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# Approaches for resolving ethical dilemmas in pediatric audiology

Ryan W. McCreery, Ph.D.

Director of Research

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#### Ryan McCreery, PhD

Ryan McCreery, Ph.D. is the Director of Audiology and Director of the Audibility, Perception and Cognition Laboratory at Boys Town National Research Hospital in Omaha, Nebraska. In addition to leading a group of 18 clinical audiologists who provide services across the lifespan, Ryan's NIH-supported research program explores the factors that influence speech recognition in children with normal hearing and children who wear hearing aids.







#### Presenter Disclosure:

- Financial: Ryan McCreery is employed by and receives a salary from Boys Town National Research Hospital and receives research grants from NIH/NIDCD. Ryan received an honorarium for this course presentation.
- Non-financial: Ryan McCreery is a consultant for the British Columbia Early Hearing Program and a member of the Joint Committee on Infant Hearing.
- Content Disclosure: This learning event does not focus exclusively on any specific product or service.
- Sponsor Disclosure: This course is presented by Salus University in partnership with AudiologyOnline.





#### Learning Outcomes

After this course, participants will be able to:

- Identify clinical situations that may present ethical challenges in pediatric audiology.
- Explain how to apply a patient- and familycentered approach to resolving ethical dilemmas collaboratively.
- Describe evidence-based processes for supporting ethical decision making by children with hearing loss and their families.





### Ryan McCreery

- Director of Research
- Director of the Audibility, Perception, and Cognition Laboratory







#### Professional Experience Related to Ethics

- Audiologist 12 + years
- Member Nebraska State Licensure Board for Audiology and Speech-Language Pathology





# Ethics in Pediatric Audiology

- Awareness is critical
- Many are avoidable or resolvable
- No cheat codes or easy buttons







#### Ethical concepts

Autonomy

 Patients should have the ability to make informed decisions about care

Beneficenc e

- Do no harm
- Patient benefit is paramount

Justice

- Awareness of vulnerability
- Avoidance of coercion







- Parent autonomy vs. child autonomy?
- What is required for autonomous decision-making?
  - Knowledge of risks and benefits
  - Acknowledgement of what information is missing
- Avoiding "autonomy theater"
- Transparency







- Weigh risks and benefits to patients and families
- Do no harm
- Acknowledge potential personal or professional benefits
- How is benefit or harm quantified?
  - Loss of opportunity?
  - Non-financial benefits?





**Justice** 

- Understanding vulnerability
  - Limited knowledge
  - Financial status
- Avoid processes or situations that exploit variability or create coercion





#### **Ethics Scenarios**

- 1. Identify possible ethical concerns
- 2. Describe how those concerns relate to:
  - Autonomy
  - Beneficence
  - Justice
- 3. Discuss potential solutions





#### Ethical Scenarios Disclaimer

- These ethical scenarios are based on situations that have occurred in my clinical career.
- Identifying details have been removed
- Some details of the scenarios have been modified to simplify the discussion.





- Hospital-based cochlear implant program
  - Surgeons determine manufacturers for patients
  - Patients are presented with surgeon's choice



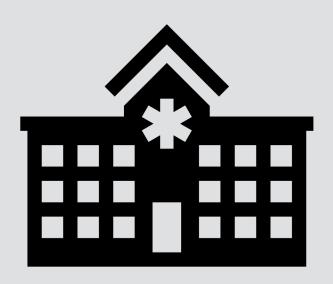
















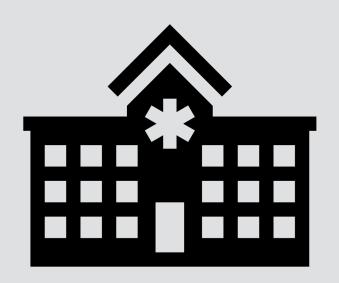
- Should patient or family have a role in decisions about device?
- What are the potential benefits to the surgeon for choosing the device?
- What vulnerabilities exist for a patient or family who does not make a decision about a device?







- How can we balance surgeon needs and family needs?
- Should families be aware of potential benefits to surgeons or hospitals?
- What is the best approach for minimizing vulnerabilities?









- Parent vs. child autonomy
  - Age at which children can exhibit autonomy?
    - Developmental or chronological
  - How to manage conflicts in ethical decision-making





- Infant with a mild-tomoderate bilateral hearing loss
- Parents are hearing and use spoken language
- Parents want to enroll child in a sign-languageonly early intervention program







- What challenges exist related to the parent's autonomy in this decision process?
- What are the potential benefits and risks to the child?







- What are our own biases that might influence how we manage this recommendation?
- How can we manage or acknowledge those biases?







### Acceptance of Ambiguity

- Do we have clinical or scientific evidence that to support a parent decision?
  - How does that evidence apply to the current situation?
- Applying research evidence to real situations can lead to ambiguity





# Expanding Evidence-based Practice

Research evidence

- Clinical data and experience
- Ethical decisionmaking concepts







- Infant with bilateral profound hearing loss by ABR
- Parents are hearing and use spoken language
- Parents want to defer the cochlear implant decision until the child can have input to the decision







- How does this scenario challenge the concept of autonomy?
  - Parent
  - Child







- What are the risks to beneficence?
  - Child?
  - Adult?







 What are some solutions to help increase autonomy and maximize beneficence?







#### Chronological age?

Developmental age?

At what age can we demonstrate autonomy?

Examples of ageappropriate autonomy

- Management of amplification
- Self-advocacy





- Infant diagnosed with moderate to severe hearing loss
- Parents are hearing and use spoken language
- Parents fail to attend appointments consistently
- Amplification is often not worn
- Early intervention reports lack of participation







- What are the risks to beneficence?
- How to balance beneficence and autonomy?
- Is this considered neglect?
- In your area, would you be required to report this under mandatory reporting requirements?



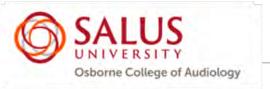




- Do parents have the autonomy to do nothing?
- How can we support the family who does not want to be supported?







# When an ethical issue becomes a legal issue

- Legal issues often manifest initially as ethical dilemmas
- Having a framework for ethical decision-making can provide legal protection
- Reasonable person standard
  - What would a reasonable person do or think in this situation?





## Legal Issues

Seek qualified legal advice

Document conversations in writing

Have a witness for interactions

This is not legal advice





- You are serving a family of a child with bilateral hearing loss and hearing aids for several years.
- The family has had considerable financial challenges.
- The family asks for a personal loan to help with expenses to avoid being evicted from their home







- What are the issues related to justice in this situation?
- What remedies might you consider to help the family?







#### Professional Boundaries

Autonomy

Influence over decision-making

Beneficenc e Protect from harm with autonomy

Justice

Creating justice through support





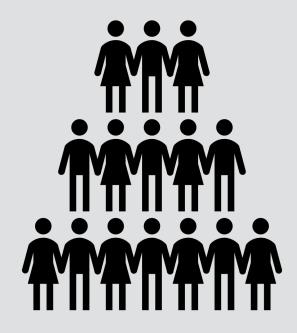
#### Boundaries challenges

- We establish relationships with families
- Often become part of their lives
- Where do we set boundaries?
  - Attending graduation event or wedding?
  - Giving and receiving gifts
  - Socializing with families





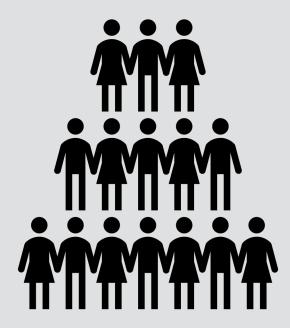
 Family of a child with hearing loss expresses noncompliance with hearing aids due to religious reasons.







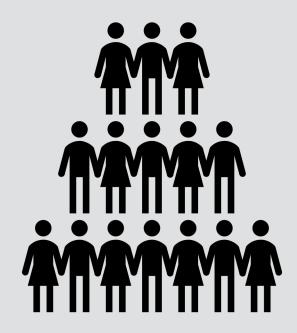
- What are the threats to autonomy?
- What are the threats to beneficence?
- What issues are related to justice?







- What options are available for treatment that are compatible with the religious views?
- Maintaining contact vs. alienation







#### Key Ethical concepts

Autonomy

 Patients should have the ability to make informed decisions about care

Beneficence

- Do no harm
- Patient benefit is paramount

**Justice** 

- Awareness of vulnerability
- Avoidance of coercion





#### Key Take-Home Messages

- Ethical dilemmas occur in all areas of our practice
- Using an ethical framework to support decisionmaking
  - Evidence-based practice
  - Ethical principles





#### **Ethics Resources**

- American Academy of Audiology Code of Ethics
  - https://www.audiology.org/sites/default/files/publications/resources/201910-CodeOfEthicsOf-AAA.pdf
- American Speech-Language Hearing Association
  - https://www.asha.org/uploadedFiles/ET2016-00342.pdf
- State-level resources
- Practicing communication ethics, Thompkins





#### Questions or comments?

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