The makeup of the team may include the teacher, food service director or manager, principal, special education coordinator, speech therapist, physical therapist, occupational therapist, physician, registered dietitian, feeding aides, nurse, and the parent (Cloud, Ekvall, & Hicks, 2005).

The first interaction of the team usually occurs during a meeting to design the Individualized Education Program (IEP). When a nutrition problem exists, it should be a part of the services addressed in the IEP. An example would be a child with spina bifida who is overweight and also has a feeding problem, which involves swallowing. A diet prescription is provided and signed by the child's physician for a reduced calorie meal that is of a consistency for safe swallowing. The intervention might include modifying the menu by a registered dietitian, and the occupational therapist or speech therapist providing oral-motor facilitation to improve swallowing. The role of the parent is to agree to follow through with the same treatment at home and to communicate suggestions for addressing a particular problem. Cultural factors should always be a consideration when plans are made.

Meetings of the IEP team should involve the food service director as often as possible. The intent of the IEP is to plan a successful program for each child. When a nutrition problem is involved, the existence of a meal prescription and inclusion of the nutrition plan are important for a positive outcome for the child.





# **Environmental Considerations**





## **Environmental Considerations**

### **Dining Environment**

The environment where the student with special needs eats is a very important part of a successful food service program. It should be easily accessible and non-threatening to the student with special needs, yet provide a setting where the child can feed himself or be fed. Generally it is recommended that the student eat in the cafeteria with all of the students. Under certain circumstances, it may be advisable for the child to eat in the classroom. The child may need to be seated away from heavy traffic areas if he is easily distracted. Or, a screen may be used to screen off sections of the room for distractible children. Seek input from other members of the school team to make the dining room as safe and functional as possible for all children. The following are some general principles for creating a user-friendly dining environment (Meeting their Needs, 1993).

### **Scheduling**

Allow ample time for the child to eat his school meal. It may be necessary to allow the child to begin eating before the other students enter the cafeteria if distractibility is a problem or if the child is a very slow eater.

### **Space**

The dining space should encourage independence. Plan for appropriate space in the dining area to accommodate wheelchairs and teachers or aides who may assist the child with meals. The following are some general guidelines to consider:

- Doorways.....32” wide
- Aisles.....34” wide

- Tables.....5-6 feet apart
  - 30” above the floor
  - 12” clearance underneath from the outer edge toward the interior of the table to accommodate a wheel chair

When considering the dining space for children with disabilities, also consider the serving line area. The width of the serving line should be wide enough to accommodate wheelchairs or walkers. Also, consider the height of the self-service areas. These areas should also be accessible to children in wheelchairs.

### **Location**

Getting to the cafeteria is also an important consideration for the child with disabilities. Ramps or handrails may be needed to make the cafeteria accessible.

### **Lighting**

Provide adequate lighting for students who are visually impaired. Use lighting to create a warm atmosphere.

### **Dealing with Distractibility**

Provide an area where a screen could be used to prevent the children who are extremely distractible from seeing other children during the mealtime. This may require rearranging a section of the cafeteria. Controlling distractibility can be a positive way to increase the amount of food the child eats. The food service director, the teacher, and other members of the team should work together to plan ways to meet the child’s needs while maintaining dignity and respect.



# **Food Safety Issues**





## **Food Safety Issues**

Serving safe food to children is the responsibility of everyone involved in handling the food. Meals for children with special nutrition needs should be prepared and handled following the same food safety procedures required for all other meals (Conklin, Nettles, & Martin, 1998). Children are particularly vulnerable to potential foodborne illnesses – especially children with special healthcare needs. From the time purchased foods are received until the time they are consumed, it is critical that safe food practices be followed. Some common food safety practices include:

- Washing hands frequently, properly, and at appropriate times
- Cooking foods to the proper internal temperature
- Using a calibrated thermometer for cooking, cooling, hot-holding, cold-holding, and reheating
- Cooling foods rapidly

Regulations related to food safety practices may vary from state to state. It is important to follow the specific requirements of your state and local health departments.





# **Glossary**





## **Glossary**

**504 Accommodation Plan** –A planning document used in schools for children who require health related services (including modified meals) but who are not enrolled in a special education program; mandated by the Rehabilitation Act of 1973.

**Americans with Disabilities Act of 1990 (ADA)** –Federal legislation enacted to protect persons with disabilities from discrimination.

**Children with Special Health Care Needs (CSHCN)** –Children with a broad range of chronic illnesses and conditions who require health and related services beyond basic, routine care. CSHCN includes children with birth defects, neurological outcomes of premature births, genetic syndromes, metabolic disorders, as well children suffering from the after effects of alcohol, drugs, and infections such as meningitis. It is estimated that 50% of the CSHCN population have nutrition problems.

**Developmental Disabilities** –A severe chronic disability attributable to a mental or physical impairment or combination of a mental and physical impairment. It is manifested before an individual is 22 years of age. It is likely to continue indefinitely, results in substantial functional limitations in three or more areas of major life activity, reflects the person’s need for a combination of special interdisciplinary or generic care, treatments or other services that are lifelong or of extended duration, and are individually planned and coordinated.

**Disability** –A physical or mental limitation which substantially limits one or more of the major life activities.

**Early and Periodic Screening Diagnostic and Treatment Program (EPSDT) –A**

preventive and comprehensive health care benefit for Medicaid-eligible individuals up to age 21 years of age. It includes screening for dental, hearing, and vision services. EPSDT allows providers, including schools, to be reimbursed for preventive and treatment services for Medicaid-eligible children.

**Handicapping Condition** –A physical or mental condition, which can lead to a disability.

This term is often used interchangeably with disability. The word “disability” is the most current terminology.

**Handicapped Participant** 7 CFR 15 b.3 (i) –Any person who has a physical or mental impairment which substantially limits one or more major life activities, has a record of such impairment, or is regarded as having such an impairment. The word “disabled” is the most current terminology.

**Individuals with Disabilities Education Act (IDEA) of 1997 (PL102-114)** –Federal education legislation which includes part B for children from 3 through 12 years of age and part C for Early Intervention Programs (birth through 3 years of age).

**Individualized Education Program (IEP)** –A planning document required annually for special education services in public schools serving children older than 3 years of age; outlines specific goals, activities, and time lines.

**Individualized Family Service Plan (IFSP)** –A planning document required for services for children from birth to 3 years of age enrolled in early intervention services.

**Major life activity** –Functions such as caring for one’s self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.



## **Reference List**





## Reference List

- Alabama Department of Education. (1999). CARE: *Special nutrition for kids*.  
University, MS: National Food Service Management Institute.
- American Diabetes Association. (2006). *Diabetes Management at School*. Retrieved April 3, 2006 from <http://www.diabetes.org/for-parents-and-kids/for-schools/diabetes-management.jsp>
- American Dietetic Association (2003). Position of the American Dietetic Association: Providing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. *Journal of the American Dietetic Association, 104(1)*, 97-107.
- American Dietetic Association Evidence Analysis Library, Diseases and Conditions, Celiac Disease. (2007). *Celiac Disease Evidence Analysis Project*. Retrieved January 20, 2010, from [www.adaevidencelibrary.com](http://www.adaevidencelibrary.com).
- American Dietetic Association Evidence Analysis Library, Guidelines, Celiac Disease. (2009). *Celiac Disease (CD) Evidence-Based Nutrition Practice Guideline*. Retrieved January 20, 2010, from [www.adaevidencelibrary.com](http://www.adaevidencelibrary.com).
- Ani, C., Grantham-McGregor, S., & Muller, N. (2000). Nutrition supplements in Down syndrome: Theoretical considerations and current status. *Developmental Medicine & Child Neurology, 42*, 207-213.
- Borowitz, D., Baker, R.D., & Stallings, V. (2002). Consensus report on nutrition for pediatric patients with cystic fibrosis. *Journal of Pediatric Gastrointestinal Nutrition, 35*, 246.

- Case, S. (2002). *Gluten-free diet: A comprehensive resource guide*. Regina, Saskatchewan, Canada: Centax Books.
- Cloud, H.H., Ekvall S.W., & Hicks, L. (2005). Feeding problems of the child with special health-care needs. In Ekvall, S.W. & Ekvall, V.K. (Eds). *Pediatric nutrition in chronic diseases and developmental disorders* ( 2<sup>nd</sup> ed.) New York: Oxford University Press.
- Conklin, M.T., Nettles, M.F., & Martin, J. (1998). Modified meals: Strategies for managing nutrition services for children with special needs. *School Foodservice and Nutrition*, 52(7), 47-52.
- Cornish, E. (2002). Gluten and casein free diets in autism: A study on effects on food choice and nutrition. *Journal of Human Nutrition Dietetics*, 15(4), 261.
- Ekvall, S.W., & Ekvall, V.K.(Eds.) (2005). *Pediatric Nutrition in Chronic Diseases and Developmental Disorders* (2<sup>nd</sup> ed.). New York: Oxford University Press.
- Food Allergy and Anaphylaxis Network.(2006). *Managing food allergies in school: Avoiding an allergic reaction*. Retrieved May 3, 2006, from <http://www.foodallergy.org/school/avoid.html>
- Food and Drug Administration. (2006). *HACCP principles*. Retrieved May 8, 2006, from <http://www.cfsan.fda.gov/-dms/fc01-a5.html>
- Fung, E.B., Samson-Fangl, L., Stallings, V.A., Conaway, M., Liptak, G., Henderson, R.C., Worley, G., O'Donnell, M. Calvert, R., Rosenbaum, P., Chumlea, W., Stevenson, R. D. (2002). Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association*, 102, 361-373.

- Horsley, J.Q., & Shockey, W.L. (1999). Nutrition management for children with special food and nutrition needs. In Martin, J., & Conklin, M.T. (Eds.), *Managing Child Nutrition Programs* (pp. 363-387). Leadership for Excellence Gaithersburg, MD: Aspen Publishers.
- Isaacs, J.S., Murdock, M., Lane, J., Percy, A.K. (2003). Eating difficulties in girls with Rett Syndrome compared with other developmental disabilities. *Journal of the American Dietetic Association, 103*, 224.
- Luder, E. (2005). Cystic fibrosis and bronchopulmonary dysplasia. In Ekvall, S.W., & Eckvall, V. (Eds.), *Pediatric Nutrition in Chronic Disease and Developmental Disorders* (2<sup>nd</sup> ed.). Oxford, UK: Oxford University Press.
- Mahan, L.K., & Escott-Stump, S. (2004). Medical nutrition therapy for food allergy and food intolerance. In Mahan, L.K., & Escott-Stump, S., *Krause's Food, Nutrition, and Diet Therapy* (11<sup>th</sup> ed.). Philadelphia, PA: Saunders.
- March of Dimes. (2006). PKU Fact Sheet Retrieved February 6, 2006, from [http://www.marchofdimes.com/professionals/14332\\_1219.asp](http://www.marchofdimes.com/professionals/14332_1219.asp).
- Matalon, K.M. (2002). Developments in phenylketonuria. *Topics in Clinical Nutrition, 16*, 41-50.
- Mayo Clinic.(2006). *Peanut allergy*. Retrieved May 3, 2006, from <http://www.mayoclinic.com/health/peanut-allergy/DS00710/DSECTION=2>.
- National Digestive Diseases Information Clearinghouse, National Institute of Diabetes and Digestive and Kidney Disease, National Institutes of Health. (2008). *Celiac Disease*. Retrieved from <http://digestive.niddk.nih.gov/ddiseases/pubs/celiac/>.

National Dysphagia Diet Task Force. (2002). *National dysphagia diet: Standardization for optimal care*. Chicago, IL: American Dietetic Association.

National Institutes of Health. (2006). *Anaphylaxis*. Retrieved May 3, 2006, from <http://www.nlm.nih.gov/medlineplus/ency/article/000844.htm>.

National Newborn Screening and Genetics Resource Center. (2006). *National newborn screening status report*. Retrieved May 1, 2006, from <http://genes-r-us.uthscsa.edu/nbsdisorders.pdf>.

Pediatric Nutrition Practice Group & Dietetics in Developmental and Psychiatric Disorders Practice Group. (2004). *Children with Special Health Care Needs: Nutrition Care Handbook*. Chicago, IL: American Dietetic Association.

Rubin, S.S., Timmer, J.H., Chicoine, B., Braddock, D., McGuire, D.E. (1998). Overweight prevalence in persons with Down Syndrome. *Mental Retardation*, 36, 175-181.

Sampson, H.A. (2005). Food allergy—accurately identifying clinical reactivity. *Allergy*, 60 (s 79), 19-24.

Sampson, H.A., Mendelson, L., & Rosen, J.P. (1992). Fatal and near-fatal anaphylactic reactions to food in children and adolescents. *The New England Journal of Medicine*, 327(6), 380-384.

Schoeller, D.A., Livitsky, L.L., Bandini, L.G., Dietz, W.W., & Walozak, A. (1988). Energy expenditure and body composition in Prader-Willi syndrome. *Metabolism*, 37, 115.

Seashore, M.R., & Wappner, R.S. (1999) Section III. Inborn errors of metabolism. In *Genetics in Primary Care & Clinical Medicine*. 1<sup>st</sup> ed. Stamford, CT: Appleton & Lange.

- Thompson, T. (2006). *Celiac Disease Nutrition Guide*. Chicago: American Dietetic Association.
- Thompson, T. (2008). *The Gluten-Free Nutrition Guide*. New York: McGraw-Hill.
- Thompson, T.S., & Brown M. (2010). *American Dietetic Association Easy Gluten-Free: Expert Nutrition Advice with More than 100 Recipes*. New York: Wiley.
- United States Department of Agriculture, Food and Nutrition Service. (2001). *Accommodating children with special dietary needs in school nutrition programs: Guidance for school food service staff*. Alexandria, VA: Author.
- United States Department of Agriculture, Food and Nutrition Services, Southeast Regional Office, & University of Alabama at Birmingham, Department of Nutrition Sciences and Sparks Clinic. (1993). *Meeting their needs: Training manual for child nutrition program personnel serving CSHCN*. Atlanta, GA: Authors.
- United States Department of Agriculture. (1999). *USDA and FNS programs nondiscrimination statements*. Retrieved October 19, 2003, from <http://www.fns.usda.gov/cr/Policy/nondiscriminationstatement.htm>
- Vining, E.P. (2002). The ketogenic diet. *Advances in Experimental Medicine and Biology*, 497, 225-231.





# Resources





## **Resources**

### **Allergies**

The Food Allergy & Anaphylaxis Network  
<http://www.foodallergy.org>

### **Celiac Disease**

American Celiac Disease Alliance  
[www.americanceeliac.org](http://www.americanceeliac.org)

American Dietetic Association  
<http://www.eatright.org>

Celiac.com  
<http://www.celiac.com>

Celiac Disease Foundation  
<http://www.celiac.org>

Celiac Sprue Association  
<http://www.csaceliacs.org>

Gluten-Free Dietitian  
[www.glutenfreedietitian.com](http://www.glutenfreedietitian.com)

Gluten Intolerance Group  
<http://www.gluten.net>  
<http://www.gluten.net/diet.html>

National Foundation for Celiac Awareness  
[www.celiaccentral.org](http://www.celiaccentral.org)

National Institute of Diabetes & Digestive & Kidney Disease  
<http://digestive.niddk.nih.gov/ddiseases/pubs/celiac/>

### **Diabetes**

Children's Hospital and Regional Medical Center, Seattle WA  
<http://www.cshcn.org/resources/DiabetesSafety.htm>

### **Inborn Errors of Metabolism**

Arizona Department of Health Teachers Guides  
<http://www.azdhs.gov/phs/oncdps/children/index.htm>

**Other Relevant Web Sites**

The ARC - Advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities.

[www.thearc.org](http://www.thearc.org)

Advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities.

Asperger Syndrome Coalition of the U.S.

[www.irsc.org](http://www.irsc.org)

Internet Resource for Special Children

Autism Society of America

[www.autism-society.org](http://www.autism-society.org)

The Center for Children with Special Needs

<http://www.cshcn.org/resources/birthdefects.cfm>

Centers for Disease Control

[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

Children With Special Health Care Needs

<http://www.northeasterncshcn.org/links.php>

Cleft Palate Foundation

[www.cleftline.org](http://www.cleftline.org)

March of Dimes Glossary of Acronyms

[http://www.marchofdimes.com/professionals/580\\_9613.asp](http://www.marchofdimes.com/professionals/580_9613.asp)

National Newborn Screening and Resource Center

<http://genes-r-us.uthscsa.edu/resources/newborn/overview.htm>

National Dissemination Center for Children with Disabilities

[www.nichcy.org](http://www.nichcy.org)

National Down Syndrome Society

[www.ndss.org](http://www.ndss.org)

National Organization for Rare Disorders

<http://www.rarediseases.org/>

Newborn Screening for Practitioners

<http://www.mostgene.org/pract/NBS%20Practitioner%202003.PDF>

PKU and Allied Disorders  
<http://pku-allieddisorders.org/>

Spina Bifida Association  
[www.sbaa.org](http://www.sbaa.org)

United Cerebral Palsy  
[www.ucp.org](http://www.ucp.org)





# **Appendices**



Appendix 1:

**Medical Plan of Care for School Nutrition Program  
(Students with Disabilities and Non-Disabling Special Dietary Needs)  
Page 1 is to be completed by a parent/guardian  
Page 2 is to be completed by a licensed physician**

- The following child is a participant in one of the United States Department of Agriculture (USDA) school nutrition programs.
- USDA regulations 7CFR Part 15B require substitutions or modifications in school nutrition program meals for children whose **disability** restricts their diet and is supported by a statement signed by a **licensed physician**.
  - Food allergies which may result in a severe, life-threatening (anaphylactic) reaction may meet the definition of "disability"; as well as any other dietary restrictions which substantially limit one or more major life activities.
  - The school food authority must choose to accommodate a student with a **disabling special dietary need** that is supported by a statement signed by a **licensed medical authority** (physician, physician assistant or nurse practitioner).
  - The school food authority may choose to accommodate a student with a **non-disabling special dietary need** that is supported by a statement signed by a **licensed medical authority**.
  - Gainesville City School Nutrition Program provides information based on label information provided to us and cannot guarantee that food products served are not processed in plants that also process nuts or other allergens.
  - Labeled foods will only note the presence of eight major allergens: milk, eggs, fish, shellfish, tree nuts, peanuts, wheat and soybeans. **While efforts will be made to avoid other allergens, the Gainesville City School District cannot guarantee that labels will disclose all possible allergens.**
  - If you have specific questions, please contact the School Nutrition Department at 770-536-5275.

**Part 1: To be completed by Parent/Guardian (all requests for special dietary needs)**

Child's Name		Date of Birth	M	F
Name of School/Center/Program		Grade Level/Classroom		
Parent's/Guardian's Name		Address, City, State, Zip Code		
( )	( )			
Home Phone	Work Phone			

**Health Insurance Portability and Accountability Act Waiver**

In accordance with the provisions of the Health Insurance Portability and Accountability Act of 1996 and the Family Educational Rights and Privacy Act, I hereby authorize \_\_\_\_\_ (medical authority) to release such protected health information of my child as is necessary for the specific purpose of Special Diet information to \_\_\_\_\_ (school/program) and I consent to allow the physician/medical authority to freely exchange the information listed on this form and in their records concerning my child with the school program as necessary. I understand that I may refuse to sign this authorization without impact on the eligibility of my request for a special diet for my child. I understand that permission to release this information may be rescinded at any time except when the information has already been released. My permission to release this information will expire on \_\_\_\_\_ (date). This information is to be released for the specific purpose of Special Diet information.

The undersigned certifies that he/she is the parent, guardian or official representative of the person listed on this document and has the legal authority to sign on behalf of that person.

**Parent/Guardian Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_  
(Signing this section is optional, but may prevent delays by allowing us to speak with the physician)

**If the child has a disability or special dietary/feeding need, please complete Part 4 of this form and have it signed and stamped with the office name and address of a licensed physician/recognized medical authority.**

<b>Part 2: Parent Signature</b>	<b>Date</b>
---------------------------------	-------------

**Additional Parent Comments:**

**Part 3: To be completed by Physician/Medical Authority**

**Disability/Special Dietary Needs**

Food allergies which may result in a severe, life-threatening (anaphylactic) reaction may meet the definition of "disability", as well as other dietary restrictions which substantially limit one or more major life activities.

Does the child have a **disability**? Yes  No

**If Yes,**

**Please identify the disability and describe the major life activities affected by the disability.**

Does the child's disability affect their nutritional or feeding needs? Yes  No

If the child **does not have a disability\***, does the child have special nutritional or feeding needs? Yes  No

(\*These accommodations are optional for schools to make)

**If Yes,** please identify the medical or other special dietary condition which restricts the diet.

**If the child has a disability or special dietary/feeding need, please complete Part 4 of this form and have it signed and stamped with the office name and address of a licensed physician/recognized medical authority.**

**Part 4: To be completed by Physician/Medical Authority**

**Diet Order**

List any dietary restrictions, such as food allergies or intolerances (list specific foods to be omitted):

**List specific foods to be added in place of omitted foods (substitution cannot be made unless section is completed):**

Example for peanut allergy and egg: "serve meal that does not contain allergens, such as chicken sandwich, hamburger, chicken nuggets, chicken salad w/ roll"

List foods that need the following change in texture. If all foods need to be prepared in this manner, indicate "All."

Cut up/chopped into bite sized pieces:

Finely Ground:

Pureed:

List any special equipment or utensils needed:

Indicate any other comments about the child's eating or feeding patterns:

Physician/Medical Authority Printed Name and Office Phone Number

Address or Office Stamp

**Physician/Medical Authority's Signature\***

Date

\*Please make sure specific suggestions are made for substitute foods when omitting foods from the child's diet. School menus are on the district website for your convenience.

Please have parent/guardian review form annually and initial/date if no changes are required. Any changes require submission of a new form signed by the Physician/Medical Authority.

Parent confirmed no change in diet order.    \_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_  
\_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_    \_\_\_ Date \_\_\_\_\_

**A copy of this form should be kept by the School Nutrition Manager and the Nurse. FERPA allows school nurses to share student's medical information regarding dietary needs with school nutrition services.**

## **Appendix 2: Foods to Avoid when Casein is omitted**

Milk: whole, low-fat, skim, sweet acidophilus, buttermilk

Goat milk

Lactose-reduced milk

Non-fat dry milk or products that contain it

Half and half

Whipped cream

Sour cream

Sweetened condensed milk

Evaporated milk

Butter, margarine

Cottage cheese

Yogurt

Cheese: American, swiss, blue, cheddar, parmesan, cream cheese

Ice cream, regular or low-fat

Sherbet, orange

Cream soups

Breads, cereal, crackers, dessert made with milk

## **Appendix 3: Gluten Free Foods by Food Groups**

This list is provided for information purposes only. Never assume a food product is gluten free. Always read food labels. If you have any questions, contact the manufacturer.

### **Fruits and Vegetables**

Gluten-free options: All fresh and plain (packed in water only) canned and frozen varieties, most dried fruit, 100% fruit juice, and 100% vegetable juice.

Check labels carefully: Frozen and canned fruit with added ingredients, dried fruit powdered with oat flour (for example, dates), frozen and canned vegetables with added ingredients, vegetables in sauce, French fries, hash brown potatoes, and boxed potato products.

Not gluten free: Any product containing wheat, barley, rye, oats, malt, or brewer's yeast unless labeled gluten free.

### **Grain Foods, Including Bread Products, Breakfast Cereals, and Pasta**

Gluten-free options: Products labeled gluten free made with naturally gluten-free grains, flours, and starches, such as corn, rice, amaranth, buckwheat, quinoa, millet, sorghum, teff, potato, soy, and tapioca.

Check labels carefully: Products made with naturally gluten-free grains not labeled gluten free.

Not gluten free: Any bread, cereal, pasta, or grain food containing wheat, barley, rye, oats, malt, or brewer's yeast, such as most "regular" sandwich bread, bagels, egg-roll wrappers, flour tortillas, pizza crust, muffins, pasta, and breakfast cereals unless labeled gluten free.

### **Meat, Poultry, Fish, and Meat Alternatives**

Gluten-free options: All fresh, plain varieties.

Check labels carefully: Processed, canned, and seasoned products, such as hot dogs, sausage, deli meats, veggie burgers, veggie hot dogs, veggie sausage

Not gluten free: Any product containing wheat, barley, rye, oats, malt, or brewer's yeast, such as most breaded fish sticks, chicken nuggets, and chicken patties unless labeled gluten free.

### **Beans, Nuts, and Seeds**

Gluten-free options: All plain, unseasoned, and unflavored varieties.

Check labels carefully: Seasoned and flavored varieties.

Not gluten free: Any product containing wheat, barley, rye, oats, malt, or brewer's yeast unless labeled gluten free.

### **Milk, Yogurt, Cheese, and Milk Alternatives**

Gluten-free options: All plain unflavored milk and yogurt, most natural cheese.

Check labels carefully: Soy milk, rice milk, flavored milk, flavored yogurt, ice cream, and frozen yogurt.

Not gluten free: Any product containing wheat, barley, rye, oats, malt, or brewer's yeast, such as malted milk, ice cream or yogurt with added cookies, and ice cream flavored with malt unless labeled gluten free.

### **Sweet and Savory Snack Foods**

Gluten-free options: Plain popcorn, as well as cookies, cakes, pretzels, crackers, and chips labeled gluten free.

Check labels carefully: All products not labeled gluten free.

Not gluten free: Any product containing wheat, barley, rye, oats, malt, or brewer's yeast, such as most "regular" cookies, graham crackers, cakes, pretzels, and crackers unless labeled

gluten free.

**Spices, Sweetening Agents, Condiments**

Gluten-free options: 100% pure spices, plain sugar (white, brown, raw), honey, molasses, 100% maple syrup, vinegar, oil, and butter.

Check labels carefully: Most ketchup, mustard and salsa is gluten free but some varieties are not. Some salad dressings are gluten free but many are not.

Not gluten free: Malt vinegar and most soy sauce and teriyaki sauce.

**Miscellaneous Products Often Not Gluten Free**

Bouillon cubes

Candy

Gravies

Imitation fish

Licorice

Seasoned rice mixes

Sauces

Seasoned tortilla chips

Seasoned potato chips

Soups

**Sources of information:**

Thompson, T. (2006). *Celiac Disease Nutrition Guide*. Chicago: American Dietetic Association.

Adamson, E., Thompson, T. (2008). *CIG to Gluten-Free Eating*. New York: Penguin Group.

## **Appendix 4: The National Dysphagia Diet (NDD)**

The National Dysphagia Diet was created to set standard terminology for a progressive diet to be used nationally in the treatment of dysphagia. The NDD requires specification of both the diet consistency and liquid viscosity.

### **Dysphagia Pureed (NDD Level 1)**

This level consists of smooth pureed, homogenous, and cohesive foods. Foods should be pudding-like.

- Avoid gelatin, fruited yogurt, unblenderized cottage cheese, peanut butter, and any food with lumps including hot cereal and soup.
- Avoid scrambled, fried, or hard-boiled eggs; soufflés are allowed.
- Mashed potatoes should be served with gravy, butter, margarine, or sour cream
- Pre-gelled slurried breads are allowed.

### **Dysphagia Mechanically Altered (NDD Level 2)**

This level consists of foods that are moist, soft-textured, and easily formed into a bolus; moist, tender ground, or finely diced meats; soft tender-cooked vegetables; soft ripe or canned fruit; slightly moistened dry cereal with little texture. No bread, dry cake, rice, cheese cubes, corn or peas.

- Meats should not exceed a 1/4 inch cube, moistened with gravy or sauce.
- Allows canned fruit (except pineapple) cooked fruit or fresh banana. Avoid skins, dry fruit, coconut, and seeds.
- Allows scrambled, poached, or soft cooked eggs.
- Cooked vegetables should be less than 1/2 inch and fork mashable.

### **Dysphagia Advanced (NDD Level 3)**

This level consists of food of nearly regular textures with the exception of very hard, sticky, or crunchy foods. Allows bread, rice, moist cakes, shredded lettuce, and tender moist whole meats. Avoids hard fruit and vegetables, corn skins, nuts, and seeds.

### **Liquid Consistency**

Spoon thick

Honey-like

Nectar-like

Thin: includes all beverages. The following are considered thin liquids: water, ice, milk, milkshakes, juices, coffee, tea, sodas, and carbonated beverages.

Source: National Dysphagia Diet: Standardization for Optimal Care (2002)