Two Flints Make a Fire: Collaborative Goal Setting with Children who Stutter

Presented to the Ohio School Speech Pathology Educational Audiology Coalition (OSSPEAC) Conference

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Disclosures

Financial:

- I am a salaried employee of Kent State University.
- I am paid an honorarium and travel reimbursement from OSSPEAC for this presentation.

Non-Financial: I have no non-financial relationships to disclose.

The Importance of Collaboration

"It takes two flints to make a fire."

- Louisa May Alcott

Or for the Scouts in the room, a flint and steel.

Session Learning Objectives

At the end of the course, participants will be able to...

- **Objective 1:** Explain the speech-language pathologist's role related to quality of life in students who stutter.
- **Objective 2:** Describe ways to engage in collaborative goal setting with students who stutter.
- **Objective 3:** Generate measurable goals to address the needs of students who stutter.

Assessment

First Step in Goal Setting: Assessment

Before we can set goals for stuttering treatment, we need a multi-factorial assessment protocol (See resources such as *School-Age Stuttering Therapy: A Practical Guide*, Reeves and Yaruss, 2013)

- Fluency: SSI-4 or TOCS and describe disfluency quality (new versions in development)
- Speech-language skills: Vocabulary, syntax, phonology
- Client's feelings and thoughts about stuttering
- How others react to the client's stuttering
- How stuttering impacts quality of life
- What is the client's communicative effectiveness (rate of speech, clarity)?
- Prior treatment history – what worked well or not so well?

The value of measuring speech disfluencies

- The purpose of this talk is NOT to encourage you to dispense with speech disfluency measurement.
- The quality and quantity of speech disfluencies produced by a client are important ways to
  - Assess whether clinically significant stuttering is present
  - Track success of modification strategies in altering speech
- For more information on counting disfluencies, see the “Scoring Disfluencies” video created by the Stuttering Foundation.
- For childhood assessment (ages 4 to 12), see the *Test of Childhood Stuttering* (Gillam, Logan, & Pearson, 2009), which helps reduce the number of words that must be monitored for stuttering. A new version is being developed.

Assessing Feelings and Attitudes

Ask the student or caregiver open-ended questions about

- feelings related to talking, stuttering, past therapy experiences
- feelings about the reactions of others to their speech
- how much stuttering impacts the client's ability to do what they want to do

Assessing Feelings, Attitudes, and Adverse Impact

- Can give formal assessments such as the Overall Assessment of the Speaker's Experience with Stuttering (OASES)
  - OASES-S (School-Age, ages 7-12; Yaruss, Coleman, & Quesal, 2010a)
  - OASES-T (Ages 13-17; Yaruss, Quesal, & Coleman, 2010c)
  - OASES-A (Ages 18 and above; Yaruss & Quesal, 2010)

Others' attitudes toward the student's stuttering

Goal is to find out if there are beliefs or attitudes that might hinder therapy progress.

- What do others in the environment know about stuttering?
- What would they see as success in treatment?
- What are the family's feelings about therapy goals?
- How does the family feel about the client's motivation in past therapy?
- What have teachers, professors, bosses, and other important people said to the client about their stuttering?

IDEA and Stuttering Assessment

- Federal law indicates that public education should provide free and appropriate services to children with disabilities so that they are "prepared to lead productive and independent adult lives, to the maximum extent possible" (c5 Aii).
- Considering the ways that untreated stuttering can adversely impact children's lives, addressing stuttering is consistent with the IDEA's aim.
- Relative to assessment, IDEA stipulates that the evaluation should "use a variety of assessment tools and strategies to gather relevant functional, developmental, and academic information, including information provided by the parent" (b2 A).
- The law also states that the local educational agency should "not use any single measure or assessment as the sole criterion for determining whether a child is a child with a disability or determining an appropriate educational program for the child" (b2 B).

Case Study

- "Jake", an 8-year-old boy, a rising 3rd grader
- Onset of stuttering at age 4, but characteristics subsided until 1st grade in stressful situations,
- By 2nd grade, the stuttering had increased in frequency and transitioned from repetitions to blocks and prolongations, occurring in most speaking situations.
- Parents and Jake had become concerned with these changes.

A version of this case study can be found in Logan and Arnold (2022) book chapter on School-Age Stuttering Assessment

Case Study

- Parents reported Jake expressing frustration when he stuttered – sometimes groaning and on rare occasion, running to his room.
- Social participation was still reportedly good between Jake and his peers.
- Reportedly performing at average or above average academically but sometimes does not explain things clearly.

Case Study

- When Jake is asked about his stuttering and communication, he says he feels “great”.
- The clinician also assessed this by telling Jake about another child who stutters when talking to friends.
- When the clinician asked Jake how that child would feel, Jake reported the child would probably feel “upset” and “embarrassed”.

Your turn: What assessment measures should the clinician use given this history?

Assessment-related Questions and Discussion

Next Move: Collaborative Goal Setting

Goal Setting Discussion

- What do we want to achieve in treatment?
- What does the student want to achieve in treatment?

Preferred Clinical Outcomes re: the Clinician

The client will demonstrate feelings, behaviors, and thinking that lead to improved communicative performance and satisfaction with the therapy process.

These outcomes can be operationally defined to include the following:

- Frequency and/or severity (duration, tension, evident struggle) of stuttering is reduced in variety of settings.
- Speech sounds natural (intonation, loudness, rate) in variety of settings.
- Speech fluency has increased.
- Client has increased volitional communication.
- Client is able to use techniques independently in a variety of settings.
- Avoidance behaviors have been reduced.
- Client has increased knowledge and understanding of speech and stuttering.

Ratner, N. B., and Quesal, B. (1998).

Perspective from a person who stutters (PWS) – perhaps a look into a student's future

Posted by a PWS on a social media support site:

Client was in therapy, which he felt was expensive. Therapy emphasized that "stuttering is okay", a message that the client indicates he adopted. The speech-language therapy, which included focus on acceptance of stuttering, prompted him to be a little more social for a while. The client noted that the therapy worked for a year but then he stopped going for various, undisclosed reasons.

Client began getting extremely tense with simple speech-language tasks such as ordering food and feels overwhelmed with the feeling of "suffocation" with the task.

The client indicates he hasn't been able to see his friends in over a year because of the stress and struggle. Even meeting with other stutterers is unbearable for the client. The client is now completely isolated.

Due to a neurological diagnosis, the client believes his stuttering is much worse than anyone else's. His thinking is that he should just tell all his friends that he will only be able to communicate through writing (texting, etc.). Although the client sees this as painful choice, he sees it at least to break his isolation.

What might help this person?

Preferred Client Outcomes

As a result of therapy, the client should be able to positively rate the following outcomes:

- I am satisfied with my therapy program and its outcome.
- My client/clinician jointly determined goals were met.
- I have an increased ability to communicate effectively.
- I feel more comfortable as a speaker.
- I like the way I sound.
- I have an increased sense of control over speech, including stuttering.
- My speech has become more fluent.
- I am independently able to employ a variety of techniques and strategies as appropriate.
- My understanding of stuttering and fluency has increased.
- My speaking skills have become more automatic.
- I have an increased ability to cope with variability of stuttering and relapse.
- I am better able to reach social/educational/vocational potential and goals.

Ratner, N. B., and Quesal, B. (1998)

How to choose goals?

- A collaboration between student and clinician after reviewing assessment findings.
- Primarily based on the student's reasons for being in therapy.
- Can have the student generate goals on their own, depending on maturity level.
- Can also provide the list of goals provided in this presentation and have the student priority rank them.

What if the student does not report or exhibit concern about their stuttering?

- Sometimes the parent(s) express concern but the student denies concern.
- In some cases, the student may not demonstrate any behavioral signs of concern (e.g., no avoidance)
- Some school-aged children may not demonstrate awareness of their stuttering.

Advice from Scott Yaruss

- Check out his blog, “Practical Thoughts Blog” at the Stuttering Therapy Resources website.
- He suggests asking the question, “*Is the child experiencing adverse impact as a result of his stuttering?”* – This highlights the importance of assessing attitudes in the dx (see OASES measure).
- If there is adverse impact, but the student does not demonstrate awareness or report concern, we may be encountering denial.
- This student would benefit from services to help him learn it is ok to stutter, even while we work on strategies to ease the process of talking.

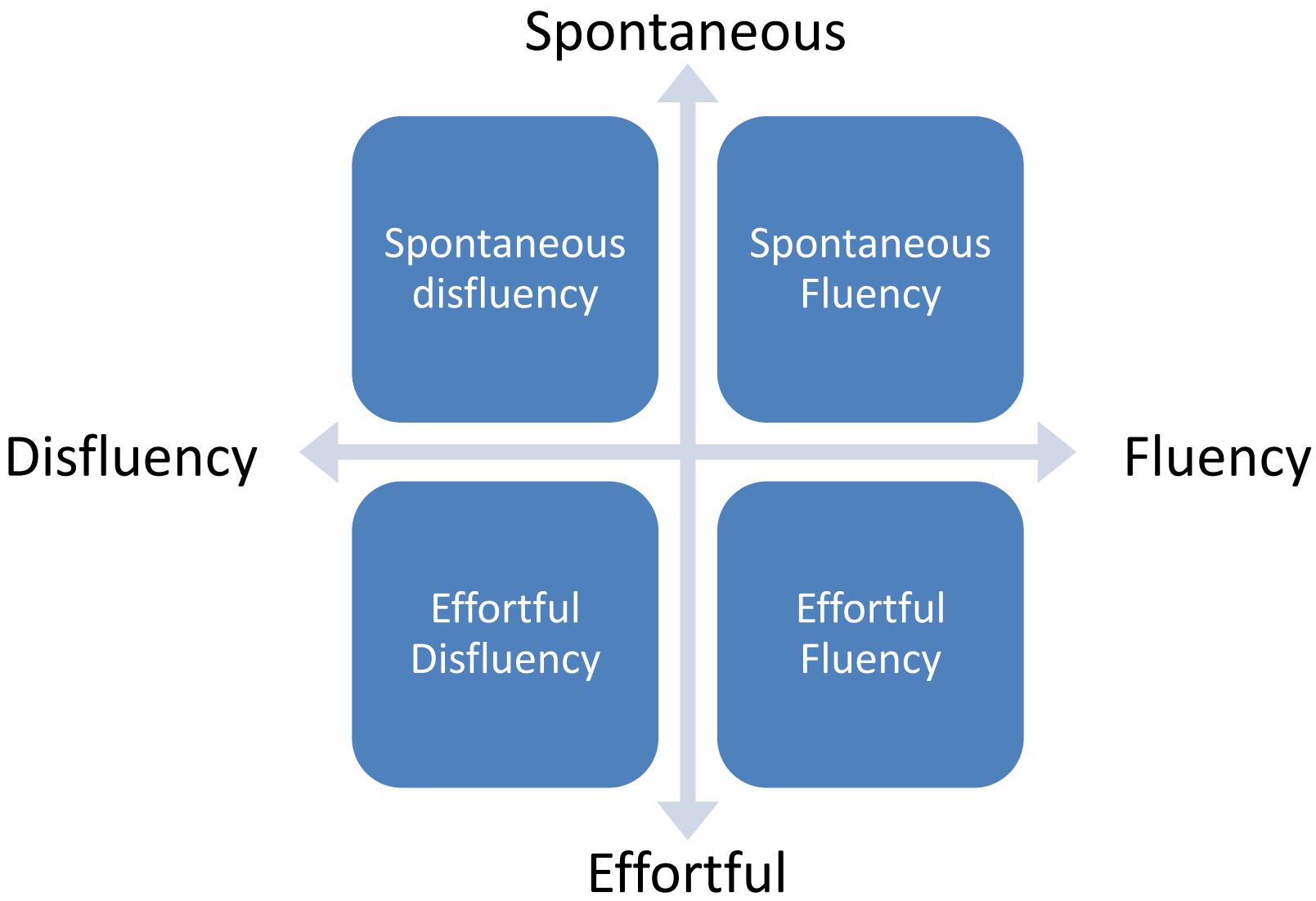
No or little impact?

- On the other hand, if there does not appear to be impact or it is minimal, the student may not need therapeutic support – that is, if the student is communicating freely and not experiencing negative reactions to his stuttering, he will not have motivation to work on strategies.
- That is, we don't need to create a problem where one does not exist.
- Our role may be educating people around the student, so he is supported by people who affirm stuttered speech as one way to successfully communicate.

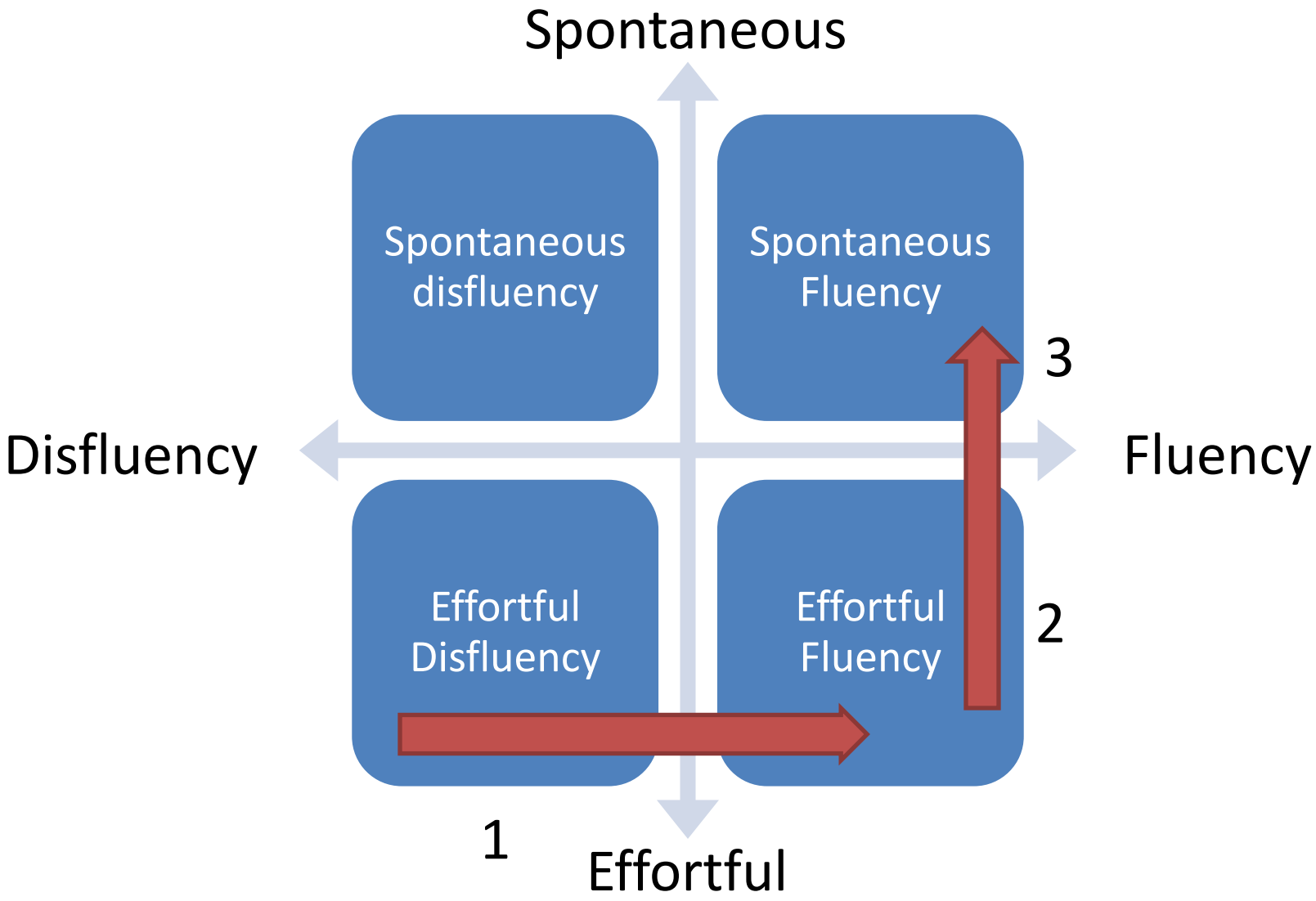
How to approach goals related to speech fluency?

A model for thinking about fluency

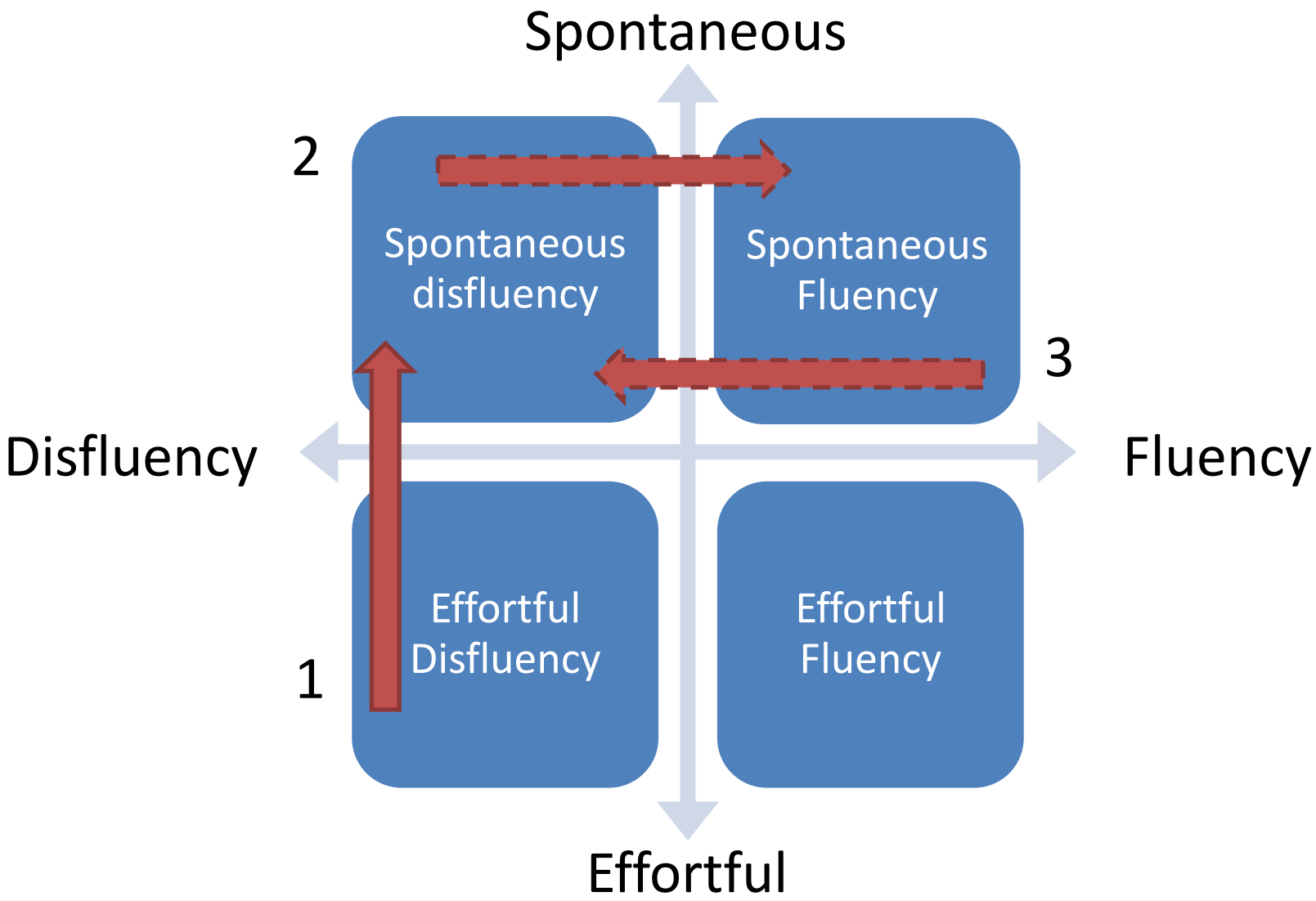
Four Quadrant Model of Spontaneity and Fluency (Constantino et al., 2020)



Spontaneous Fluency through Effortful Fluency (Constantino et al., 2020)



Spontaneous Fluency through Spontaneous Disfluency (Constantino et al., 2020)



Questions about Treatment Goals (from Constantino, 2021)

- Do they aim to relieve suffering or to normalize?
- Do they maximize quality of life or minimize difference?
  - Fluency is neutral – it only become positive if it improves quality of life.
  - Fluency becomes concerning if it decreases quality of life.

Overarching Treatment Goals for Stuttering (for any treatment program)

- Embrace the stuttering identity
- Develop autonomy, agency, and approach behavior
- Make speech easier and less effortful

Preferred Client Outcomes – Use as a "menu" for students

As a result of therapy, the client should be able to positively rate the following outcomes:

- I am satisfied with my therapy program and its outcome.
- My client/clinician jointly determined goals were met.
- I have an increased ability to communicate effectively.
- I feel more comfortable as a speaker.
- I like the way I sound.
- I have an increased sense of control over speech, including stuttering.
- My speech has become more fluent. *
- I am independently able to employ a variety of techniques and strategies as appropriate.
- My understanding of stuttering and fluency has increased.
- My speaking skills have become more automatic.
- I have an increased ability to cope with variability of stuttering and relapse.
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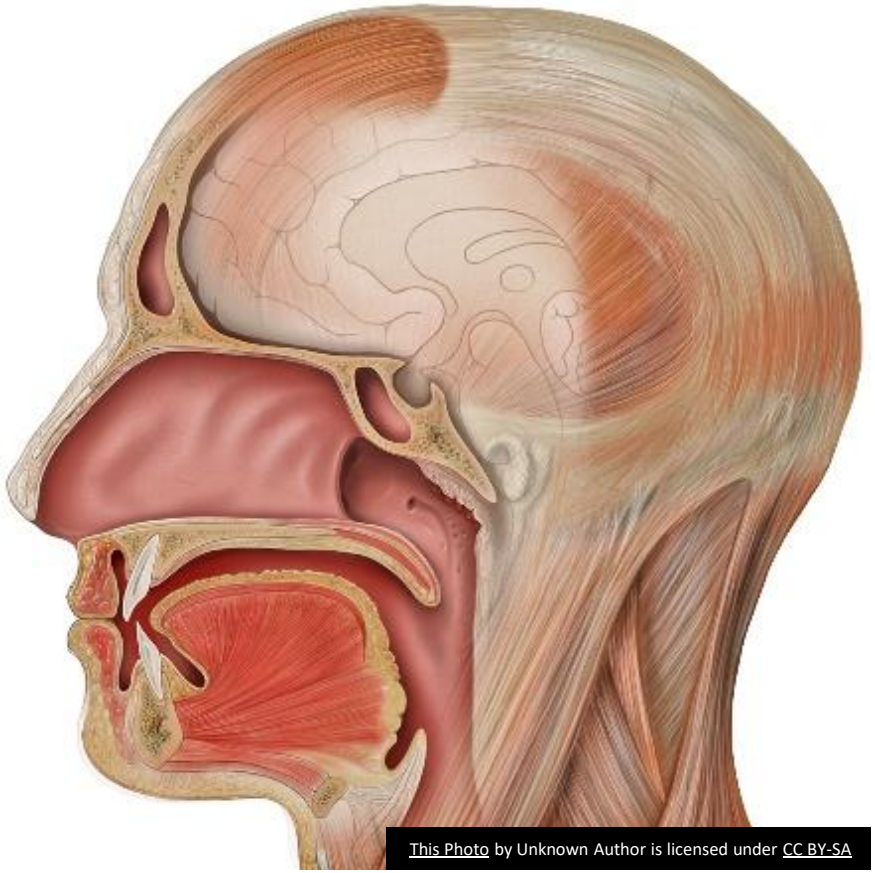
Ratner, N. B., and Quesal, B. (1998)

* Outcome directly related to increasing speech fluency

Learning about the speech mechanism

- Speech is so automatic – people don't typically know how speech happens
- In order to advance students' feelings of autonomy and agency, it is important to help them understand the speech mechanism



Exploring Stuttering – Learning about the speech mechanism – From Conture (2001):

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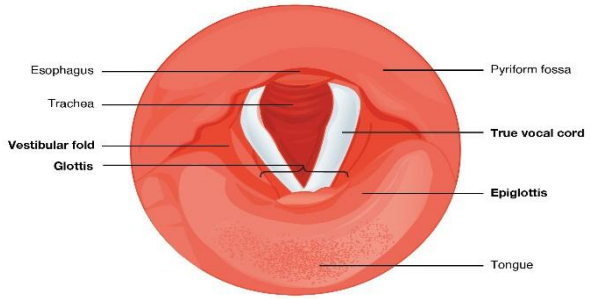

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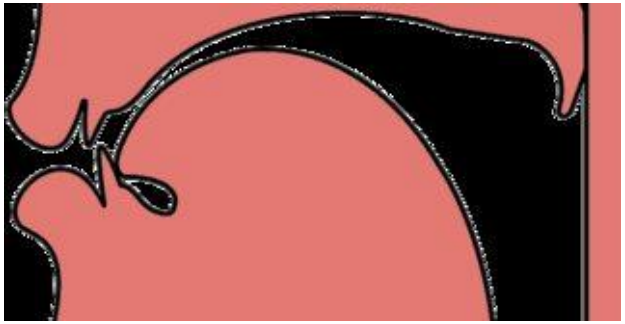

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Learning about stuttering

Based on your assessment, you may learn that the student does not have much knowledge about stuttering in general, or their own pattern of stuttering in particular

Therapy can focus on exploring stuttering

What we know about the cause?	Myths about stuttering	What is the client's stuttering like – where is there tension – patterns of sound, word, or situational avoidance?

Example of using breath holding to illustrate how tension feels in the lips vs. larynx

Understanding the how and why of speech techniques

- We can teach techniques that the client can use to decrease the severity of stuttering (stuttering modification) and increase fluency (fluency shaping)
- However, it is important that the client understands the purpose of each technique
- Once the client understands and can use the techniques, they can increase autonomy by prioritizing the techniques they like the most.
- What might a therapy goal related to this look like?

Addressing avoidance

- Many clients avoid sounds, words, or situations
- When this is extreme – it is called covert stuttering - which can have adverse impact on the client's ability to fully participate in society
- Therefore, it is important to increase participation
  - Desensitize to fears – including the fear of stuttering– use cognitive behavioral strategies – testing hypotheses
  - Increase awareness of thoughts and feelings and teach ways to change and regulate them

Fear Hierarchy

- Work with student to establish their fear hierarchy.
- Can have them write different situations on index cards, then arrange them in order from easiest to hardest.
- Start with the student approaching the easiest situation and work up the hierarchy (exposure therapy)

Consider going for Excellence in Communication

- Sometimes we set our goals too low – Becoming a “better” communicator
- What if we worked toward *excellence in communication,* particularly in communication tasks important to clients.
- This means we work on ALL aspects of communication, *not just speech fluency*.

Blank Center Ratings Example

Creating a rubric like this for communication excellence, then applying it to relevant speech tasks could be a therapy technique

See more about the Blank Center for Stuttering Education and Research here: https://moody.utexas.edu/centers/lang-stuttering-institute/research-resources

Competency	Exceeds expectations, no further focused practice is needed (100)	Meets expectations, but additional practice is needed to transition to highest level of competency (50)	Needs continued focused practice to meet and/or exceed expectations (0)
Competency 1: Communicates the thesis/specific purpose in a manner appropriate for the audience and occasion	100 — 0 100 — 0		
1a) Was the presentation's structure logical, with an introduction telling the audience what would happen, a main body and a conclusion? 1b) In their introduction, did the presenter(s) clearly state the purpose of the presentation? 1c) If they had been given the task of solving a problem or answering a specific question, did the introduction include a clear statement of the question or problem and outline of how they were going to go about answering or solving it?			

Building Social Supports

- Findings by Boyle (2015) indicate that quality of life for adults who stutter is positively associated with
  - Self esteem/self efficacy
  - Social support from family
- These findings were <u>independent</u> of stuttering severity
- Considering these findings, what goals might we develop?

Build a supportive community around a student who stutters

- Inaccurate beliefs about stuttering are common – and they are associated with
- Less than helpful reactions toward people who stutter are common (Arnold & Li, 2016)
  - Finishing sentences, interrupting
  - Making light of the stuttering
  - Demonstrating feelings of pity
- Familiarity with people who stutter is associated with more helpful reactions toward them (Arnold & Li, 2016)
- *Unapologetic* self-disclosure is associated with more positive perceptions of people who stutter (Byrd et al, 2016, 2017).

Potential ways to improve reactions toward our students who stutter

- Have the student (ideally) educate those at school, work, and community about stuttering
- Increase familiarity between the student and those in their environment by increasing approach behaviors (decreasing avoidance)
- Increase positive attitudes by having students disclose their stutter to others.
- The best advocate for our students ARE our students.

What goals might we develop for this?

What is stuttering self disclosure?

Stuttering self disclosure has been defined by Boyle and Gabel (2020) as "sharing of, or making visible, personal information that links a person to the identity of someone who stutters."

How this disclosure occurs can vary

- Disclosure statement
- Openly stuttering, both voluntarily and involuntarily

How often do individuals who stutter self disclose?

- In a 2013 study of adolescents, only 19% told others that they stuttered. A majority (62%) concealed their stuttering (Erickson & Block, 2013).
- Boyle (2018) reported findings that
  - 48% did not hide their stuttering, but did not seek opportunities to disclose their stuttering
  - 7% of adults who stutter (AWS) disclosed to trusted and understanding people
  - 4% reported stuttering voluntarily and actively sought out situations to disclose stuttering to others

Why do individuals who stutter conceal their stuttering?

- To avoid negative reactions from others, including possible discrimination
- To benefit from the privileges conferred upon the typically fluent speaker – can be seen as an act of resistance to a hostile society (Constantino, Manning, & Nordstrom, 2017)
- To bypass the momentary feelings of stress and vulnerability that can be associated with overt stuttering (Gabel & Boyle, 2020).

What are the costs of stuttering concealment?

- For some, stuttering cannot be concealed, and listener perceptions when there is no disclosure are more negative
- Often leads to excluding oneself from fully participating educationally, vocationally, or socially.
- Decreased quality of life (QOL)

How can we as SLPs interrupt stuttering-related stigma?

Gerlach-Houck and Constantino (2021) article centers around this.

Five Recommendations:

1) Help clients consider healthy therapy options (communication/participation is important)
2) Commit to using inclusive language (e.g., frequent or tense instead of bad/worse)
3) Respect/amplify the work of stuttering support/self-help groups
4) Recognize/resist institutional barriers through education/advocacy (e.g., against only accepting fluency-based measures)
5) Involve people who stutter in the knowledge-making process through community engagement

Quality of Life (QOL)

Defined as an individual's reported satisfaction and/or fulfillment in activities and experiences in important life domains, and in life in general (Endicott, Nee, Harrison, & Blumenthal, 1993).

Disclosure's Impact on Quality of Life (QOL)

- Boyle et al. (2018) surveyed 322 adults who stutter about their overall QOL and about their levels of stuttering disclosure.
- Participants were categorized in three groups: low, average, and high.
- Results indicated that those in the low QOL group had significantly lower disclosure scores than the average and high QOL groups.
- People who attended self help groups were significantly more likely to have high levels of stuttering disclosure.

Listener Reactions to Disclosure

- Most studies, which assessed explicit bias, have shown that stuttering disclosure results in more positive listener ratings of individuals who stutter (Boyle et al., 2018; Byrd et al., 2017)
- A recent study assessed the effect of stuttering disclosure on implicit bias against stuttering (Ferguson, Arnold, & Roche, 2019). Disclosure positive impacted both explicit and implicit bias, albeit more slowly for implicit indicators.

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Contents lists available at ScienceDirect

Journal of Fluency Disorders

Associations between beliefs about and reactions toward people who stutter

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Our survey research of public attitudes toward people who stutter (PWS) indicate that familiarity with PWS as positively associated with more helpful reactions toward PWS (Arnold & Li, 2016).

What types of statements do adults who stutter use to self disclose?

- Educational
- Apologetic
- Direct

McGill et al. (2018)

Which of these approaches will result in more positive listener ratings?

Best Practices for Self Disclosure

- Shared at the beginning, rather than the end, of the communication (Healey et al., 2007)
- Confident and positive (Boyle et al., 2017)
- Non-apologetic (Byrd, Croft et al., 2017; Collins & Blood, 1990)

The role of self-help groups

- Groups such as Friends and the National Stuttering Association (NSA) can greatly facilitate all therapy goals, including those that address fluency and those that do not.
- These groups have the potential to
  - Decrease avoidance/increase participation
  - Provide a safe place to try new communication strategies (e.g., self disclosure, modification techniques)
  - Increase self esteem and self efficacy
  - Build social support around the client
- Encourage clients to become involved – for many it is as impactful (and sometimes more so) than our therapy.

Group Activity

- Find a neighbor or two with whom to collaborate.
- Choose a student aim around which to write a goal. Choose a non-fluency-related goal.
  - Knowledge about stuttering
  - Social supports
  - Approach behavior (self disclosure, participation, desensitization)
  - Communication skills
- Write a SMART (specific, measureable, attainable, realistic, and time-delimited) goal that goes with that general aim.
- Share your goal during our broader discussion.

Questions?

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