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Addressing Ethical Challenges Associated with Serving Children with Feeding and Swallowing Disorders in Schools

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Moderated by:
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Ethical Challenges Serving Children with Feeding/Swallowing Disorders in Schools

Lissa Power-deFur, Ph.D., CCC-SLP
Longwood University



Learning Outcomes

After this course, participants will be able to:

- Explain the ethical challenges of serving children with feeding and swallowing issues in schools.
- Identify strategies for addressing ethical challenges associated with feeding and swallowing issues in schools.
- Explain principles and rules of the ASHA Code of Ethics that may apply to ethical dilemmas associated with feeding and swallowing.

Disclosures

- Lissa has a financial relationship with ContinuEd for this presentation.
- Lissa authored a chapter on ethical and legal issues in Emily Homer's book on feeding and swallowing disorders in school.
- Lissa is not an attorney and her review of statutes and case law should not be considered legal advice.

continued

Have you experienced one of these dilemmas?

- Child was maintained on oral feeds for a period, is now too sick for a PEG and uses an NG tube. The school staff is uncomfortable with NG feeding.
- Special education team does not consider feeding and swallowing issues to have an “adverse educational impact”

continued

- The parents expect their child to eat regular school diet, yet information from MBS indicates that child does not have a safe swallowing with anything besides nectar-thick texture
- The packed lunch is limited to chips, as “that’s what he’ll eat”

continued

continued

- The parents bring a doctor's script ordering 4 hours of swallowing therapy per week.
- Paraprofessionals need to feed multiple children during 25 minute lunch period, with result that food is often "poured" down the children's throats.
 - When the issue is raised, the SLP is told not to be concerned.
- School-based SLPs do not address feeding and swallowing because of limited experience

continued

- There is generally no single "right" answer to resolve the moral and ethical angst we perceive in these situations.

continued

Prevalence

- ASHA schools survey 2016
 - 10.5 % of school-based SLPS report having children with swallowing disorders (avg of 2.3 children)
 - Fairly constant since 2004
 - 9.3% - 12.3%
 - Average of 2 – 4 children

Nutrition field

- 17% children under age 18 have developmental disability requiring a food substitution/modification (Castillo et al, 2010)
- 25 – 35% of normally developing children and up to 80% of children with neurodevelopmental disabilities have feeding and swallowing problems (Cerezo, et al)

continued

Why the disconnect?



- Different
 - Conditions
 - Populations
 - Sampling
 - Definitions

continued

Federal requirements

Special education

Nutrition

continued

Special ed eligibility

- Based on adverse educational affect and need for special education (specially designed instruction) and related services
- A team decision, including parents
- Must be eligible for special education to receive related services
 - Necessary to benefit from special education

Does the child need special education?

- Special education is specially designed instruction designed to meet the unique needs of a child with a disability
- Specially designed instruction is ...
 - adapting the content, methodology or delivery of instruction to address the unique needs of the child that result from the child's disability
 - ensuring access of the child to the general curriculum to meet the educational standards that apply to all children



Related Services are “... developmental, corrective, and other supportive services ... as may be required to assist a child with a disability to benefit from special education ...” (34 C.F.R. Sec. 300.34)

- Include
 - Speech-language services
 - Occupational Therapy
 - Physical Therapy
 - Psychology
 - Nursing
 - Transportation
 - School health services



What are medical services? school health services?

- Medical services: “procedures for diagnostic and evaluation purposes only” (34 CFR Sec 300.34(a))
 - Provided by “a licensed physician to determine a child’s medically related disability that results in the child’s need for special education and related services” (34 CFR Sec 300.34(c)(54))

continued

- School health services: “health services designed to enable a child with a disability to receive FAPE as described in the IEP. ... may be provided by either a qualified school nurse or other qualified person”

(34 CFR 300.34 (c)(15))

continued

How do children qualify for a related service?

1. Must be eligible for special education
2. The related service must be needed for the child to benefit from special education.

continued

continued

If the child only needs related services and **not** special education, the child is **not** a child with a disability who is eligible for special education

(34 CFR Sec 300.8(a)(2)(i)).

See also US Dept. of Education letter to ASHA (2007).

- IF the related service is not needed to benefit from special education, it is not the purview of IDEA.

continued

Who makes the decisions about a child's eligibility for special education and related services?

An interprofessional team.
Which may include school nursing and school nutrition.

continued

continued

What is the definition of speech-language impairment in special education?

- “a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects a child’s educational performance” (IDEA 34 CFR Sec 300.8 (c) (11))

continued

Does “speech-language impairment” include dysphagia?

- Original definition from 1975
 - Before dysphagia part of our scope of practice
- USDOE did not change in 2000s, but offered “we believe that the definition is sufficiently broad to include services for other health impairments, such as dysphagia” (Assistance to States, 2006).

continued

continued[®]

School Health Services vs. Medical Services

- Related services includes school health services
 - "... health services that are designed to enable a child with a disability **to receive FAPE** as described in the child's Individualized Education Program (IEP).

continued[®]

- School nurse services are services provided by a qualified school nurse.
- School health services are services that may be provided by either a qualified school nurse or other qualified person ..."
 - Like an SLP!

continued[®]

continued

What about physicians' orders?

- School nursing and school nutrition require orders
 - Medication, nutrition, diet changes
- Special Education teams must consider, but are not required to follow orders related to education

continued

Special education case law: Tatro and Garrett (US Supreme Court)

- Tatro (1984) defined “clean intermittent catheterization” as a school health service
 - Established that children with health care needs may receive services to address their day-to-day needs
- Garrett (1999) established that students with health care needs will attend school
 - And receive services to stay there and receive FAPE

continued

continued

What can we learn from SPED due process hearings?

- New Mexico (2003)
 - Provision of adequate diet is part of school health services
- New Hampshire (2004)
 - District failed to attend to student's safety in feeding, resulting in hospitalization for aspiration and pneumonia

continued

- Arkansas (2012)
 - Need for health and emergency plan
- Louisiana (2013)
 - Failure to adhere to feeding procedures (by substitute) led to child's choking

continued

School nutrition

- National Student Lunch Program includes a wellness component (Castillo 2010)
 - Including nutrition guidelines for children with dysphagia
- USDA regulations specify that diet changes must be provided (Obara, 2009)
 - With order from authorized medical provider

How can we apply this information?

- Talk with nutrition about poor nutrition/hydration on academic success to share with school teams
- Include nutrition and nursing on special education teams for these students
- Address feeding and swallowing as a school health service provided by a team (SLP, nurse, nutrition)

continued

- Consider “other health impaired” as a disability category
 - “having limited strength, vitality, or alertness ... that is due to chronic or acute health problems such as ... and adversely affects a child’s educational performance.” (34 CFR Sec. 300.8(c) (9))
 - Enables focus on health care needs that facilitate staying in school
- Services for swallowing and feeding issues are not likely to be “specially-designed instruction” but are likely to be “related services”
 - Can be speech-language pathology services OR school health services

continued

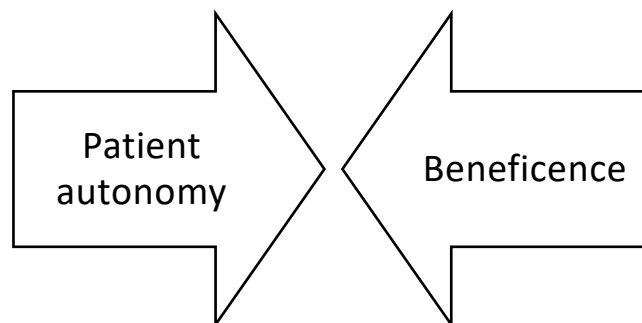
- Document school’s reasonable attempts to prevent students from foreseeable injury
- Create individualized school health plan for students with feeding and swallowing concerns
 - Include (AND practice) emergency procedures
 - Generally school nurse’s responsibility

Ethical decision-making

Purpose is to create an outcome that resolves the situation and prevents future problems.

Key: fully explain and understand the situation

Feeding and swallowing dilemmas



Ethical decision-making approach

- First – Identify the ethical issue
- Step 2: Gather information to explain the situation
- Step 3: Identify and consult resources
- Step 4: Brainstorm solutions to resolve and prevent
- Step 5: Select action

ASHA Code of Ethics 2016

Identify the ethical issue(s)

- The preservation of the highest standards of integrity and ethical principles is vital to the **responsible discharge of obligations** by audiologists, speech-language pathologists, and speech, language, and hearing scientists who serve as *clinicians, educators, mentors, researchers, supervisors, and administrators*.

<http://www.asha.org/Code-of-Ethics/>

Four Principles of Ethics

- I. responsibility to persons served professionally and to research participants, both human and animal;
- II. responsibility for one's professional competence;
- III. responsibility to the public; and
- IV. responsibility for professional relationships.

Principle I: Responsibility to the persons served

- Provide services competently
- Use every resource, including referral, to ensure high quality service is provided
- Shall not discriminate
- Shall not misrepresent credentials of persons under supervision
- Shall not delegate tasks that require unique skills
- Shall not guarantee results

continued

- Maintain and secure records
- Shall not reveal professional or personal information without authorization
- Shall accurately bill for services and products dispensed
- Seek professional assistance if affected by substance abuse, addiction, or health-related conditions, or, when appropriate, withdraw from practice
- Shall not discontinue services without reasonable notice

....

continued

What rules of ethics may be implicated with feeding and swallowing issues in schools?

continued

Principle II: Professional Competence

- Engage in only those aspects of the professions that are within the scope of practice and individual competence
- Engage in lifelong learning
- Shall not permit staff to provide services or conduct research that exceed competence ...
- Ensure any technology and instrumentation is in working order and properly calibrated
- ...

What rules of ethics may be implicated with feeding and swallowing issues in schools?

continued

Principle III: Responsibility to the Public

- Shall not misrepresent credentials, competence, education, ...
- Shall not participate in a conflict of interest
- Shall not refer based on personal interest
- Shall not misrepresent research, diagnostic information, services, results of service, products dispensed
- Shall not defraud in connection with payment, reimbursement, grants, research
- Shall adhere to professional standards in statements to the public
- ...

continued

What rules of ethics may be implicated with feeding and swallowing issues in schools?

continued

continued

Principle IV: Responsibility to the Professions

- Shall work collaboratively in the profession and with other professions
- Exercises independent judgement
- No knowingly permit anyone supervised from violating Code of Ethics
- Shall not engage in dishonesty, fraud, deceit, misrepresentation
- Shall not engage in any form of harassment
- Shall not discriminate in relationships

continued

What rules of ethics may be implicated with feeding and swallowing issues in schools?

continued

Embed yourself in the Code of Ethics



Step 2: Gather information to explain the situation i.e., “Get the story straight”

- Many ethical dilemmas stem from a lack of facts and/or failure to explain the problem
- Ask yourself ... what is the major issue?
- What information am I missing?

continued

The first to present his case seems right, until another comes forward and questions him.
Proverbs 18:17

"If you are convinced of the facts before you start investigating, even the smallest bit of evidence that seems to match your presuppositions will blind you to the full story." Ken May

continued

Step 3: Identify and consult resources



- Local special education policies and procedures
- Special education regulations
- State licensure requirements
- State education guidelines

continued

continued^{ed}

Discuss with a trusted colleague

- Former faculty
- Specialists
- Colleagues
- Supervisors
- ASHA staff
- State ed staff



continued^{ed}

Review ASHA's Ethics Resources and Practice Portal

- <http://www.asha.org/Practice/ethics/>
- <http://www.asha.org/practice-portal/>

continued^{ed}

continued

Step 4: Brainstorm a variety of courses of action

What solutions are you looking for?
Which will be most successful?
Achievable?



continued

Step 5: Act

Focus on a solution that will **resolve** the issue and **prevent** future issues

continued

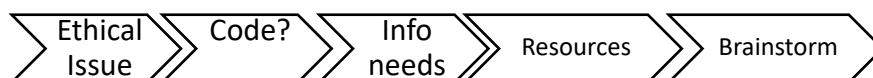
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Let's apply the
decision-making model
to resolving those
ethical challenges

continued

Case: Child whose dysphagia
progresses

- Child was maintained on oral feeds as long as possible. Now needs NG tube (too sick for PEG).
- School staff is uncomfortable with safety of NG feeding while at school.

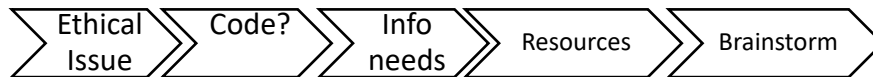


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Case: District does not deem feeding/swallowing to have an adverse educational effect

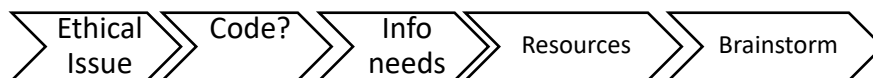
- Special education team leaders strictly view eligibility based on “adverse educational impact”



continued

Case: District directs SLP to “handle” all feeding/swallowing cases

- District encourages SLP to “take care of” these children, with no encouragement to create school-based teams.

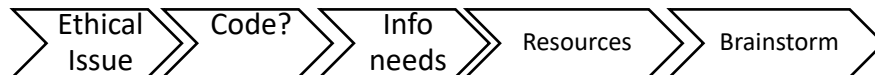


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Case: SLP is not involved with children with feeding and swallowing issues.

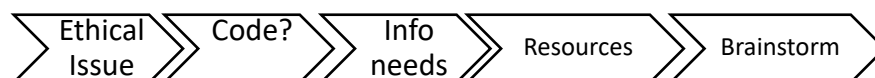
- The district has nurse (LPN) and special education paraprofessionals handle all feeding and swallowing cases.



continued

Case: Paraprofessionals feed multiple children during lunch

- Without sufficient time to feed children, the paraprofessionals virtually “pour” the food down the children’s throats.

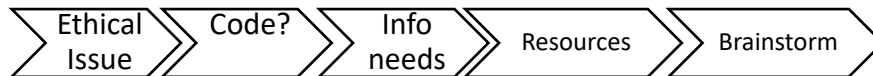


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Case: Student is isolated from peers during snacks and meals.

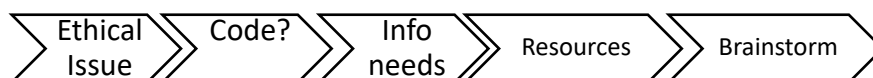
- Student is fed in separate room (e.g., the nurse's or SLP's office) or in a corner of the room.



continued

Case: Parents want the child to eat in a manner the SLP believes is unsafe

- Parents want the child to eat the school lunch or will pack a lunch with foods the child will “eat” but are unsafe.
- MBS indicates that only safe swallow is with nectar thick
- What if the parents disagree?

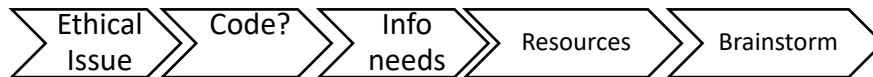


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Case: Parents want child to be fed regular diet and refuse to provide copy of MBS report

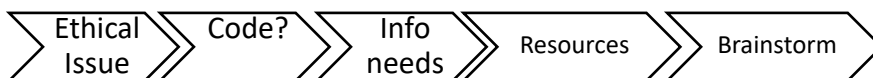
- Parents do not want their child to get special treatment and want their child to eat with their peers at lunch.
- Child had MBS within last 3 months, but parents have not provided a copy.



continued

Case: Parents provide doctor's "script" for "regular diet."

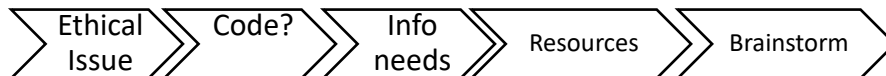
- Child has severe oral motor weaknesses, cannot chew most textures, chokes regularly during snacks and meals.



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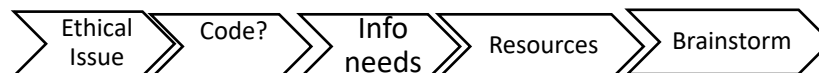
Case: No SLPs in the district have experience with feeding/swallowing.

- Although all SLPs had dysphagia coursework and experience in graduate school, they have not had experience since (3 – 10 yrs.) and no experience with children.



Case: The teacher notices that the child is having increased medical/behavioral issues during snacks/meals.

- The following are observed:
 - Coughing – spitting – gagging
 - Pulling away – moving food away – hands overhead – arching – grimacing
 - Gurgly vocalizations
 - Drooling - regurgitation



continued

Suggestions to minimize emergence of ethical dilemmas

continued

Learn more!

- Be purposeful about hearing and understanding different opinions
- Recognize the limits of your own knowledge and skills
 - Research
 - Pursue cont. education
- Regularly ask yourself “what am I missing?”

continued

Establish policies and procedures

- Create collaborative team
 - SLP, nutrition, nursing
- Gather medical records
- Create health care plan
- Develop protocols for training ...
paraprofessionals, substitutes ...
- Create and practice emergency procedures

Collaborate externally

- Develop relationships with external medical providers and SLP
- Share records (with permission)
- Communicate your observations about the child's feeding and swallowing experience at school
- Participate in MBS, if possible

Create trusting relationships

- With fellow team members
- With outside providers
- With the student and family



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Do whatever it takes to avoid
fooling yourself into thinking
that something is true that is
not, or something is not true
that is.

Neil deGrass Tyson, astrophysicist
Director, Hayden Planetarium

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