



## Chapter

# EVALUATION & TREATMENT OF FEEDING DISORDERS IN EDUCATIONAL PROGRAMS

Children may be referred for evaluation of their feeding in several ways: a child who has been previously identified may transfer from another program; a parent may request assistance or information about their child's feeding; an IEP/IFSP team may note risk factors such as those listed to on page 43.

Effective management of a feeding disorder begins with a thorough assessment of the eating/feeding process and its component problems. While feeding an infant or child with normal capability is generally considered a simple task, feeding a child with a neuromuscular disorder is much more complex. Because such a child may lack the ability to control oral musculature, a number of considerations are presented for the feeder. The child may have difficulty keeping food and liquids in the mouth and may be deficient in the ability to chew, suck, or swallow. In addition, the child may have a tendency to choke/aspirate easily. A student may experience a seizure while eating. For these reasons, it is critical that a child with feeding difficulties be fed only by individuals who are appropriately trained and monitored by licensed specialists with specific expertise in feeding.

To insure safe feeding, an evaluation of the student's positioning needs, oral motor skills, calorie and nutrient requirements and food texture (tolerance/needs), medications, general health, and possible allergies, must be completed prior to development of the feeding protocol or mealtime plan, and implementation of feeding at school. Chapter III describes in detail the steps which should make up the process, from evaluation through training and implementation of an individualized mealtime program. It also covers the procedural safeguards which must be observed in conducting any evaluation for a child on an IEP/IFSP.

### Process

At the outset of the feeding evaluation, it is essential that key information be gathered about the student. This should include a thorough **Nursing Assessment**, using a format such as the one provided in the **Sample Forms** section, which gives a detailed history obtained from the parent or caregiver. Medical records pertinent to feeding should be requested and information included in the history. It may be necessary to consult the student's physician if medical questions remain after obtaining the history. The team should also review educational records, including the IEP/IFSP.

Following the history, the team conducts the actual assessment of the child's eating/feeding skills. It may require more than one observation session to evaluate the child's eating and behavioral patterns. It is considered best practice to have the parent present during the feeding evaluation to demonstrate how the child is fed at home. Similarly, school staff should be observed feeding the child as they typically do.

Once the assessment is completed, the team will develop a safe mealtime plan for the child. The plan, which must be in writing, should address positioning, specialized equipment, food textures, oral care, food likes/dislikes, allergies, feeding procedures, techniques for communicating, precautions and emergency protocols, guidelines for medication administration and documentation of training.

### **Determining the Need for a Medical Feeding Evaluation**

If the educational feeding team suspects that a student may be at high risk for choking/aspiration if fed orally, a referral may be necessary to obtain a feeding evaluation from a medical feeding disorders clinic. (Some medical feeding clinics in Oregon are found at Doernbecher Children's Hospital and the Child Development and Rehabilitation Center at the Oregon Health Sciences University, Shriners' Hospital for Children, Emanuel Hospital, all in Portland; Salem Regional Rehabilitation Center; and Rogue Valley Medical Center, in Medford.) Effective management of a feeding disorder may require a thorough medical assessment of the major components that influence the feeding process. Medical team members may include a pediatric gastroenterologist, and/or developmental pediatrician, a diagnostic radiologist, a speech/language pathologist, an occupational therapist, a physical therapist, a nurse, a social worker, and a Registered Dietician.

When the school district refers a child for a medical evaluation, it is important that they communicate to the child's family and physician their reasons for the referral. Based upon the information provided by the team and family, the child's physician determines whether or not to refer the child on for the requested evaluation. It is imperative that the team communicates as clearly as possible their specific concerns about the child's eating. Most often, the child's primary physician has not had an opportunity to observe the child during mealtime. The observations of the feeding team provide valuable information to the child's physician and the medical team. A **Physician Letter Requesting Medical Evaluation** is included in **Sample Forms**, as an example of a letter from a school district feeding team, listing the risk factors they have observed.

A comprehensive evaluation completed by a multidisciplinary medical team will encompass any medical diagnostic procedures needed to determine the child's health and physical status. It will also include assessments of normal and abnormal movement and postural components relative to feeding, nutrition, oral-motor performance, swallowing, and finally, the psychosocial and behavioral influences of the feeding disorder on the child and the family.

If a swallowing disorder is suspected, referral for a videofluoroscopy may be recommended for the child's health and safety. A videofluoroscopy is a medical evaluation which must be done in a facility where there is specialized equipment and trained pediatric specialists to perform the test and analyze the results. Videofluoroscopy is a videotaped x-ray of the child, taken while the child is eating. This test gives a picture of whether a child is aspirating (inhaling) food or liquid into the lungs. It can also show if the child is experiencing Gastroesophageal Reflux, where the contents of the stomach flow backward into the esophagus. When aspiration and/or reflux occur, the child is at high risk for severe respiratory difficulties or infection. These conditions can be life-threatening. The videofluoroscopy helps the medical team to provide information and recommendations to the family, the physician and the education-based feeding team regarding positioning for feeding, and food types, textures, temperatures and amounts that the child can safely manage. The test may indicate that the student is not safe for oral feeding or drinking. While the videofluoroscopy may be costly, it is essential in the management of children who have a swallowing disorder. It is the single most informative source of information that will help develop an understanding of the implications of the child's feeding difficulties.

Robert Beecher, M.S., CCC/SLP, has developed a list of criteria which his team at the Children's Hospital of Wisconsin uses to determine warning signs which indicate a possible need for a videofluoroscopy. His document, titled, ***Criteria for Oral-Pharyngeal Motility Studies*** is included in ***Resources. Clinical Signs of Gastroesophageal Reflux*** may also be found in the ***Resources*** section.

## **Determining the Need for a Nutritional Screening and Assessment**

Children with feeding disorders are at high risk for malnutrition because of poor nutrient intake and poor utilization of nutrients. Children with nutritional disorders may be small for their age, thin, and may be listless, with limited alertness. Poor nutrition is associated with decrease immune system, diminished physical activity, and long term impairment in cognitive development, academic performance and socio-affective competence. If allowed to continue, nutritional problems can lead to Failure to Thrive if the child's growth and development becomes impaired. It can be life-threatening. Nutritional problems usually arise secondary to other physiologic and psychosocial problems and may not be resolved permanently without addressing the underlying conditions that affect the child. Nutritional problems can be prevented through early identification of children at risk, nutritional assessment, intervention and monitoring the success of the intervention. Assessment of children at risk for nutritional disorders should include the following: nutrition screening, nutrition assessment, health and feeding history, dietary assessment, growth profile, physical examination, feeding assessment and certain specific laboratory testing. The Nutrition Screening form "A Look at Diet and Health" (see ***Sample Forms***) identifies nutrition concerns for the child. The purpose of the nutrition screening is to identify children who appear to have nutrition problems that require further investigation or who are at-risk for developing a nutrition problem. Anyone working to assure the health of infants or children with special needs may use the Nutrition Screening form. The completed Nutrition Screening form should be reviewed and scored by a care coordinator or other health professional to determine the level of nutrition risk. The scoring system assigns numbers based on severity of the nutrition risk factors. Adding up the points assigned to each screening question produces a total score indicating the degree of risk: no risk (total score of 0), low risk (total score of 1 to 4) or high risk (total score of 5 or more). The total nutrition screen score provides a quick and easy way to determine what action to take. Anticipatory guidance and information may be provided to families of children with low levels of nutrition risk, potentially preventing the need for further nutrition services. For those children with a high level of nutrition risk, the children may need to be referred for other services for a more in-depth nutrition or medical assessment.

A more in-depth guide to using the Nutrition Screening form may be obtained by contacting the Registered Dietician at CDRC. Contact information is included in the ***Resources*** section.

## **Feeding Intervention and Treatment**

When the feeding evaluation is completed, a mealtime plan is developed for the child. Depending upon the findings of the evaluation, the plan may include a protected feeding protocol, goals and objectives for the child's IEP, precautions to be observed or a combination of these.

A **Protected Feeding Protocol** is a program developed by a qualified specialist or a team of specialists to minimize the effects of a student's oral-motor disability on eating while at school. A protected feeding program is needed for any student at risk for aspiration/choking. A protected feeding program includes safe feeding procedures that are utilized to assure that the student is not exposed to an undue risk of choking and/or aspiration. It insures that the student is adequately

hydrated and nourished during school hours. All safe feeding practices outlined in the child's feeding protocol must be observed. Protected feeding is required under IDEA as a related service because it is necessary in order for the student to benefit from special education (34 CFR 300.24). Accommodations, modifications and supports to staff with regard to feeding should be listed as such on the IEP/IFSP in the appropriate sections. (Example: "Feeding team to provide written feeding protocol, attached.") If a student requires specific intervention to be fed safely due to an eating disorder, the feeding protocol may be attached to the IEP/IFSP for documentation. In addition to safe feeding practices, a feeding protocol may include remedial feeding goals or objectives related to the student's acquisition of eating skills. A sample format for developing a feeding protocol may be found in the section titled, **Sample Forms**. Examples of some completed feeding protocols are given in the **Sample Feeding Protocols** section. These are examples only, and are not intended for use as individually-designed programs for specific children.

A **Remedial Feeding Program** is a program designed and monitored by a qualified specialist or team of specialists with the intention of helping the student acquire new eating skills. Remedial feeding uses specific therapeutic techniques to facilitate the development of oral-motor movement or to inhibit abnormal oral-motor reflexes. Remedial feeding is a part of a student's specialized instruction and as such includes student goals and objectives as part of the IEP/IFSP. The decision to include remedial feeding must be based on the child's unique needs. The program is developed by the child's IEP/IFSP team through the IEP/IFSP process which includes input from the parent. A remedial feeding program is designed for a specific student when his/her eating ability is judged to impede educational progress and to have potential for change. A student may also have goals and objectives about nontherapeutic feeding issues, such as gaining independence in the lunch room, making correct food choices or requesting assistance appropriately.

While it is the obligation of a school district to provide safe eating for **all** students, districts are **not** obligated to provide a remedial feeding program for all students who have feeding disorders. **The acquisition of eating skills must be educationally and/or developmentally relevant.** A district is not obligated to provide a remedial feeding program unless the IEP/IFSP team includes goals and objectives on the student's IEP/IFSP that pertain to the acquisition or improvement of eating skills.

If it is the decision of the IEP/IFSP team to include remedial feeding/eating in the IEP/IFSP as part of the student's specifically designed instruction, the following criteria should be met:

- The IEP/IFSP should reflect functional eating outcomes as goals.
- Objectives must be measurable, with the expected dates of completion designated on the IEP/IFSP.
- Remedial feeding/eating should take place as a learning activity, not necessarily during mealtime.
- Remedial or protected feeding takes place only when specifically trained personnel are available to feed the student.

### **Pre-Feeding Skills Training**

Pre-feeding skills are the prerequisite steps or subskills necessary for eating food orally. Coordination of swallowing and breathing is an important pre-feeding skill, as is the ability to use the tongue to transfer food from the front to the back of the mouth, or the ability to tolerate certain food textures. In some cases, the IEP/IFSP team, in collaboration with the feeding team, may decide that

pre-feeding goals are most appropriate for an individual child before remedial feeding instruction can take place. Pre-feeding goals, such as increasing tolerance of various smells, or various textures in or around the outside of the mouth, may include oral-motor stimulation. Such goals should be written in collaboration with the knowledgeable specialist. Work on these goals would be integrated throughout the child's day, during naturally-occurring routines such as face-washing or tooth-brushing, or during appropriate classroom activities such as art, craft or cooking activities, dressing down for PE, community living skills instruction, vocational skills, etc.

For children whose educational program includes oral-motor stimulation activities, it *may* be appropriate to practice chewing under safe, supervised conditions specified by a feeding specialist, such as a snack time. See the **Resources** section for a listing of ***Foods that Encourage Chewing***.

## Developing a Feeding Plan for an Individual Child

Certain general considerations should be taken into account when planning to feed students with special feeding needs. All such children have individual issues which are unique to them and their particular environment. In all aspects of feeding, the clinical judgement of the specialist is of paramount importance in insuring that the child is safe when eating at school. ***General Guidelines for Facilitating Safe Feeding*** have been included in **Resources**. These guidelines are general in nature, and may not apply to every student.

## Factors Affecting Safe Feeding

The many factors that can influence the student's response to a feeding program often interact and it can be very difficult to determine the exact cause of an observed problem. Some of these factors are listed below:

### Health Factors:

Some students may have health problems that will affect their response to the mealtime program. Factors such as fatigue, medications, allergies, fluctuating tone or alertness can influence feeding safety from day to day or even during the meal, and should be considered on an ongoing basis. A more thorough listing, titled ***Health Factors that Affect Feeding*** can be found in **Resources**.

### Nutrition and Hydration:

Children who have swallowing difficulties are at risk for losing weight, or not maintaining healthy weight gain as they grow. They also risk dehydration on a daily basis for several reasons: often they are unable to tend to their own needs when they are thirsty; they are often prevented from drinking liquids for reasons of safety; they may simply be averse to the unpleasant sensation of attempting to swallow liquids. In any of these cases, it may be necessary to offer liquids and foods which are easy for the child to swallow and which boost calorie intake. The **Resources** section provides **Recipes** for simple preparations which facilitate swallowing and promote hydration.

### Constipation and Proper Elimination:

Although stool frequency is often used to distinguish between normal and abnormal elimination, stool volume and consistency are usually of greater importance. Constipation is a common complaint in children with developmental disabilities due to generalized hypotonia, limited bowel muscle function, inadequate fluid intake, low fiber intake and limited physical activity. Diarrhea

## **Feeding in Early Intervention: General Issues**

1. Consultation is to the parent, rather than to school staff unless the child is in an educational group setting (such as a toddler group):
  - Opportunity to promote family behaviors that foster the general health and safety of the child.
  - Outcome of the intervention is influenced by parent, who may be unfamiliar with sequence of normal feeding development, and have difficulty understanding that their child's feeding is abnormal.
  
2. Feeding environment is the home, but may include toddler group setting:
  - Opportunity to enhance the environment to promote safe feeding.
  - Structure of the mealtime environment can impact effectiveness of the intervention.
  
3. Eating is an emotional issue for families:
  - Feeding is typically a bonding experience between parent and child.
  - Opportunity to influence the emotional dynamic which can develop when the parent experience difficulties feeding their child or when the child seems not to accept or like what the parent offers them.
  
4. Eating is a new experience for the young child:
  - For ages 0-3, oral motor structures and surrounding supportive musculature are still developing. The feeding process should be evaluated in the context of other developmental areas:
    - Are there delays in speech development as well?
    - Are there sensory issues related to the feeding difficulties?
    - Are feeding problems related to a developmental behavioral issue?
  - There can be a window of opportunity for intervention in the child's development while they can experience success, and before maladaptive physiological or behavioral patterns can develop.
  
5. Team Process:
  - While the expertise of a multidisciplinary team is often needed, the impact of multiple professionals entering the home on a regular basis can have a negative impact upon the family. A single contact person is most desirable.
  - It is important to reinforce concepts to parent consistently across team members.
  - Interdependence and communication among team members is critical.

refers to an increase in the frequency, fluidity or volume of stool compared to the individual's normal pattern. Either constipation or diarrhea may impact the student's appetite and ability to participate in a feeding program.

#### Transition from Tube-Feeding to Oral Feeding:

When it does become appropriate to begin oral feeding at school, it is important that the feeding team and school staff work closely with the family and health care providers. Cooperation between home, school and health care providers assures continuity and safety in the development of a feeding protocol in the school setting. During this transition time, it may not be necessary for the child to eat orally at school if they are receiving adequate nutrition via the gastrostomy tube.

A list of **References** from current literature on feeding children with special needs at school is included in **Resources**. Books available for loan through the Regional Services for Students with Orthopedic Impairment (RSOI) are noted with an asterisk.

#### Environmental Factors:

Environmental factors may also impact health and safety when feeding students in school. When considering program location, external stimuli, (e.g., noise, interruptions, interfering activities), may cause a student to react in a way that makes feeding even more unsafe. Frequently, children with feeding disorders may stiffen up in response to external stimulation, preventing safe swallowing from occurring. A quiet location with minimal stimulation is recommended for the student with feeding difficulties. This may mean that a student cannot be fed in the school lunch room or preschool snack environment. If this is the case, it may be possible to feed the student in a quiet place and then bring him to the lunch room for socialization. However, feeding should never occur in isolation. All building personnel should be knowledgeable about how to access emergency assistance. Other environmental factors of concern are a student's right to privacy, food preparation, classroom hygiene and eating utensils.

1. **Right to Privacy** - Students with feeding difficulties often have trouble closing their lips, therefore they lose food and liquids from their mouths. If the student is sensitive about eating or being fed in the presence of his peers, he should have the option of eating in a private place. Also, if the peers are particularly insensitive about the eating/feeding process, they may need to engage in some class discussion about feelings and teasing. In the meantime, privacy of the student with feeding difficulties may be best protected by being fed in a private area. Socialization, which is often a goal that causes the student to be fed in the school cafeteria, cannot be promoted unless the necessary groundwork is laid.
2. **Food Preparation** - Because students with feeding disorders often have food specially prepared for them in the classroom, care should be taken to insure that food is prepared, handled and served in compliance with current health standards. Cafeteria staff may be willing to prepare and store food, and clean dishes and other equipment. Staff preparing food in the classroom need to be cautious of additional factors affecting the health of the students who are eating foods prepared by them. Microwaving of foods can create hot spots with possible resultant burns to the mouth of a student. Repeated warming and/or lack of refrigeration can cause bacterial contamination of foods. Guidelines need to be developed and followed to assure healthful food handling, preparation and storage, use of gloves, adequate refrigeration, and judicious heating of foods.

3. Classroom Hygiene - When students eat and are also toileted and/or changed in their classroom, special care needs to be given to insure adequate hygiene. The diaper changing area should be located away from food preparation areas. Handwashing policies need to be developed for staff and students. Classroom surfaces, (i.e., sink, countertops, bathroom, towel holders, waste receptacles, refrigeration, storage, food containers), should be cleaned and disinfected in compliance with health regulations.
4. Eating Utensils - Students with feeding difficulties, whether self-feeding or fed by others, often require special eating utensils. These utensils can help facilitate independence with the self-feeding student or promote ease and safety while feeding a student. Eating utensils may include such things as a cutout drinking cup, plastic coated youth spoon, or spoon with a built-up handle. Metal and/or flimsy plastic eating utensils are not recommended for use, as they may cause unsafe feeding conditions to arise. The feeder may feed too large a portion or the child may sustain injury to the oral cavity from unanticipated head and arm movement.
5. Food Characteristics – Children with feeding and or swallowing problems can sometimes eat only certain food textures or temperatures recommended by their physician or knowledgeable specialist. A “Dysphagia Diet” is sometimes prescribed by the physician for a specific patient with a swallowing disorder, or “dysphagia”. These diets are scaled lists which designate food types and textures which may safely be given to a specific patient. Because there are a variety of Dysphagia Diets in use, it is important to know which diet is being referenced when a particular diet level is prescribed. For that reason, it is recommended that school-based practitioners refer to the ***Descriptions of Food Textures***, given in the ***Resources*** section when writing protocols for protected feeding, in conjunction with the recommendations of the child’s physician.

Sara Rosenfeld-Johnson has developed a list of foods that should generally be avoided by people who have feeding and/or swallowing difficulties. The list also provides a brief explanation of why those foods may be problematic, and gives suggested alternatives. See ***Resources*** for these guidelines, entitled ***Foods to Avoid***.

### **Training and Monitoring of Mealtime Programs**

Training and monitoring of people who feed children at school is the responsibility of the feeding specialist/ team. Strict compliance with the feeding protocol must be emphasized in staff training, with periodic monitoring by the designated specialist. It is necessary to train at least two people who are familiar with the student to insure the availability of a feeder every day. Trained feeders are required to sign that they have received training in the protocol, and agree to implement it as directed by the feeding team. To maintain proficiency, it is recommended that a feeder feed the child at least once per week. This also provides the child with a variety of feeders so they don’t become dependent on just one person.

A specialist who is well trained and highly experienced in safe feeding techniques should be responsible for training. He or she should be competent in handling and positioning children with neuromuscular disorders, be skilled in assessing oral-motor dysfunction, and have the ability to develop and implement an appropriate feeding program. In addition to demonstrating technical

expertise, the specialist should be skilled in and comfortable with the training of others. Physical therapists, occupational therapists and speech/language pathologists are expected to follow professional guidelines when training others, which are set forth in their practice acts. Training that is documented and then periodically reviewed allows for consistency in program implementation and identifies additional training needs. See page 38 for a suggested training sequence.

As explained above, on page 7, some procedures must be taught and monitored by a nurse. As defined by the Nurse Practice Act, “delegation” means that a registered nurse authorizes an unlicensed person to perform special tasks of client/nursing care in selected situations and indicates that authorization in writing. The law specifies which tasks fall under this designation. The delegation process includes nursing assessment of a client in a specific situation, evaluation of the ability of the unlicensed person, teaching the task and insuring supervision and follow-up training.

#### Responsibilities of the Trainee:

No person should ever undertake the feeding of a child with a feeding disorder without appropriate training by a licensed specialist. The trainee has the responsibility to carry out the child’s feeding program as directed and monitored by the specialist. It is the responsibility of the trainee to:

- Have available the Safe Feeding Checklist;
- Have available any adapted/specialized equipment the child may use;
- Have available and know the student’s written Feeding Protocol and Emergency Plan;
- Inventory and maintain equipment;
- Problem-solve with the staff any issues that may be anticipated to impact the feeding program, (e.g., comfort level of feeder, staff time and schedule constraints, ability of staff to maintain program consistency);
- Make sure that others are available to help if an emergency should arise. Feeding should never occur in isolation.

Safe feeding may begin when the person feeding the child meets the recommendations listed below:

- The feeder demonstrates proficiency in the feeding protocol and has been signed off by the feeding specialist/team.
- The feeder is knowledgeable in general Guidelines for Facilitating Safe Feeding (p. 49).
- The feeder knows the specific feeding needs of the individual student.
- The feeder is current in CPR and Heimlich Manuever.
- Training is routinely monitored by professionals.
- The feeder recognizes when modification of current feeding practices is needed and notifies designated specialist for direction.
- The feeder is backed up by an equally knowledgeable and trained replacement.
- The feeder is aware when additional consultation is needed.
- The feeder recognizes that the feeding plan and correct feeding practices can only be modified by the specialist.

#### Monitoring of Mealtime Programs and Feeding Protocols:

Feeders should be trained until they demonstrate proficiency in the feeding protocol and are comfortable with the procedures. In addition to the initial training of staff members in safe feeding, regular ongoing supervision on the part of the responsible specialist is necessary to insure safety. After the period of initial training, monitoring should take place on a regular schedule, (i.e., weekly,

bi-weekly, monthly) at the discretion of the feeding specialist/team, but at least yearly. In addition, the responsible specialist should plan occasional unscheduled visits to ascertain that the procedures followed during the scheduled visits are also followed at other times. The **Observation of Trained Feeder** form, provided in **Sample Forms**, may be used to document observation of staff who feed students. The protocol should be updated at least annually.

Monitoring of a student's feeding program should include consideration of questions such as the following:

- Have the student's oral-motor or feeding skills changed?
  - Has the child grown?
  - Have there been changes in the child's eating or posture?
  - Has the child experienced any hospitalizations, surgeries?
- Is the protocol being followed?
  - Is it still effective?
  - Do changes need to be made?
- Feeding environment for the student:
  - Is it safe?
  - Is it socially appropriate?
  - Is it free of distractions?
  - Is it sanitary?
- Is the staff comfortable with the feeding protocol?
  - Are staff questions being solicited and answered?

The specialist must plan to periodically retrain all staff who are doing feeding to insure the necessary techniques and procedures are fresh in their minds. Of course, any change in the child's ability to chew or swallow, physical growth or changes, change in alertness, seizure status, etc., since the feeding protocol was initiated, should be called to the attention of the responsible specialist and should receive prompt attention.