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Ethical Considerations When Working with Those who Stutter

Lisa R. LaSalle, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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Ethical considerations when working with those who stutter

Lisa LaSalle, Ph.D., CCC-SLP

Professor and Chair

Communication Sciences & Disorders

University of Redlands

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Learning Outcomes

After this course, participants will be able to:

- Describe the key components of ASHA's ethical standards related to stuttering.

- Discuss how stigma, advocacy, caseload management, and our competencies matter in various settings.

- Describe ways to solve ethical dilemma cases involving people of various ages who stutter.

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Outline

- Introduction; ASHA Ethical principles/code (:10)

- Stuttering: Stigma and (self-) advocacy (:20)

- Caseload management; Professional competencies in working with people who stutter (:30)

- Structure of various settings: Assessment of stuttering (e.g., Screening) (:45)

- Structure of various settings: Treatment of stuttering (e.g., IEPs) (:60)

- Cases involving children who stutter (:70)

- Cases involving teens and adults who stutter (:80)

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Introduction:
ASHA Ethical principles
ASHA Code of Ethics (2016)

(:10)

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CONTINUED

Introduction

- Morals: Self-guidance about right v. wrong
- Ethics: Rules (not laws) of an external source (e.g., workplaces)
- There are a number of different workplaces we encounter as SLPs and Audiologists:
  - Health care settings (hospitals, SNFs)
  - Schools
  - Private practices
  - Clients' homes/public places for generalization

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Introduction continued:

- What's a motto? (Hakuna matata or…? ☺)
  - A phrase best representing ideals or beliefs
  - See vision, missions, etc./"elevator pitch"
  - Do morals fit ethics?
- Why this topic of ethics and stuttering?
  - ASHA 2020 CEU Ethics requirement
  - When/where/how/why do helping professionals "treat" stuttering?
    - Which helping professionals?
    - Is it "help" to PWS?

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Caveat:

- I chose not to address research conduct, types of research-based ethical considerations, as I renew my training annually (e.g., The Belmont report)
- Suffice it to state: ASHA Code of Ethics (2016): *Principle II, Rule C – New Rule Individuals who engage in research shall comply with all institutional, state, and federal regulations that address any aspects of research, including those that involve human participants and animals.*

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ASHA's 4 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.

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Specifics of some of these principles

- Do not delegate tasks requiring unique skills:
  - Do you have the credentials to treat?
  - If you do not have the skill set/expertise, learn it or access CEU opportunity
  - If you do not have the time/$ for the learning, this is a different topic (e.g., workplace advocacy).
  - Are referrals appropriate? (e.g., counseling)
- If you discontinue services, give notice.
- Maintain and secure records.

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Kenny, Lincoln & Balandin (2010)

- Five major themes reflected participants' approaches to ethical reasoning:
  - (i) focusing on the well-being of the client
  - (ii) fulfilling professional roles/responsibilities,
  - (iii) attending to professional relationships,
  - (iv) managing resources, and
  - (v) integrating personal and professional values.

- SLPs demonstrated a range of ethical reasoning processes, for example, narrative reasoning, when managing ethical dilemmas in the workplace.

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ASHA Board of Ethics and the complaint process

- The Board only has jurisdiction to receive, deliberate, and act upon complaints filed against ASHA members or individuals who hold the Certificate of Clinical Competence (CCC).

- The person filing the complaint (the "Complainant") does NOT have to be an ASHA member;

- The Board does not accept anonymous complaints or complaints filed against an organization or employer;

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CONTINUED

ASHA Board of Ethics and the complaint process

- The Board accepts complaints filed via mail only and will not accept complaints filed via telephone, e-mail or facsimile; and

- A copy of the complaint form, a written statement of complaint, and all supporting documentation will be provided to the individual against whom the complaint is filed (the "Respondent").

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Stuttering:
Stigma and (self-) advocacy

(:20)

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What is a stigma?

A trait or attribute (e.g., stuttering) that is devalued or disapproved of by a particular social group (e.g., those who do not stutter or those not educated about stuttering)

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Why do we fear the word **stuttering**?

- Perhaps due to the stigma of stuttering.
- Stigma prevents us from communicating directly, when we would like to communicate directly
- When we write clinical reports about people who show developmental stuttering, but we never use the words "stutter" or "stuttering" in the report, we are not communicating directly.
- "Fluency disorder" is an umbrella term for different labels: Developmental stuttering, cluttering, psychogenic / late onset stuttering etc.
- A person who stutters may identify as a "stutterer."

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Stigma-related studies:
For example, stigma among teens who stutter (TWS):

- Blood, Blood, Tellis & Gabel (2003) found:
  - Stigmatizing conditions for a majority (65%) of TWS did not include stuttering.
  - However, 60% "rarely" or "never" discussed their own stuttering.
  - Younger TWS perceived stuttering more negatively and in more stigmatizing ways than older TWS.

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Unfortunately, stigma can leads to:

"self-stigma," or the internalization of negative public beliefs and reactions

(e.g., Boyle, 2013; Glover, St. Louis & Weidner, 2019)

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CONTINU**ED**

Our ethical obligation is to decrease stigma and/or the impact of stigma.

- Advocate on behalf of people who stutter:
  - May is Better Hearing & Speech Month
    - Second week in May is National Stuttering Awareness Week
      https://www.stutteringhelp.org/NSAW
  - International stuttering awareness day (Oct 22) ISAD online conference
  - Workshops, consultations, "in-services," etc.
- Require graduate students to pseudo stutter (e.g., Hughes, 2010; Hughes, Palasik & Ellis, 2015)

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Our ethical obligation is to decrease stigma and/or the impact of stigma.

- Invite those who stutter to "meet" others who stutter, maybe podcasts (www.stuttertalk.com), or:
  - Group sessions led by an SLP (support groups)
  - Group sessions not including an SLP (self-help groups), e.g, National Stuttering Association
- Use and monitor progress via the *Self-Stigma of Stuttering Scale (4S)* (Boyle, 2013)
- …Just to name a few

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Caseload management and our professional competencies in working with people who stutter

(:30)

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Caseload management

- SLPs in the Kenny et al. (2010) study reported two basic strategies:
  - Distribute services equally across caseload (e.g., each client gets a predetermined number of sessions, waitlists 1- to 2-yr)
  - Weighing treatment priorities based on who would benefit the most or who was at higher risk if/when services are withheld.

- Children whose stuttering does not resolve in ~ a year are at higher risk of stuttering chronicity

- "I'm so glad you are here! Will you be taking over all of our stuttering students?" Reeves (2012)

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CONTINUED

Our potential professional competencies in truly helping people who stutter depend upon and inform *both* our ethics and our scope of practice.

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Related to stuttering, ASHA Scope of practice (2016) reflects advances in:

- Collaboration → Interprofessional practice
  - Teachers, Psychologists/Psychiatrists, etc.
- Counseling:
  - "empower the individual and family to make informed decisions related to communication…
  - educate the individual, family, and related community members about communication…
  - provide support and/or peer-to-peer groups for individuals with disorders and their families
  - provide individuals and families with skills that enable them to become self-advocates"

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Counseling continued:

- "discuss, evaluate, and address negative emotions and thoughts related to …
- refer individuals with disorders to other professionals when counseling needs fall outside of those related to (a) communication and (b) feeding and swallowing."

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Structure of various settings:
Assessment of stuttering
(e.g., Screening)

(:45)

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Related to stuttering, ASHA Scope of practice (2016) reflects advances in:

- Prevention and wellness:
  - Children who have been stuttering for more than a year (considering multiple risk factors)

- Screening:
  - 100-300 words of connected speech is enough for screening → evaluation:
    - Is the child repeating or prolonging 3 or more times?
    - Is there visible/audible physical tension/loss of control? Parental concern?

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CONTINUED

Related to stuttering, ASHA Scope of practice (2016) reflects advances in:

- Assessment:
  - Not using standardized tests when our client who stutters, who perhaps has another communication disorder/difference, is not represented by the norms that are included in the test manual (e.g., English Language Learners)

- **Treatment:** Is there Evidence Bases for the Tx?

- Modalities, technology, and instrumentation; and

- Population and systems…

- *But also…*

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Related to stuttering, ASHA Scope of practice (2016) reflects advances in:

- Advocacy and outreach:
  - The art of planning "in-services" to teach others the basics about stuttering
  - Stuttering incidence is 5/100 and prevalence is 1/100: Check the ratio in your setting
  - Stuttering can be invisible/silent/covert. Who has recently stopped contributing/raising hand? Initiating new ideas? Etc.
  - Other ways that PWS might be "falling through the cracks" of (appropriate) service delivery?

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ASHA Scope of practice

- **Supervision:** Competency of supervisor/supervisee, for example, in attitude assessment of teens who stutter; Stuttering Modification as well as Fluency Shaping approaches; in Demands Capacity Model-based treatment as well as Lidcombe approach.

- **Education:** "Embarrassment of riches of stuttering CEU events in some areas; webinars, SFA, stuttertalk.com podcasts etc.

- **Research:** Answering the call for the need; Planning your own research projects related to stuttering

- **Administration/leadership:** What does the whole school or hospital staff need to know about how to interact with those who stutter?

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Diagnosogenic Theory

- The origin of stuttering is diagnosis of normally fluent speech as stuttering (Johnson & Associates, 1959).This theory complicates the ethics of stuttering:
  - The 1939 Mary Tudor thesis ("monster study")
  - "Type A"/Highly-anxious/perfectionistic mothers (not fathers, per se) brought about stuttering

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Diagnosogenic Theory (continued)

- It was one of the first, but only one of many other important theories, decades later: Anticipatory Struggle Hypothesis, Demands-Capacity Model, Covert Repair Hypothesis, EXPLAN, Learning theory, Multifactorial Dynamic Pathways Theory, to name a few

- How do each of these theories inform the way we screen or assess a person who stutters, especially, or perhaps ONLY when the PWS is reaching out for help?

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Ethics according to Fletcher, Miller & Spencer (1997, as cited in Rao & Martin, 2004):

- "Beneficence, doing good for others;
- Non-maleficence, or avoiding doing bad for others;
- Respect for patient autonomy, which protects and defends the informed choices of capable patients;
- Justice, fairness of access to health care and to issues of rationing at the bedside (p.12)."

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Rao & Martin's (2004) Ethics continued:

- What about patient privacy/confidentiality?
- Honest communication about Dx/Tx/prognosis?
  - E.g., "the stuttering is all in your head" when only a short sample of speech has been elicited from an adult who stutters and it's a covert type of stuttering
- Determine who makes what decisions
- Conduct an ethically valid process of informed consent with the patient, as needed

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Structure of various settings: **Treatment** of stuttering (e.g., IEPs)

(:60)

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Issues in ethics statements relating to supervision

- Audiology Assistants (2014)
- Clinical Services Provided by Audiology and Speech-Language Pathology Students (2013)
- Responsibilities of Individuals Who Mentor Clinical Fellows in Speech-Language Pathology (2013)
- Speech-Language Pathology Assistants (2014)
- Supervision of Student Clinicians (2010) http://www.asha.org/practice/ethics/ethics_issues_index/

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The *only* support for defending the assessment/treatment approach we are using:

- Rationale
- Rationale based on the evidence base to the Tx
- Rationale, EBP-based, delivered empathetically

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In other words, what is the good, evidence-based rationale for the Tx that the person who stutters is currently receiving?

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Please do not defend the IEP goals for a child who stutters because "they were handed down to you by the last SLP."

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Client Abandonment

- A professional who abandons their clients without making effective efforts to provide for the clients' continuing care violates Principle I of the Code, which states that the professional must "honor their responsibility to hold paramount the welfare of persons they serve professionally."

- Give sufficient notice

- Protect client records

- Monitor competencies of the new clinician

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Treatment

- When progress plateaus or stuttering severity worsens, it is our ethical obligation to check:
  - Does the literature support the current treatment program?
  - Are there available learning opportunities/CEUs related to the child's case?
  - What are parents'/child's/adult's informed wishes for stuttering/fluency?

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Evidence base to stuttering Tx

- Disordered breathing does not cause stuttering, at all ages of onset
- Stuttering perturbs breathing
  - Does breathing underlie phonatory, fluency facilitating changes? Of course!
  - Could deep breathing as part of a meditation practice be helpful for some individuals who stutter? Of course!
  - Should the goals for treating stuttering be exclusively about breathing? No!

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Cases involving **children** who stutter

Cases built around the idea that truth is stranger than fiction, so there are bits of truth and fiction in each case for the sake of confidentiality and for embedding the ethical learning. "Many areas of gray."

(:70)

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Case of "Fluency group"

- Three fourth graders who stutter are grouped for a 20-min session 2x a week in your school. You are "SLP I" and you and "SLP II" divide up your caseload.

- "SLP II" tells you that she is delighted that she was just recently able to group these 3 students who stutter together. She learned from her graduate training years ago that "you're not alone" is a good philosophy related to stuttering. She admits to you that this is all she really knows or recalls about stuttering treatment.

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Case of "Fluency group"

- "SLP II" is contacted by some local university students, who, based on being in an undergraduate fluency class, want to observe the Fluency group for a class assignment.

- Both of you have been swamped with a high caseload and a lot of paperwork.

- One day, you observe her telling one of the undergraduate students observing "I need to work on some paperwork. You'll be great at this group! Take over from here. Please come back next week with a detailed lesson plan. I'll be down the hall if you need me."

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CONTINUED

- *What else do you want to know about the case?*
- *What are the ethical considerations and/or dilemma?*
- *What would you do?*

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CONTINUED

Cases of "Katelyn" and "Carter"

- Referral: Graduate student clinician family member (K)
- Referral from both a mom who stutters and a dad who stutter (C)
- Long commute (K)
- Parents work a considerable amount and have a considerable commute (C)
- Telepractice not yet established (K & C)

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- *What else do you want to know about the case?*
- *What are the ethical considerations and/or dilemma?*
- *What would you do?*

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CONTINUED

Cases involving
teens and adults
who stutter

(:80)
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CONTINUED

Case of Ellen

- Ellen has Mosaic Down Syndrome.
- She is a sophomore in a high school in which you work as an SLP.
- She stutters severely with 11-15 sec duration blocks.
- Ellen has learned, and sometimes uses, fluency shaping and stuttering modification techniques.
- You are currently working with Ellen on a consultant basis.

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CONTINUED

Case of Ellen

- One of Ellen's teachers pulls you aside and says "I think Ellen would benefit from using the Proloquo2Go like that other student you had last year."

- The student last year she is referring to was a student with autism who was non-verbal.

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- *What else do you want to know about the case?*
- *What are the ethical considerations and/or dilemma?*
- *What would you do?*

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CONTINU ED

Case of Miguel

- Miguel is an adult who stutters and a Spanish-English bilingual speaker.

- He is in a Speech-Language Pathology Master's degree/graduate program.

- You are one of two of his supervisors; your colleague, Mary is the other.

- Miguel asks to meet with the two of you. At that appointment, he tells the two of you, "I stutter. You will hear me stutter from time to time. My stuttering is one reason I want to be part of this profession…"

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CONTINU ED

Case of Miguel

- "…I don't let my stuttering hold me back. You can ask me any questions you want about my stuttering."

- Miguel mentions Nina G, a comedian who stutter, whom he really likes, and hands over an article about her work (Gerlach, 2019).

- Mary tells him "Ok, well thanks, but you need to seek out speech-language pathology services for your stuttering, and then show proof to us that you have done so".

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- *What else do you want to know about the case?*
- *What are the ethical considerations and/or dilemma?*
- *What would you do?*

57

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Questions…
And possibly some answers

(:90)

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