Swallowing and Feeding in the Schools: Legal, Ethical, and Educational Relevance

Emily M. Homer, CCC-SLP
Students Eat Safely, LLC, Consultant
ISHA Convention
February 7, 2019
Chicago, Ill.

Today

• Brief overview of dysphagia and feeding disorders in the school setting and why it is important to address it. Review the signs and symptoms of swallowing and feeding disorders and identifying students who are at risk.
• Answer the WHY by discussing legal mandates and cases, ethical considerations, IDEA regulations and school food services regulations in regards to swallowing and feeding in the schools.
• Determine how we can address the disorders while complying with federal (IDEA) and state regulations and meeting our ethical obligations.
• Establish a proposal to present to district supervisors for a system-approved procedure.

Swallowing and Feeding in the Schools and the ISHA Convention

• This course will lay the foundation for addressing swallowing and feeding, talk about WHY and provide the information and structure for creating a proposal for your district.
• The next course will go over a step-by-step, time tested procedure for addressing swallowing and feeding using a team approach. It follows this course at 5:00.
• The last course, tomorrow at 8:00 – 10:00 will share how to maintain safety, manage students in the district and provide therapeutic intervention when indicated.

Disclosures

Financial
• Honorarium from ISHA for this presentation
• Royalties from Plural Publishing for Managing Swallowing and Feeding in Schools
• Royalties from Medbridge Education for videos
• Compensation for presentations to school districts and professional organizations on this topic

Nonfinancial
• Consultation to SLPs, their school districts, and state departments of education on this topic with no financial gain
Raise your hand if:
• Your district is addressing swallowing and feeding using a system approved procedure.
• Your district is addressing swallowing and feeding but it is not district approved and not with a set procedure
• You are doing what you can but no district buy in
• Currently talking about it but not addressing it
• Not addressing it at all or talking about it yet

Foundations for Addressing Swallowing and Feeding in the Schools
1. Know and understand WHY school districts should address swallowing and feeding.
2. Obtain administrative support for a swallowing and feeding procedure.
3. Establish a detailed system-approved procedure
4. Utilize a team approach with trained professional staff (SLPs, OTs, PTs, and nurses)

But first let’s get on the same page:
Swallowing disorder (Dysphagia)

Oral Phase: Oral Preparatory and Oral Voluntary
This is where the food or liquid is manipulated in the mouth into a bolus and propelled backwards to exit the oral cavity. Choking risk, under nutrition

Pharyngeal Phase:
When structurally there is a problem that interferes with the swallowing mechanism protecting the airway or with food or liquid going directly into the esophagus. Aspiration risk, under nutrition, dehydration, frequent illness and absences

Esophageal Phase:
The food is swallowed, goes into the esophagus but there are medical issues that result in reflux, pain, vomiting, and inflammation. Food refusal, disruption during meals, under nutrition, absences

Feeding Disorder
• Delays, and/or disorders in the development of eating/drinking skills that affect weight and nutrition.
• When children need special equipment (special bowls, cups), utensils (spoons), and/or positioning (adaptive chairs) in order to eat.
• When children have behaviors or sensory concerns (food aversion, feeding jag) that result in a limitation of the foods that they eat.
• When a student needs someone to assist them with eating at school (directives as to food choices, amount on spoon, food to drink ratio, pacing).
Student may have a feeding problem without dysphagia but cannot have dysphagia without having a feeding disorder!
Incidence

NOTE: About ½ million children (3-17 years old) diagnosed with dysphagia in US in 2012
– About 1% of all children in US annually
National Hospital Discharge Survey; CDC 12/2013
Bhattacharyya, N. Laryngoscope 2014
Childhood Assessment of Normal and Dysfunctional Feeding and Swallowing Maureen A. Lefton-Greif, PhD, CCC-SLP, BCS-S & Joan C. Arvedson, CCC-SLP, BC-NCD, BCS-S (MedBridge)
• This is believed to be a low estimate and does not include children with feeding disorders and no dysphagia.

What will be reported or what do we look for?
• Repeated respiratory infections
• History of recurring pneumonia
• Weight loss/failure to thrive
• Difficulty chewing
• Coughing/choking during or after swallowing
• Maintains open mouth posture
• Drooling
• Food refusal
• Prolonged feeding times
• Poor oral motor functioning
• Nasal regurgitation
• Wet/gurgle voice/sound after meal
• Difficulty initiating swallowing

Take a minute to think of students at your schools that might be at risk for a swallowing and feeding disorder.
Pull out Handout #1.
Use the top to write down a student that you think may be at risk.
Check this list: does the student you identified in the activity have any of these conditions?

Children from 3 to 21 years old with:

- Developmental disabilities
- Neurological disorders (cerebral palsy, PDD, TBI, etc.)
- Neuromuscular disorders (Muscular Dystrophy)
- Genetic syndromes (Down’s Syndrome)
- Structural abnormalities
- Sensory issues
- Behavioral factors
- Complex medical conditions
- Autism
- Cognitive deficits
- Students taking certain Medications (such as diuretics, antihypertensive, and antidepressants)

What can we do about these students?

Foundation #1: Know why districts must address swallowing and feeding

- Legal mandate—requiring provision of FAPE and Health as a related service.
- IDEA—responsibility to provide a safe environment for students at school, including mealtimes
- USDA Regulations - “Schools must make substitutions in lunches and after school snacks for students who are considered to have a disability under 7 CFR 15b.3 and whose disability restricts their diet.” (7 CFR 210.10(m)
- Ethical responsibility of SLPs, OTs, school nurses to “hold paramount the welfare of the persons they serve professionally.”

District and professional responsibility to student safety

Legal Considerations, IDEA, Food Services Regulations and Ethical Consideration to Addressing Swallowing and Feeding in the School Setting
"Does IDEA require us to address swallowing and feeding?"

- Individual with Disabilities Education Act (IDEA)
- Funding law that provides and protects student’s rights to special education
- States must comply with IDEA but then set up their own policies and procedures
- School districts follow the policies and procedures of their individual states which are based on the national law which secures funding.

IDEA

- Ensures that children with disabilities have a free and appropriate public education (FAPE) which ALL children are entitled.
- Ensures that students with disabilities have special education services including related services.
- Related services include speech and language pathology, physical therapy, occupational therapy, health services, adapted PE, etc.

Supreme Court cases supporting dysphagia in the schools

- Cedar Rapids Community School District vs. Garret F, 526 U.S. 66 (1999) Upheld Tatro, ruling that if the services are supportive services that the student needs are critical for the student to attend school and benefit from his education, and that they are not medical (do not need to be performed by a licensed physician) then the school division must provide them.

State cases supporting dysphagia in the schools

- New Mexico Department of Education (2003) – ruled with the parents that the student needed access to foods that comply with the mechanical soft diet prescribed, upright positioning during and after eating, thickening of all liquids...and careful monitoring for signs of reflux or aspiration in order to attend school.
- Contoocook Valley School District– New Hampshire (2004) –ruled that inadequate feeding practices by the district "appear to have led to two hospital admissions for aspiration pneumonia". District ignored the child's safety.
**Case Profile**

- Special needs student who was hearing impaired, non-verbal, and visually impaired.
- 15 years old
- Had an IEP which stated:
  - Finger foods independently and spoon/fork with assistance.
  - Needs to be monitored while eating to prevent him from eating too fast and swallowing without chewing.
  - Food should be cut up in bite sized pieces.
  - Helpful to put "spoon foods" into a separate bowl so he does not get his finger in them when finger feeding.
- Added in the IEP that during the summer he began regurgitating his food and incidents should be reported to parents.

**How would you make the things stated on the IEP happen?**

What does the side note: "during the summer he began regurgitating his food" indicate?

---

**Court ruled:**

- District was aware of the special needs
- IEP required close and careful supervision while eating to prevent him from eating too fast and swallowing without chewing. Also required that his food be bite sized.
- IEP also recognized that lack of close supervision and monitoring while eating presented a serious risk of choking.
  
  District was negligent and did not provide adequate supervision

**Let’s think about this.**

What were the issues?
1. Lack of adequate supervision. Why?
2. Improper diet given to the student. Why?
3. Ambiguity in how to safely feed the student. Why?
IDEA Regulations

• Supreme Court cases, Tatro and Garret, established that districts had to provide health as a related service, if it was necessary for a child to be able to attend school.
• These regulations are in IDEA and school districts are required to provide health related services provided by a school nurse or other qualified professional.
• This is why we have nurses in our schools!

USDA Regulatory Requirements: School Lunch Program

• For districts that participate in these programs, these regulations require substitutions or modifications in meals for children who are considered disabled and whose disabilities restrict their diet [7 CFR, Sec 210.10(g)(1)]. Included are children with feeding and swallowing disorders who are IDEA- or 504-eligible.

The school team must provide the food services program with the IEP which contains the following information:
• Information about the child’s physical or mental impairment that is sufficient to allow the School Food Authorities to understand how it restricts the child’s diet.
• An explanation of what must be done to accommodate the child; and
• The food or foods to be omitted and recommended alternatives, if appropriate.

Code of Ethics: Safety of Client/Patient

• ASHA “individuals shall honor their responsibility to hold paramount the welfare of the persons they serve professionally.”
• AOTA “an obligation to not impose risks of harm even if the potential risk is without malicious or harmful intent.”
• NASN “school nurses actively promote student health, safety, and self worth”
• www.asha.org/Code-of-Ethics/

Ethics-Competency in Area of Practice

• Professionals have a responsibility to be competent in their area of practice.
• Obtaining and maintaining competency:
  SLPs, OTs and nurses all have language that stresses the responsibility of the professionals to acquire the knowledge and skills needed to work with a disorder.
Determining professional competency
District’s responsibility that the professionals who work for them have the certification, knowledge and skills to work in their area. (CEC Policy Manual, 1997 Section Three, Professional Policies, Part 1 Chapter 3, Special Education in the Schools)
1. Survey of district personnel. (See Handout #4)
2. Knowledge and skills documents for both SLP and OT

Challenge for school-based SLPs and OTs:
• Often will have very few cases, however, this may not be true for your school
• Cases of students with swallowing and feeding are extremely different and require individual student approach (food refusal student is different from a cerebral palsy student!)
• There are few medical supports in the schools such as physicians, dieticians, neurologists to consult

District plan for establishing and maintaining professional competency
District with NO trained SLPs or SLPs who have never used their skills.
• Fill new or open positions with SLPs who have training and experience in swallowing and feeding.
• Contract with health care agency
• Partner with local university to offer a graduate level course, after school, available to SLPs.
• Provide opportunities for professional development

Updating the knowledge and skills of SLPs who have some competency
• Sending staff to professional development
• Bring in national speakers
• Webinars and recorded sessions
• Shared learning
• University sponsored sessions
• Professional organization’s conventions
• Hospital sponsored training
**District plan for establishing and maintaining professional competency**

District with **NO** trained SLPs or SLPs who have never used their skills.
- Fill new or open positions with SLPs who have training and experience in swallowing and feeding.
- Contract with health care agency
- Partner with local university to offer a graduate level course, after school, available to SLPs.
- Provide opportunities for professional development

**Mentoring and collaboration**

- Providing opportunities to meet and discuss cases
- Therapists with hospital experience mentor those without experience

**Individual learning**

- Use knowledge and skills documents to identify areas of need.
- Reading current research, attending lectures, webinars
- Observing other professionals
- Researching and preparing a presentation

“Be an expert in the swallowing and feeding for the student(s) that you have on your caseload. Know everything you can about those specific children.” Homer

**Foundation #2: Administrative Support: Don’t go it alone!**

- **Procedural** – establish a system procedure
- **Financial** – provides funds for VFSS, equipment such as blenders, nuk brushes, cups, etc. Provide funds for Westmoreland Intermediate Unit consultative services for swallowing and feeding.
- **School-based personnel support** – when there are parent concerns, upper administration knows and understands the disorder and the team procedure and attends meetings to support school-based personnel.
- **Legal support** – provides access to legal team when there are concerns
Who are the administrators?

- Coordinators or Lead Therapists in your district including Speech, OT, PT, and school nurses.
- Supervisors and Assistant Supervisors of Special Education (may be called Director of Special Education)
- Supervisor of Food Services Programs
- Assistant Superintendents who address special education issues

Foundation #3: A System-approved Procedure

“The keys to minimizing liability exposure are planning, procedures, training, and the proper execution of those procedures.”

Robert L. Hammond, School Board Attorney

…and the documentation of these procedures!

Emily M. Homer

Key Words!

- Planning
- Procedure
- Training
- Execution
- Documentation

District policies

- There are policies and procedures for disciplining students, taking students on field trips, dress codes, etc.
- Special education departments may have their own procedural manual that addresses the many issues that are associated with working with special needs students.
- It is in the interest of students, school personnel, parents and the district that a procedure for addressing dysphagia is adopted.
Benefits of a district wide procedure

- **Consistency:** same procedure is used throughout the district
- **Accountability:** makes school personnel accountable for following the procedure
- **Clarification:** of roles and responsibilities of staff
- **Documentation:** provides the forms, etc. necessary to document the procedure
- **Safety:** ensures a safe mealtime environment for students with dysphagia

Foundation #4:
Team Approach to Swallowing and Feeding in the School Setting

What is an Interdisciplinary Team Approach?

- The interdisciplinary approach involves each member of a group of professionals, each whom brings a specific area of expertise.
- A true interdisciplinary approach involves each member of the group sharing the philosophy for diagnosis and treatment in addition to being willing and able to work with other team members within the group. (Arvedson & Brodsky, 2002)

Why a team approach is important:

- **Shared decision making**
- **Contribution of each discipline's knowledge and skills and perspective**
- **Defined roles clarifies each professional's role in implementing the procedure**
To work effectively as a team each member must be willing to:

- Be aware of each person’s role
- Share information
- Realize personal professional limitations in relation to dysphagia
- Be open to suggestions and to problem solving
- Have open communication among the team members

Suggested roles for swallowing and feeding team members

- Each team member will bring their own level of knowledge and expertise.
- The district and the individual professional will be responsible for increasing their knowledge and skills in swallowing and feeding.

School-based Swallowing and Feeding Team Members

- Speech/Language Pathologist
- Occupational Therapist
- Physical Therapist
- School Nurse
- Parent
- Special Education Teacher
- Regular Education Teacher
- Paraprofessional
- School Administrator
- Social Worker
- Physician(s)
- Hospital Based SLP
- Dietician
- Cafeteria Workers

All members of the swallowing and feeding team:

- All members are referral sources
- All are responsible for Monitoring the student’s swallowing and feeding
- All are responsible for the safety and well being of the student at school
Team Leader for Swallowing and Feeding Students

- Person designated to oversee the process.
- Ensures that the procedure is followed with fidelity for each student, that team members are kept informed and that the process is documented.
- Typically, the SLP takes on the role of Swallowing and Feeding Team Leader

Speech Language Pathologist’s Role:
- Referral source
- Serves as team leader
- Initial identification of students at risk
- Coordinates assessment/treatment
- Attends ARD meeting
- Attends Video fluoroscopic Swallow Studies/Modified Barium Swallow Studies
- Writes swallowing and feeding plan and trains teachers
- Treats oral/pharyngeal phase dysphagia
- Seeks consults & monitors esophageal phase dysphagia
- Monitors feeding and implementation of the swallowing and feeding plan
- Responds to issues and concerns regarding the student’s swallowing disorder

Typical role of the occupational therapist:
- Referral Source
- Conducts the interdisciplinary observation (clinical evaluation) with the SLP
- Brings knowledge of neuromuscular, positioning, sensory awareness, adaptive equipment, and environmental modifications.
- Attends the ARD when possible or indicated
Typical role of the school nurse

• Monitors the health of the students
• Writes the individualized health plan and trains personnel
• Monitors student’s weight
• Monitors lungs periodically during meals
• Assists in contacting physicians
• Consults with parents and teachers
• Helps to secure the medical history
• Attends the ARD

Typical role of the classroom teacher

• Responsible for:
  • preparation of the student’s food according to the swallowing and feeding plan.
  • implementation of the swallowing and feeding Plan
• Must be able to recognize changes in student’s feed or swallowing
• Serves as an information source
• Functions as the teacher with IEP authority at ARD
• Keeps Individualized Health Plan and Swallowing and Feeding Plan in place of easy reference

Role of classroom teacher cont.

• Oversees the feeding of the swallowing and feeding students in his/her classroom
• Must be able to follow the individualized health plan in the event a child chokes
• Contacts swallowing and feeding team leader as soon as there’s a concern
• Follows through on oral motor exercises when recommended by the SLP or OT

Typical role of parent/guardian

• Shares knowledge of child’s feeding habits, food preferences and mealtime environment
• Participates in decision-making
• Provides medical information and history
• Shares cultural view regarding food and eating
• Implements swallowing and feeding goals
“Working with students who have dysphagia can certainly be difficult, but understanding the families' perspectives can prove not only helpful, but in many instances, crucial to developing and implementing effective programming.” (Angel, Bailey, Nicholson, & Stoner, 2009)

### Family issues and concerns facing families

- Medical Concern – frequent hospital visits and illnesses
- Financial Concerns – increased medical bills, time off work, specialized sitters and therapies.
- Concerns for the Future – After 22 years?, aging parents?,
- Toll on Family Structure – mealtimes, socialization
- Managing Family Dynamics – siblings, extended family

### Emotional issues and concerns facing families

- Depression
- Guilt
- Lack of confidence in ability to raise the disabled child

“School-based professionals should work toward developing an appreciation of the impact that having a child with a developmental disability can have on the family and develop sensitivity for the complexities that families with disabled children face.” (Handleman, 1995)
What can a district do?

- Educate parents to help them to understand their child’s swallowing and feeding disorder (research supports that parenting stress is reduced when parents learn about their child’s medical problems and conditions)
- Share intervention techniques and feeding procedures that are successful
- Communicate regularly
- Validate the parent’s/guardian’s perspective

What a district can do, cont.

- Be sensitive to cultural values in regards to food and mealtimes
- Listen to them and seek their input
- Connect them with other families and organizations
- Follow the swallowing and feeding procedure which includes working closely with parents.
- “Work towards a child having a meaningful and functional mealtime experience both at home and school while maintaining safety and efficiency.” (Arvedson & Lefton-Greif (Medbridge, 2017).

Addressing Swallowing and Feeding using a Team Approach

There are several ways that a district can address swallowing and feeding in the schools. They all should involved a team approach.

The model you choose will depend on the resources you have available in your district.

Every district is different and therefore every team approach will be a little different as well.

These are the models that I have found work best in most cases:

Reasons why having a school-based team whenever possible is recommended:

- Facilitates regular monitoring of students
- Allows for more involved dysphagia therapy
- Team members available to interact frequently with other school staff as well as with parents/guardians
- Most knowledgeable dysphagia professional is on campus for emergencies
- Team members know the students at staff at the school
Models for addressing dysphagia in the schools

Swallowing and feeding team models will look different depending on the make up of your district:

• School-based teams
• System core team
• Combination teams

School based team

Team members who are assigned to the school make up the swallowing and feeding team for that school. SLP, OT, PT, nurse, teacher, etc.
The SLP, OT, and PT, etc. that work with the students on therapy, also provide swallowing and feeding services.
Each school in the district is assigned a swallowing and feeding Team Leader (typically the SLP) to oversee the team process.
The school-based team evaluates the student’s swallowing and feeding and establishes a safe feeding protocol.

Pros and Cons of a School-based Team

Pros:
• Facilitates regular monitoring of students
• Allows for more involved dysphagia therapy
• Team members available to interact frequently with other school staff as well as with parents/guardians
• Most knowledgeable dysphagia professional is on campus for emergencies
• Team members know the students at staff at the school

Cons:
• Requires large number of dysphagia trained SLPs
• Professional development could be more difficult
• Small swallowing and feeding caseload prevents becoming experienced in a number of swallowing and feeding cases.

System core team

A separate team, comprised of an SLP, an OT and school nurse who specialize in swallowing and feeding, travels to various school sites to serve the students with dysphagia.

• This team works collaboratively with the school-based personnel (including teacher, administrator, SLP, OT, and nurse).
• Trains school staff to follow swallowing and feeding plan and to report concerns and changes to the core team.
Pros and Cons of a Core Team

Pros:
• Works well for small districts or districts with few dysphagia trained SLPs
• Core team members have a larger swallowing and feeding caseload and as a result develop more experience and knowledge
• Ongoing training and staff development is easier to achieve

Cons:
• Underutilization of trained professionals on campuses
• Trained professionals are not based on campus: communication and access to team is difficult

Combination team

District has some schools with dysphagia trained SLPs & some schools without dysphagia trained SLPs
• When possible, teams are school-based, which allows the person most knowledgeable to be on campus
• For schools where this is not possible, a system core team serves the students with dysphagia working closely with school personnel

Pros and Cons of Combination Team

Pros:
• Professionals with the knowledge and skills are able to use them to address swallowing and feeding at their schools.
• Moves district toward the goal of the School-based Team.

Cons:
• Takes additional administrative attention to coordinate schools that use a Core Team and those that are School-based.

Sample Team List
Team Model Discussion

How to prepare a Proposal for a Swallowing and Feeding Team Procedure in Your District

Look at the proposal worksheet in your handouts. Let’s go through it quickly!!

Steps for obtaining approval for a system wide procedure:

1. Talk with your supervisor about the need for a swallowing and feeding procedure, stressing legal, ethical and regulatory concerns. I want to stress the chain of command.
   • Please communicate with your immediate supervisor before you distribute any surveys or begin anything.
   • Supervisors NEVER like surprises.
   • Always keep them informed.
2. Suggest that a task force of SLPs, OTs, PTs, nurses etc. could work on preparing a proposal with your immediate supervisor.
   Note: It is always better to present something to a district as a team rather than an individual!!

When preparing the proposal:

1. Summarize educational relevance and legal responsibilities (IDEA, 504, ADA, FDA)
2. Gather the following information to share with administrators:
   • An estimate of the number of students with swallowing and feeding issues
   • Safety issues related to dysphagia
   • Identify and estimate expenses
3. Prepare summary of safety issues
   Educating and providing information through the process is very important.
Defining the Problem/Identifying the Solutions

5. Present the information on the Proposal Worksheet to district supervisors for approval
6. Add system-wide procedure to the district’s procedural handbook
7. Choose a team model to use district-wide
8. Secure the management requirements of the team process


You will need:

- a clear definition of dysphagia, its signs & symptoms & the effects of dysphagia *(Who and What Summary Sheet in handouts)*
- estimate of the number of students *(distribute Survey of Signs and Symptoms to estimate number of students in the district who are high risk – only do this with permission from district supervisor)*
- a plan for how your district can address dysphagia *(determine team model that works best for your district and who will administrate the swallowing and feeding team program)*
- a plan for the personnel necessary to implement a dysphagia procedure *(distribute the Training and Experience Survey to SLPs and OTs with permission from district supervisor)*
- a cost analysis for the district *(estimated cost of materials, equipment, training, and swallow studies)*

Preparing a proposal

In Summary

- Swallowing and Feeding children at in every school district in the country.
- The Supreme Court and various lower court cases have mandated that school districts meet the safe swallowing and feeding needs of students while they are attending school.
- The result is that in order to provide FAPE a district must provide health as a related service to help reduce absences due to under nutrition and dehydration; to help students to receive adequate nutrition and hydration at school in order to have the attention and stamina to access their curriculum, and to help them to be as efficient eaters as possible to eat within the designated time frame at school.
- School Food Services programs have the responsibility to adapt the school lunch to meet the needs of students who require special diets, including those with swallowing disorders.
Summary continued
• SLPs, OTs, PTs and school nurses all have language in their Code of Ethics that they have an ethical responsibility to use their skills when indicated for the health and safety of their clients.
• They ethically also have a responsibility to obtain and maintain the skills necessary to perform their job.
• There are some essentials to providing swallowing and feeding services:
  • Administrative support
  • Team approach
  • Definition of Roles and Responsibilities
  • System-approved procedure that establishes and maintains safety during mealtimes at school.

The next course which starts at 5:00 today will go through a time-tested, step-by-step procedure that utilized a team approach for establishing and maintaining safety.

The procedure and accompanying forms will be available to you, as well as other important information. I hope that you will join me!

For more information, electronic copies of the forms, and/or questions contact:
Emily M. Homer
emijhom@gmail.com
www.emilym homer.com