Ethics in Stuttering Treatment in the Schools: Issues and Intersections

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ABSTRACT

When the challenges of providing speech-language pathology services in school settings intersect with the complexities of meeting the unique needs of students who stutter, clinicians may encounter a variety of ethical issues. This article explores some of the ethical challenges of treating stuttering in school settings by discussing three clinical scenarios. Seedhouse's Ethics Grid is provided as a scaffold to support the critical analysis of school-based stuttering treatment issues. Factors examined include creating and respecting autonomy, serving student needs, doing good and minimizing risks, and telling the truth and keeping promises. In addition, clinical outcomes are considered in terms of their impact on students and family members, clinicians, students with communication disorders other than stuttering, and school personnel. Finally, some of the practical concerns when treating stuttering in school settings are discussed, including the law, codes of practice, wishes of others, as well as the effectiveness and efficiency of actions.

KEYWORDS: Ethics, stuttering treatment, schools

Learning Outcomes: As a result of reading this article, the reader will be able to (1) identify at least three examples of ethical dilemmas encountered by school-based speech-language pathologists while treating stuttering; (2) describe at least two ways school-based clinicians may create and respect student autonomy when treating stuttering; (3) explain two specific ethical duties and motives related to treating stuttering in school settings; (4) identify at least four individuals and/or groups that must be considered when making ethical decisions about stuttering treatment priorities in school settings; and (5) describe at least three examples of external factors that must be considered when making ethical clinical decisions in the treatment of stuttering in school settings.

Schools are the primary work setting for speech-language pathologists (SLPs) in the United States, with over 50% of American Speech-Language-Hearing Association (ASHA) members reporting that they provide services in school sites.[1] As school-based SLPs work to balance the demands of their positions, clinical decision making is often complex, particularly when these decisions are mediated by ethical considerations. The challenges of ethical decision making in school settings may be accentuated when addressing the complexities of stuttering assessment and treatment. Nearly 70% of school-based SLPs report that they provide services to students who stutter, with a mean number of two students served per month.[2] When the demands of school-based services intersect with the complexities of meeting the unique needs of these students, the result is a perfect storm for ethical dilemmas.

To support SLPs in reaching ethical decisions that are grounded in thoughtful rationales, several ethical guides are available.[3–6] Most of these processes incorporate consideration of the four key ethical principles described by Beauchamp and Childress[7]: respect for autonomy, nonmaleficence, beneficence, and justice. Seedhouse's[8] Ethics Grid provides a nonsequential framework that acknowledges the importance of these principles while identifying a wide range of issues and consequences in addressing ethical dilemmas. These considerations extend beyond the law, which represents a minimum standard[9] and may not necessarily correspond with moral reasoning.[8] Although thinking and acting in an ethical manner is supported by the principles and rules of ASHA's Code of Ethics,[10] additional guidance may be needed to reach specific ethical clinical decisions. Seedhouse's Ethics Grid[8] provides a practical and accessible reminder of several factors that may impact our choices and actions in identifying, assessing, enrolling, treating, and dismissing students who stutter.

In brief, the Ethics Grid[8] consists of four layers. Central to the grid, and found in the first layer, are the fundamental principles of creating and respecting student/family autonomy. Layer 2 addresses SLPs' duties and motives in the services they provide. The third layer encourages clinicians to understand the consequences of their decisions and clarify their priorities. Finally, external considerations are explored in Layer 4 and assist SLPs in identifying the realities of providing stuttering services in school settings. These layers, related elements, and examples of issues associated with stuttering intervention in school settings are presented in Table 1. In this article, we will apply this Ethics Grid to three clinical scenarios that present challenging ethical issues for school-based SLPs. Keeping in mind that making ethical decisions is rarely a black-and-white process,[3] it is hoped that this application will provide a scaffold for broadening SLPs' perspectives as they tackle difficult issues in difficult times, as well as when they complete their daily activities and clinical decision making in stuttering treatment.

SCENARIO 1

Michael, an itinerant SLP for two middle schools and a high school, receives a call from a mother of a gifted and talented student who has recently moved to Michael's school from another in the same district. The mother reports that her son, Charlie (chronological age (CA) = 11), stutters and seems to be talking less at home; however, he did not qualify for services in his previous school. She wants him in therapy and asks Michael, "Will he qualify at your school? What treatment do you use? Does it work?" Michael informs the mother that if Charlie did not qualify at the previous school, he probably would not be eligible for services at this school. Michael does, however, let the mother know that he uses the "Bumps Today–Smooth Speech Tomorrow" program and has seen good results. Michael has Charlie's mother sign an assessment plan and initiates Charlie's evaluation. However, Michael is conflicted because his caseload is quite full and Charlie really does not want to receive services. Michael considers enrolling Charlie so he can get started in treatment and has the SLP assistant implement the "Bumps Today-Smooth Speech Tomorrow" program.

Table 1   Ethics Grid: Ethical Issues in the Treatment of Stuttering in School Settings

Layer 1: Core Principles

Create autonomy
- Educate students/families about treatment options/outcomes (e.g., costs/benefits)
- Communicate in a nonpaternalistic manner, remaining sensitive to potential power differentials
- Provide best available evidence, supporting different approaches in different treatment contexts (e.g., individual versus group)

Respect autonomy
- Jointly determine therapy decisions
- Be prepared to accept and resolve differences in desires
- Incorporate opportunities to revisit decisions with students/families

Respect persons equally
- Make decisions that are in the best interest of individual students
- Understand and respect differences across ages, cultural groups, and stuttering profiles

Serve needs first
- Incorporate differential assessment and treatment for each student
- Understand needs in the context of academic and nonacademic environments

Layer 2: Duties and Motives

Do the most good
- Consider if the benefits of treatment outweigh the costs

Tell the truth
- Be truthful about what you know and do not know about different treatment approaches
- Recognize that truth may be compromised in the omission of information as well as in misinformation
- Provide rationales for your recommendations based on facts and ethical deliberations
- Understand that by agreeing to treat, you are conveying that you are qualified to treat

Keep promises
- Consider the direct or indirect ''promises'' made on the treatment plan (e.g., required student efforts, treatment outcomes, length of time in treatment, long-term posttreatment outcomes, and relapses)
- Understand that ''broken'' promises will impact current *and* future clinical relationships

Minimize harm
- Consider the impact of intervention in terms of the student's communication, self-image, relapse, and perception of treatment

Layer 3: Consequences and Priorities

Most beneficial outcome for the individual
- Assess your current competency in stuttering assessment/treatment
- Identify areas of needed continuing education and commit to obtaining training
- Be realistic in your self-evaluation and make referrals as needed

Most beneficial outcome for the SLP
- Understand the impact of decisions on your other responsibilities

Most beneficial outcome for a particular group
- Consider if your decision is fair and just for *all* groups of students
- Consider if your decision will set a precedence that could impact future services for students who stutter

Most beneficial outcome for society
- Reflect on how decisions will impact the student's communication, quality of life, and contributions as a member of society

Table 1 (*Continued*)

Layer 4: External Considerations	
Wishes of others	• Consider how decisions will impact other individuals (e.g., teachers, administrators, other SLPs, family members, peers)
The risk	• Identify how your actions may put the student at risk (e.g., disruption of academic and/or other activities, negative peer reactions) or put others at risk (e.g., less time for other students, disruption of classroom activities, increased demands on teachers) • Consider how actions may impact the student's or family's perceptions of stuttering and treatment
The law	• Understand how IDEA 2004 relates to stuttering admission, treatment, and dismissal • Know state and local statutes as they relate to services for students who stutter, including the use of SLP aids in supporting services
Codes of practice	• Ensure that decisions are consistent with ASHA's Code of Ethics and school district policies • Be certain that decisions are in alignment with ASHA's Scope of Practice and, more specifically, within your personal scope of practice
Resources available	• Consider fiscal and support personnel resources • Understand responsibilities associated with delegation and supervision of SLP assistants • Investigate alternative scheduling and service delivery models • Enhance your knowledge and skills through continuing education and specialty recognition in fluency disorders
Effectiveness and efficiency of action; disputed evidence/facts; the degree of certainty on which action is taken	• Identify evidence supporting long term effects of different approaches and service delivery models (e.g., group versus individual, intensive versus nonintensive) • Evaluate the strength of the evidence for supporting your decision (e.g., systematic reviews of stuttering treatment, empirical treatment efficacy studies) • Enlist others' support for your decision • Develop your personal database by tracking treatment outcomes, examining the effects of different approaches delivered within different contexts • Collaborate with others when making decisions (e.g., through personal communications, listservs) • Partner with a fluency expert

ASHA, American Speech-Language-Hearing Association; SLP, speech-language pathologist; IDEA, Individuals with Disabilities Education Improvement Act of 2004.
Adaptation of Seedhouse's[8] Ethics Grid.

Determining Student Needs and Eligibility

Michael recognizes the ethical importance of a thorough assessment to determine Charlie's needs (Layer 1). He knows that he is responsible, both ethically and legally, for understanding local, state, and federal law to make sound clinical decisions. Michael knows that, according to the Individuals with Disabilities Education Improvement Act (IDEA 2004),[11]

Charlie may qualify for services not based solely on academic achievement, classroom performance, and stuttering rates but because of the impact of his communication difficulties on extracurricular and nonacademic settings (e.g., recreational activities, lunch room, etc.).[11] Michael has reviewed helpful resources, including Lisa Scott's[12] discussion of stuttering treatment eligibility based on IDEA 2004 regulations and eligibility guidelines used in other states.[13,14] From this review, Michael understands that he will need to use a variety of evaluation tools and strategies to obtain relevant information about the different aspects of stuttering that are unique to Charlie (Layer 1), such as the functional (e.g., response to bullying, confidence to communicate when, where, how, and with whom he wants), developmental (e.g., mother's information about how Charlie's speech has changed and is now affecting his communication), and academic (e.g., curriculum benchmarks related to oral language).[12]

Treatment Approaches and Delegation

If, at the end of this assessment process, Michael finds evidence of functional limitations (e.g., a decrease in Charlie's frequency of initiating conversations) and that these limitations are of educational relevance to Charlie's stuttering (e.g., a reduced "level field" with his peers due to lack of classroom participation), he may conclude that Charlie would benefit from, and is eligible for, treatment. Michael realizes that legally, if a student qualifies and requires services, he must identify and enroll the student regardless of the size of his current caseload; such decisions support the clinician's respect for and efforts to meet the needs of all students (Layer 1; Code of Ethics, Principle I, Rules B, C).[10]

Michael also recognizes that the treatment approach he uses with Charlie should demonstrate effectiveness and efficiency of action, address disputed evidence and facts, and be undertaken with a degree of certainty based on the available evidence (Layer 4).[8] Review of evidence to support treatment decisions has been particularly difficult in the area of school-aged stuttering where there are limited studies.[15,16] Michael should consider his and others' experiences that support different procedures

and service delivery models. He also should consider what he knows about how stuttering develops in children and adults as well as common pathways related to shifts in behaviors, feelings, and thoughts. In hindsight, Michael may recognize that his comments to Charlie's mother about his use of one specific program may have been inappropriate, given that he had not yet determined Charlie's needs. He may also wish to reconsider the message delivered to the mother by the title of the specific program he referenced (i.e., "Bumps Today–Smooth Speech Tomorrow") and question if it borders on the unethical practice of promising outcomes (ASHA Code of Ethics, Principle I, Rule J).[10]

Michael should rethink his idea of assigning Charlie to an SLP assistant, particularly because Michael has concerns that Charlie may have a social-emotional component to his stuttering. Michael should carefully review guidelines regarding the use of assistants[17,18] and be cautious about incorporating their support in Charlie's services (Code of Ethics, Principle I, Rule E).[10] Nevertheless, Michael also needs to consider that adding Charlie to his caseload may have consequences for the other students Michael serves, Charlie's teachers, and his district (see Layer 3). Serving Charlie will increase Michael's paperwork, require additional planning, and, more than likely, necessitate multiple meetings with several teachers. Michael may need to explore alternate models of service delivery that have been examined when providing treatment for youth with communication disorders other than stuttering.[19,20] Such options may include consideration of the format of treatment (e.g., group versus individual), the dosage (e.g., frequency, duration), and the treatment settings (e.g., pullout versus classroom settings). In addition, with Michael's advocacy, the district may be willing to share clinicians with expertise in stuttering.

Student and Parent Collaborations in Decision Making

Michael's decisions about treatment options for Charlie will be guided by his clinical knowledge and the foundations of the discipline. However, the requirements of the Individualized Education Program (IEP) process must be followed

(Layer 4). These legal requirements are grounded, for the most part, in the principle that services are provided by trained professionals with clinical expertise. Michael must work to create and respect Charlie's and his mother's autonomy when making clinical decisions about both enrollment and treatment procedures (Layer 1). Zebrowski[21] and Manning[22] have discussed the significance of the therapeutic alliance in stuttering treatment, suggesting that effective stuttering treatment outcomes may be mediated by the relationship between the clinician and the client.

Further, Michael must be truthful and propose plans that will allow him to "keep promises" (Layers 2 and 3). To enhance autonomy, relationships, and therapeutic alliances, Michael will need to jointly explore with Charlie and his mother, during the IEP process, possible treatment options (Layer 1). However, students and families cannot express free wishes unless they understand the situation (e.g., the assessment outcomes, service delivery options, treatment approaches) and the possibilities available to them.[8] The differences of opinion between Charlie and his mother require the attendance/participation of both during the IEP decision-making process. This collaboration may lead to specific goals to address Charlie's needs and may help compensate for Charlie's lack of autonomy in the enrollment decision.

SCENARIO 2

Joseph, a Spanish-English bilingual 6-year-old, is referred to Susan, a monolingual, English-speaking SLP, by his classroom teacher (who is also monolingual and speaks English) and the school's Instructional Support Team (IST) due to concerns about possible stuttering. When Susan receives the referral and realizes Joseph is bilingual, she immediately requests that he be transferred to one of the bilingual SLPs who works in her district. Her request for transfer is denied as the caseloads of those bilingual SLPs are currently beyond capacity. Susan then attempts to contact Joseph's parents to determine if they share his teacher's concerns regarding his fluency. The referral documentation and Joseph's

teacher indicate that, although they were invited, the parents never came to the IST meetings. Susan wonders if she should just drop the case because of lack of response.

Determining Initial Course of Action

Although she does not yet have a signed parent consent, Susan feels it is important to respect the teacher's concern regarding Joseph's speech fluency (Layer 4). Susan decides to contact her Program Manager who reminds Susan that parents have rights to deny assessment and enrollment in special education, particularly on an initial assessment. However, the Program Manager encourages Susan to continue to attempt to contact the parent, perhaps with the help of an interpreter, a bilingual administrative assistant, or someone else who speaks the parents' primary language. After a few attempts, Susan and the interpreter make contact with the parent, explain the process, and secure a signed assessment plan.

Risk for Misdiagnosis

In her first meeting with Joseph, he does not talk very much, but does exhibit nonfluent speech. However, Susan realizes that normative data regarding the type and frequency of disfluencies that are characteristic of bilingual children who stutter do not yet exist (Layers 1 and 4). Furthermore, Susan learns that although there are data that suggest stuttering may occur more frequently in bilinguals than monolinguals,[23,24] recent findings indicate that these data may be compromised (Byrd C, Bedore L, Ramos D, personal communication, 2011). Susan learns that bilinguals who do not stutter produce mazes at high rates[25] and that repetitions of sounds and syllables, a standard type of stuttering-like disfluency, have been reported as the most common mazelike behaviors produced by bilingual Spanish-English children.[25] Thus, Susan realizes that Joseph, simply as a result of being bilingual, may be at unique risk for misdiagnosis of stuttering (Layers 2 and 4).

Implementation of Best Practice

Susan learns that it is generally accepted that to diagnose a true stuttering problem, a bilingual

individual must exhibit stuttering-like behavior in both languages[26–30](Layers 1–4). For this reason, Susan will need to collect an English and a Spanish sample from Joseph. Susan also recognizes that although she should be able to accurately identify stuttering in Spanish, a language she does not speak,[28] she still needs to include a bilingual assistant or interpreter.[31] In addition to these structured analyses, Susan and the assistant observe Joseph in the classroom and on the playground to see if there are different types of speech patterns that occur in diverse locations (Layer 1). Susan also asks Joseph's teacher to transcribe the instances of stuttering that the teacher has found to be of concern so that she can better understand what types of disfluencies prompted the teacher to refer Joseph for a speech evaluation (Layer 1).

When reviewing all collected data, Susan will note if Joseph predominantly produces revisions, interjections, and/or repetitions of syllables (with more syllable repetitions occurring in Spanish than English). She will also listen for any atypical rate or rhythm or production of secondary behaviors during these moments of disfluency. Based on these observations, she may tentatively conclude that Joseph does not appear to stutter and that the types of disfluencies he produces in both language samples are characteristic of mazes that have been demonstrated in the output of other typically developing nonstutterers[25] (Layers 2, 3, and 4).

Respecting Parent Autonomy

Susan will need to contact the family to review the data she has collected and to determine if the behaviors she observed at school are consistent with his behaviors at home. It is possible that these conversations will reveal no parental concern regarding fluency, as empirical studies of bilingual children who do not stutter have suggested that they produce higher rates of disfluencies than monolingual English-speaking children[25]; as such, it seems reasonable to assume that the parental threshold for concern for disfluent speech may differ (Layers 1 and 2). Whether or not the parents express concern about Joseph's disfluencies, their participation

will again be sought during the postassessment IEP meeting.

SCENARIO 3

Marie has been treating Patrick's (CA = 16) stuttering for the past 3 years. In order to meet Patrick's needs, Marie has reviewed her texts on stuttering, attended a number of conferences addressing the treatment of stuttering, and participated in a webinar on stuttering and concomitant problems. Since she first saw Patrick, Marie has seen very little progress in meeting the therapy goals, which focus on using easy onsets in a variety of speaking situations, and she has observed little generalization of speech modifications to situations outside of their therapy sessions. In addition, Patrick is presenting with difficulties in socializing with his peers. He has made comments about how he has few friends and is not going to events that he attended previously. Marie is concerned about the effectiveness of her treatment and has no further ideas about how to help Patrick. She believes she has done all she can and that Patrick would benefit from more intensive treatment from someone who is more knowledgeable about stuttering. After explaining this situation to her Special Education Director, she is told that this referral is inappropriate and should not be made.

A Free Appropriate Public Education

Marie is most likely conflicted, as she is compelled by the ASHA Code of Ethics[10] to, if necessary, refer to a qualified provider (Principle I, Rule B), but at the same time, she is denied permission to do so by her employer. Her administrator's negative response may be due to limited resources to support outside services. If this is the case, Marie's knowledge of federal law will be critical, as IDEA 2004 states that cost cannot be a consideration for service recommendation (34 CFR SS 300.17). The *appropriate* referenced in free appropriate public education (FAPE) has been defined by the courts not as the "best" service, but as the service that allows a student to receive educational

benefit.[32] Marie will need to carefully determine Patrick's current needs as they relate to possible functional, developmental, and/or academic limitations. In addition to resource concerns, it is also possible that the Special Education Director does not realize the complexities of the nature of stuttering. School administrators, special educators, and teachers all have been found to hold negative stereotypes of people, including students, who stutter.[33–35] Perceptions have included that these individuals are shy, insecure, frustrated, anxious, and self-conscious. Healey suggests that such negative stereotypes and reactions to stuttering may be due to lack of information and/or understanding about stuttering.[36] Marie's advocacy efforts on behalf of Patrick should include assisting her director in recognizing the full nature of Patrick's communication needs and the complexities of his treatment. Finally, Marie will need to consider any potential risks associated with a decision to refer, such as reduced family trust in her treatment.

Clinician Competence

When considering the consequences of her decisions, Marie will contemplate what is most beneficial for the individual (i.e., Patrick) and for herself. Although she has committed to increasing her knowledge and skills about stuttering treatment, she is questioning her effectiveness as a clinician. Marie is not alone in her concerns about her skills, as many SLPs have reported reduced competence and confidence associated with the treatment of stuttering, a low incidence communication disorder.[37–39] ASHA's Division 4 has identified competencies needed to assess and treat stuttering, which may assist Marie in her self-assessment of her current knowledge and skills.[40] After this self-reflection, Marie will be better able to identify specific areas where she needs support, which may involve collaborating with a clinician who has more experience and expertise. Specifically, Marie may now believe that Patrick's needs extend beyond using speech modification tools to enhance fluency, and she may feel ill equipped to address these issues. She knows that by continuing with her current treatment plan, she may be making ethical compromises

that do not allow her to "tell the truth" and "keep promises" (Layer 2) that are inherent in the approved IEP. Marie is not naïve, however, as she is aware of the perceptions of her Special Education Director, who may think that Marie is making the referral simply to reduce her caseload and to get out of working with a challenging student. She also has concerns that her director may view ASHA's Scope of Practice[41] as equivalent to her personal scope of practice and assume that she has expertise in all areas described in this document.

In the end, Marie will consider whether the benefits of this recommendation will outweigh the risks. She knows that she may have technically relieved herself of the responsibility that she has under the law by alerting her director to the need for a referral; ultimately, it is her employer who is responsible to follow through on this recommendation. Marie remains concerned, however, about whether her actions are ethical and in alignment with her moral compass.

Client-Driven Treatment

As decisions are made, Marie will need to support and honor Patrick's autonomy in the therapy process (Layer 1). Client-driven treatment may be enhanced with student-led IEP meetings.[42] Through candid conversations that explore treatment options, Patrick is provided an opportunity to enhance his autonomy, allowing him to make meaningful choices and increasing his opportunity to better adapt to life-changing circumstances. These conversations may also assist Marie with how to proceed in the event that the referral continues to be denied. Marie's ethical dilemmas may lead her to consider the following: (1) seek a supportive opinion from a lead SLP or union leader; (2) contact a regional support or state level agency for help; (3) appeal to her director's supervisor; (4) meet again with her director with additional information (e.g., complexities of stuttering, her personal scope of practice, ASHA Scope of Practice) to request additional training and also to request a consultation with a fluency expert; and (5) continue treatment with Patrick but with a dedication to improving her own knowledge and skills, with the help of a fluency

expert for ongoing support and guidance and with an increased focus on Patrick's involvement in determining the course of his treatment.

CONCLUSIONS

As Seedhouse reminds us, "Ethical intervention takes place in a perceptually uncertain world of limitations."[8] Unfortunately, many clinicians may not connect research with their clinical practice, as seen in a survey of recently certified SLPs whose primary work sites were school settings.[43] Although tracking the treatment evidence in the many communication disorders, including stuttering, may be an overwhelming, time-consuming task,[44] recent developments in ASHA's Center for Evidence-Based Practice in Communication Disorders have facilitated clinicians' abilities to access stuttering treatment guidelines and systematic reviews of research, as well as summaries of these reviews.[45,46]

Furthermore, as these scenarios illustrate, clinical decisions about the treatment of stuttering in schools revolve around multiple ethical considerations and, as such, have critical implications. Local, state, and federal mandates cannot be used alone to guide proactive, deliberate, and ethical actions that are part of our routine practice. Ethical practice requires a process of deliberate introspection that builds upon our personal experiences and professional points of view. Although two clinicians may not reach similar solutions following such systematic deliberation, each should be able to provide the rationales to justify their clinical actions. It is hoped that clinicians will be able to use the Ethics Grid to work through, rather than avoid, ethical dilemmas to reach "good results" that are "carried out with integrity."[8]

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