

Stuttering Is...

From the Perspective of People Who Stutter

Speech-Language-Hearing Association of Virginia

Disclosures

- Members of the National Stuttering Association (NSA)
- The experiences discussed in this presentation are reported by people who stutter

Meet the Panel



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NSA Opening Words

Welcome to the Charlottesville Chapter of the National Stuttering Association. If you are a person who stutters or has a special interest in stuttering, you are welcome here.

For the time we meet here, this room is a very special place. It's a place where we are accepted and supported. It's a place where we can stutter openly without fear and embarrassment.

Together, we will help each other and we will help ourselves to accept and cope with our stuttering, to build our self-confidence, and to improve our communication skills.

We who stutter, and those who support and help us, are not alone. Together we are changing lives.

Stuttering is...

What causes stuttering?

The “cause” is still unknown.

What do we know thus far?

- Increased activation in the left inferior frontal gyrus (Chow et al., 2023)
- There is currently no “cure” or “fix”
- Strong Genetic Link

Chow, H. M., Garnett, E. O., Ratner, N. B., & Chang, S.-E. (2023a). Brain activity during the preparation and production of spontaneous speech in children with persistent stuttering. NeuroImage: Clinical, 38, 103413. <https://doi.org/10.1016/j.nicl.2023.103413>

Prevalence/Incidence

About **5%** of all children go through a period of stuttering that lasts six months or more.

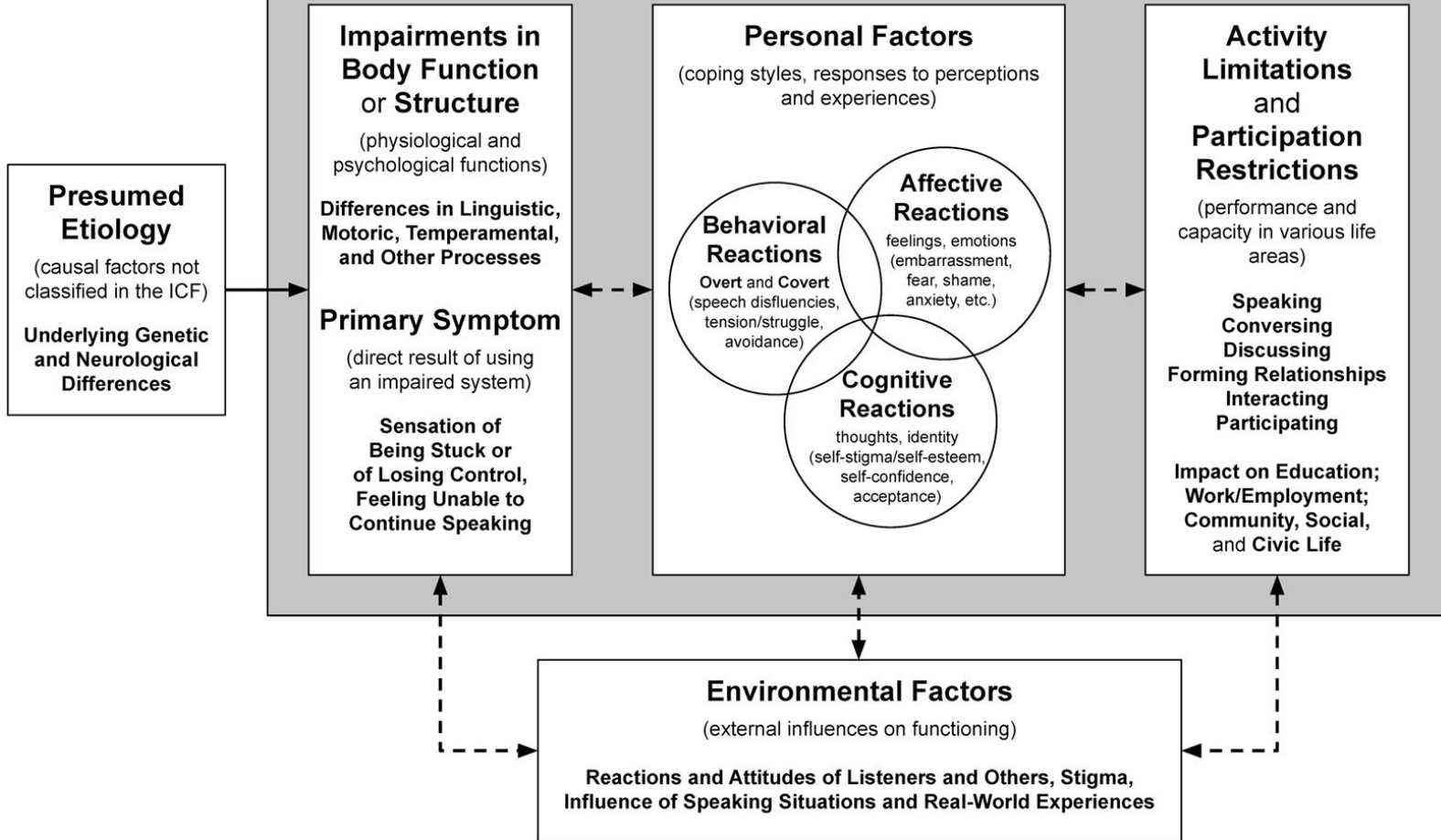
75% of those, who begin to stutter, will stop stuttering.

This leaves about **1%** of the population with long-term stuttering
(*Prevalence 2011*)

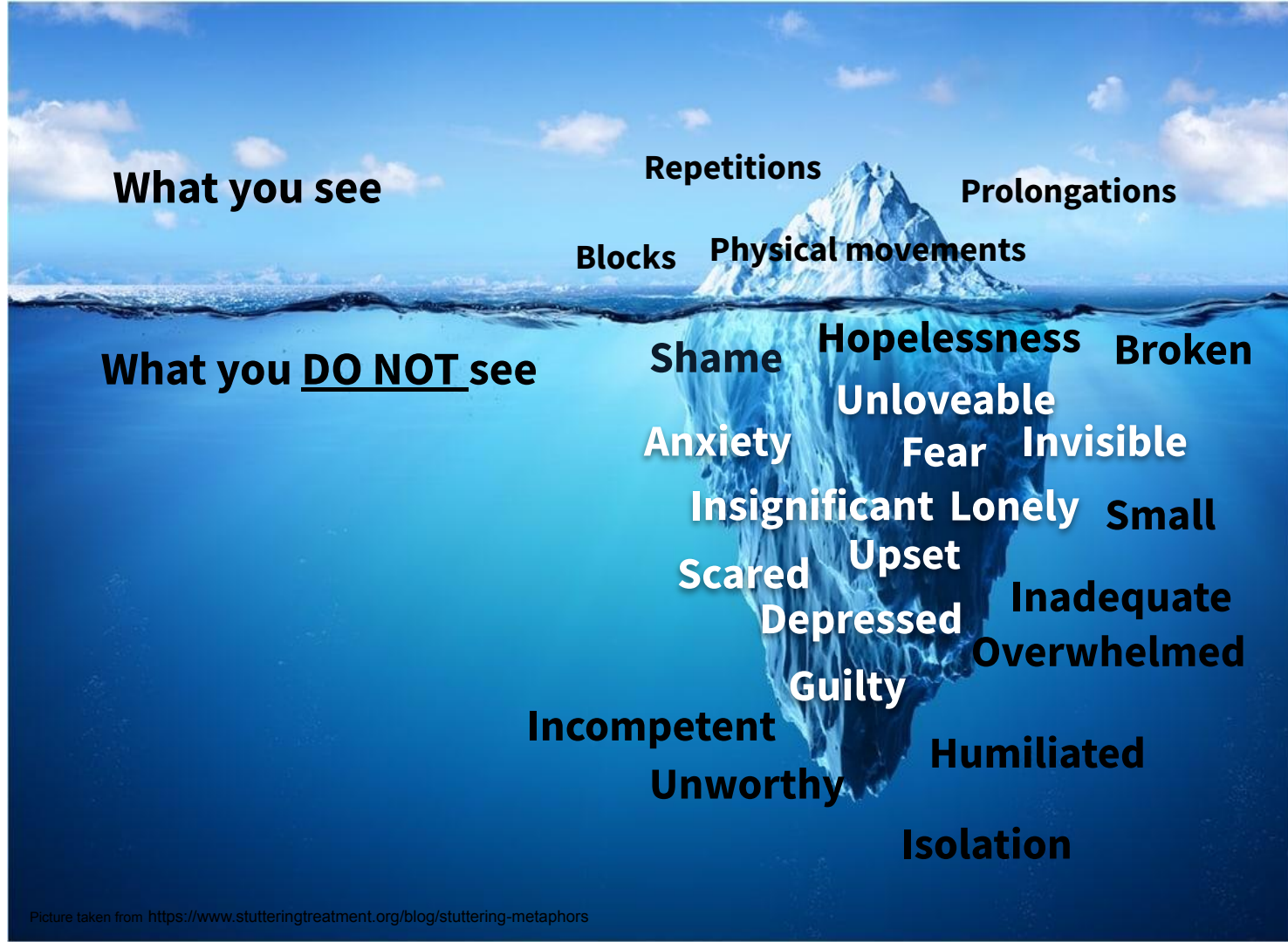
Prevalence. Stuttering Foundation: A Nonprofit Organization Helping Those Who Stutter. (2011, November 4).

<https://www.stutteringhelp.org/prevalence#:~:text=About%205%25%20of%20all%20children,with%20a%20long%2Dterm%20problem.>

The Experience of Stuttering



The Stuttering Iceberg

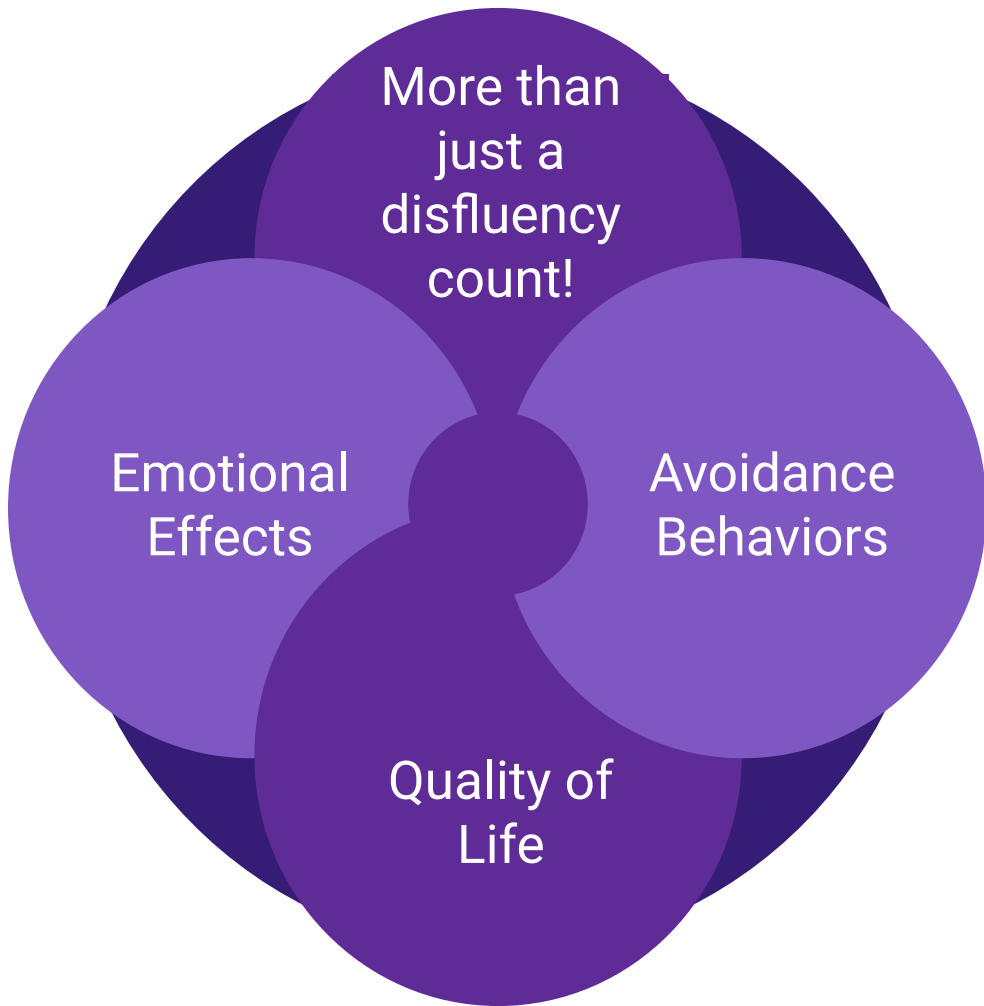


Myths

- Anxiety *causes* stuttering.
- People who stutter are not intelligent
- Stuttering can be cured
- Being bilingual causes stuttering
- Stuttering can be “caught” by listening to someone who stutters
- Saying “just take a deep breath” really helps a person who stutters.
- People who stutter can use strategies to ALWAYS sound fluent.

Facts

- Stuttering *exacerbates* Anxiety
- No correlation between Intelligence and Stuttering
- There is no known “cure” as of today
- Around 3 million people in the U.S. stutters
- People who stutter CAN utilize strategies to aid in *tension* release
- There is a strong genetic component to stuttering



Assessment

- More than just a disfluency count!
 - If a fluency count is taken, make sure it is known that stuttering is variable and will change based on environments, communication partners, etc.
- Look out for avoidance behaviors
 - Loss of eye contact, switching words, avoiding words, tapping, squeezing, gulping, grimaces
- Measurement of emotional effects?
 - Interview with client/student
 - Are you satisfied with the way you talk?
 - Would you change anything?
 - Overall Assessment of the Speaker's Assessment of Stuttering (OASES)
- Quality of Life (What does it affect?)

Starting Therapy: Counseling for SLPs

- Education!
- Help the PWS (person who stutters) learn about their own speech
 - Get to know the who, what, where, when, why, how
- The expert in therapy is the PWS
- Be vulnerable and build trust
 - Red, yellow, green light tool
- Some counseling activities:
 - Make a stuttering iceberg
 - Make a stuttering hierarchy with most feared/least feared speaking situations
 - Discuss weekly highs/lows
 - Watch and discuss stuttering videos
 - Read and discuss blog posts/articles/social media posts
- Stuttering therapy is all about the small wins and making them feel huge



Focus of Goals:

- Support the client's ability to *communicate effectively*
- Support the *client's communication goals* (educate them on what possibilities & determine what they want to work on)
- Revisit client's goal throughout the year

It is important to note that due to the nature of stuttering, severity may range from mild-severe depending on contextual communication and environmental factors.





Areas of Goals

- Knowledge of stuttering
- Knowledge & understanding of techniques & strategies
- Self-Advocacy
- Reducing avoidance behaviors

Example Goals

- XX will report a helpful thought related to a speaking experience
- XX will identify an avoidance behavior
- XX will report reducing an avoidance behavior
- XX will demonstrate knowledge on stuttering
- XX will demonstrate knowledge on the impact of stuttering in his life
- XX will report/demonstrate coping skills in response to speaking experiences
- XX will complete 1-2 speaking analyses each session
- Given one verbal cue, XX will demonstrate use of a preferred fluency enhancing, stuttering modification, or desensitization technique in 9/10 opportunities...
- Given education on stuttering, XX will demonstrate knowledge of the topic by correctly answering questions about stuttering with at least 90% accuracy...
- Given introductions with new peers/teachers, XX will advocate for himself by disclosing that he stutters in 4/5 opportunities...
- Given education on stuttering, XX will give a presentation on stuttering to a class of peers in order to advocate for himself 3x during the semester...

Microaggressions



- “A statement, action, or incident regarded as an instance of indirect, subtle, or unintentional discrimination against members of a marginalized group such as racial or ethnic minority”
- The world expects fluency – How do we change this?
- Watch your (body) language...
 - Verbal examples: “What you have to say is important,” “Wow, you made a great point,” “I love listening to you talk,” “Can you teach me more about stuttering?”
 - Non verbal examples: Patience, holding eye contact, reducing time pressure by adding slight pauses

Resource: “Microaggressions in the Lived Experience of Stuttering” by Mark O’Malia, M.S., CCC-SLP (Blog post from the American Institute for Stuttering)

The Language We Use

Instead of ...	You can say/do ...
“Let’s try that with again, but with a strategy”	“You make a good point, thanks for sharing”
“Oh, but you barely stutter”	“Can you teach me more about it?”
“Remember to slow down when you talk”	“I love listening to what you have to say”
“Did you use a strategy?”	“Tell me how that stutter felt”
“You did great, you barely stuttered!”	“Wow, you made some great points during your presentation”
Filling in words during a block to “help”	Try to reduce time pressure (i.e “the look”)
Interrupting (yes, even if it takes a while)	Wait patiently, maintain eye contact

The Language *They* Use

They say ...	You can model ...
“My stutter was worse over the weekend”	“So you stuttered <i>more</i> over the weekend?”
“My voice is so stuck right now”	“You mean you’re feeling <i>tension</i> ?”
“I can’t talk today”	“But you still <i>chose</i> to talk today”
“I wish I didn’t stutter”	“I love talking to you whether you stutter or are completely fluent. What would change if you didn’t stutter?”

- Stuttering is just like any other difference that humans may experience (hair color, eye color, heart conditions, diabetes, gluten free, etc.)
- We need to promote/model **resilience**, especially in young children who stutter
- Treat it as a “scrape on the knee” for young children

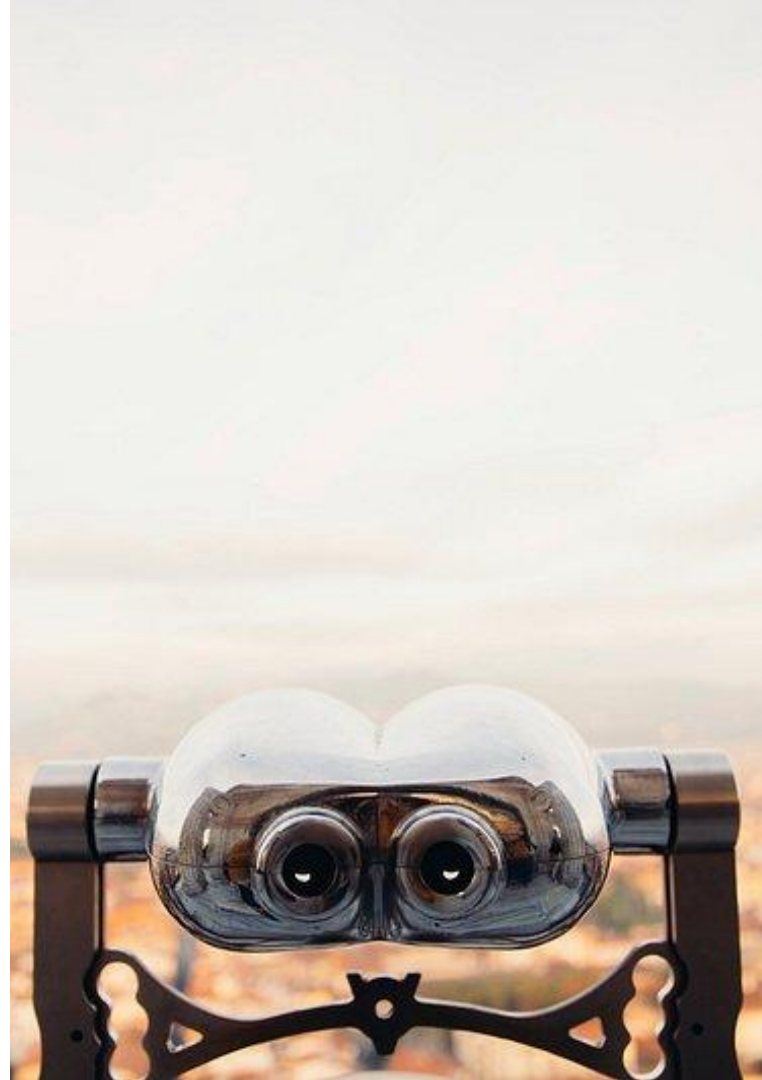
Adverse Impact of Fluency-Shaping

- Consider the message you are sending a Person Who Stutters when teaching them about “Fluency-Shaping” or “Stuttering-Modification”.
- Don’t frame it as “These strategies will help you become *fluent*”
- Fluency should *not* be the goal.
- The goal is **Communication Efficiency**.
 - Is your client comfortable communicating in school, work, or familial situations?
 - Is your client avoiding certain speaking situations?
 - Are they talking to adults in a schools setting?
- Imagine the message you’re sending by saying “it’s okay to stutter” but then teach them ways of hiding their stutter.

“A Point of View about *Fluency*”

This article reflects on key things many people who stutter wish SLPs knew about stuttering.

Tichenor SE, Constantino C, Yaruss JS. A Point of View About Fluency. J Speech Lang Hear Res. 2022 Feb 9;65(2):645-652. doi: 10.1044/2021_JSLHR-21-00342. Epub 2022 Jan 4. PMID: 34982943; PMCID: PMC9135003.



Major key points from that article

- If SLPs based treatment off of “fluency” then they might miss the clients needs for the experiences of stuttering beyond dysfluency
- “Fluency” might encourage SLPs to only focus on fluency-based strategies.
- Fluency suggests the absence of effort...fluency speech for people who stutter is effortful.
- “Every moment of stuttering is seen as a failure of fluency”
- By focusing on fluency...it suggests that stuttering is undesirable.
- “Fluency” suggests that if people who stutter can achieve Fluency their lives will drastically improve.
- Fluent speech for PWS is still effortful

Types of Stuttering Therapies

- Cognitive Behavior Therapy
 - Thoughts impact emotions, & these emotions contribute to patterns of behavior
- Solution-Focused Brief Therapy
 - Solution-building rather than problem solving
- Mindfulness
 - Tension; body awareness
- Avoidance Reduction
 - Identifying & peeling away escape behaviors
 - Reducing the “struggle” related to stuttering

**What I wish my SLP would
have known/done**

Q & A



NSA Closing Words

May the spirit we have shared tonight help us be more comfortable with our speech in the coming weeks.

May we go into speaking situations, without force or struggle, accepting ourselves regardless of our fluency,

We are never alone. Together we are changing lives.

Resources

- Life on Delay by John Hendrickson
- Every Waking Moment by Chris Anderson
- National Stuttering Association (NSA)
- American Institute for Stuttering (AIS)
- International Stuttering Association
- The Stuttering Foundation (website & podcast)
- Stuttering Therapy Resources (website, instagram)
- Open Stutter (YouTube Channel)
- Spero Stuttering, Inc.

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