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## Stuttering Assessment and Treatment: A Holistic Approach

Guest Editor: Craig Coleman, MA, CCC-SLP, BCS-F, ASHA-Fellow



## Best Practices for Stuttering Assessment and Treatment Including the Role of Support Groups

Katie Gore, MA, CCC-SLP;  
Craig Coleman, MA, CCC-SLP, BCS-F, ASHA Fellow

Moderated by:  
Amy Natho, MS, CCC-SLP, CE Administrator, [SpeechPathology.com](http://SpeechPathology.com)





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continued<sup>®</sup>



## Disclosures

- Craig Coleman - Financial: Craig Coleman was paid an honorarium for this presentation. He is co-owner of the Stuttering Academy, and co-authored and receives royalties for the OASES. Non-financial: Craig is a board-certified specialist in Stuttering, and serves on the ASHA Board of Directors.
- Katie Gore - Financial: Katie Gore was paid an honorarium for this presentation. She is the founder/director of a communication therapy and consulting company in Chicago. Nonfinancial: Katie is a founder and former leader of a National Stuttering Association chapter, former member of the NSA Board of Directors, and founder and current Board Member of Shared Voices Chicago.
- Content Disclosure: This learning event does not focus exclusively on any specific product or service.
- Sponsor Disclosure: This course is presented by SpeechPathology.com.



## Learning Outcomes

After this course, participants will be able to:

- Name 3 different stuttering support communities, and the special focus of each group.
- Create 2-3 realistic, community-oriented treatment goals that are within the scope of speech therapy.
- Describe two cultural issues pertaining to SLP involvement in stuttering communities, and best practices for navigating this as a non-stuttering clinician.
- Describe assessment principles to target all aspects of stuttering across age ranges.
- Describe at least 3 treatment activities for children and adults who stutter.



# Hello!

I love the stuttering community.

- Founder and president of speech IRL
- Founder and former chapter leader of the City of Chicago NSA Chapter
- Former National Stuttering Association Board Member
- Co-founder and Community Outreach Chair of Shared Voices Chicago
- Instructor of Stuttering & Fluency Disorders at Rush University

9

# Agenda

- Introductions
- Overview of stuttering communities
- Bringing community into the speech therapy session
- Writing goals for community engagement
- Cultural and historical considerations of community growth and participation
- The role of the SLP
- Closing

10

## Stuttering Community-Focused Organizations

- National Stuttering Association (NSA)
- Friends: The National Association of Young People Who Stutter (Friends)
- SAY: The Stuttering Association for the Young (SAY)
- Stutter Social
- International
- Canadian Stuttering Association (CSA)
- British Stammering Association (BSA)

11

## Other stuttering resources

- Stuttering Foundation of America (SFA)  
([stutteringhelp.org](http://stutteringhelp.org))
- Informationally-focused organization
- Summer camps
- Numerous and diverse!
- Local organizations
- Shared Voices Chicago  
([sharedvoiceschicago.org](http://sharedvoiceschicago.org))
- American Institute for Stuttering  
([stutteringtreatment.org](http://stutteringtreatment.org))

12



CONTINUED

- Founded in 1977
- Emphasis on self-help and raising awareness of stuttering, by and for PWS
- Annual conference: children, teens, parents, adults, SLPs, researchers
- Chapter meetings: support groups led by local volunteers in all 50 states
- Other activities
- [westutter.org](http://westutter.org)



Q3 13

CONTINUED

## The National Association of Young People Who Stutter

- Founded in 1997
- Emphasis on providing support and information for children and families
- Annual conference: children, teens, parents, SLPs, “bonus” adults
- Regional one-day conferences
- Mentoring program
- [friendswhostutter.org](http://friendswhostutter.org)



Q3 14

CONTINUED

## continued

- Founded in 2001 in New York City
- Emphasis on providing support and empowerment to PWS ages 8-18
- Year-round after-school programs centered on the performing arts (NYC, DC, Australia)
- Camp SAY
- Camp SAY Across the USA (one-day)
- [say.org](http://say.org)



Q1 15

## continued

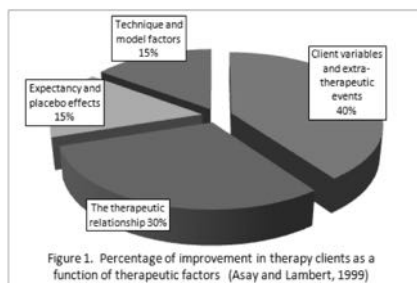
- Founded in 2011
- Emphasis is using virtual communication to connect PWS globally
- Scheduled, facilitated Google Hangouts that PWS can log into
- Participants across all time zones, representing over 70 countries
- [stuttersocial.com](http://stuttersocial.com)



Q2 16

## Why community?

- Common Factors Model
- Speech therapy is just one slice of the pie
- Client participation in community activities strengthens their individual change-oriented variables
- SLP familiarity and support of extra-therapeutic activities strengthens therapeutic alliance



17

## ...but I only see the client from 4-5pm on Tuesdays

- Exploration
- Client isn't ready or willing to engage in community activities
- Participation
- Client is willing to attend activities, may participate actively or passively
- Change
- Client takes on a new communication challenge offered by a community opportunity

18

## Community-oriented therapy activities

- Exploration
- Consume media by other PWS about their personal journey
- Consume media by other PWS specifically about community participation (“My first NSA conference experience”)
- Listen to podcasts by PWS talking about their personal experience
- Watch videos (asynchronous or livestream)
- Research chapters and events happening locally
- ...work on these in the therapy room!

19

## Community-oriented therapy activities

- Participation
- Attend a chapter meeting
- Log onto a live virtual event
- Attend a conference or workshop event
- May listen, or actively participate
- ....Use speech therapy session to post-process the activity, learnings, emotions, ideas

20

## Community-oriented therapy activities

- Change
- Lead a meeting or discussion
- Serve as a panelist at a stuttering event or class
- Be interviewed on a podcast or livestream
- Post about stuttering on social media (TikTok, Insta story, FB Live)
- Give a presentation about stuttering
- ...work on these in speech therapy!

21

## Goal-writing for community engagement

- DO
  - Include rationale about community engagement and its connection to communication goals
  - Focus on the therapy-appropriate activity or target
  - Ensure that the goal can be fully executed within the speech therapy session
  - Consider parameters like virtual vs live, asynchronous vs real-time, passive vs active participation to create a hierarchy of engagement

Q4

22

## Goal-writing for community engagement

- DON'T
  - Write goals that require the client to do something you can't control
  - You cannot kidnap a client and forcibly drive them to a chapter meeting
  - Write goals that require significant outlay of resources
  - Conferences are expensive
  - Write goal activities that require specific environmental opportunities
  - Panels don't grow on trees

Q4 23

## Practice!

- Sample rationales
  - To increase knowledge of stuttering, client will...
  - To decrease shame about being a PWS, client will...
  - To increase communication confidence, client will...
- REMEMBER: Goals can be a binary complete/incomplete "project" that a client works up to over a series of sessions ("by week 8")

24

# Cultural and Historical Considerations

- SLPs mean well...but we haven't always done well
- "Safe space" → safe from SLPs

## StutterTalk

Changing how you think about stuttering...one podcast at a time.

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### SHOULD SLPs TREAT STUTTERING?

1 Nov 2017

**Should Speech-Language Pathologists Treat People Who Stutter? (Part Six with Dr. Bob Quesal, Ep. 634)**

Podcast: [Play in new window](#) | [Download](#)

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**Bob "the Expert" Quesal** joins Peter Ramirez to discuss if speech-language pathologists (SLPs) should continue to evaluate and treat people who stutter. This is episode 392 in a series on the topic.

Dr. Quesal shares his huge disappointment in how the field of speech-language pathology trains SLPs to understand and treat stuttering. Dr. Quesal states, "The reason we are in the mess we are in right now is because ASHA has been involved", "I have been appalled by the number of well educated SLPs who don't understand stuttering at all" and "We can lobby ASHA until we are blue in the face. But ASHA has demonstrated over the last 50 years

**ABOUT STUTTERTALK**

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**HELP KEEP US THRIVING**

25

- SLPs are invited to learn about stuttering
- Nobody needs SLP-splaining
- Stuttering communities are for PWS first, allies second



### WHAT DOES IT MEAN TO BE AN ALLY TO PEOPLE WHO STUTTER?

A stuttering ally is a fluent person who is in solidarity with their friends and family who stutter. Being in solidarity with people who stutter means not only valuing and respecting them as individuals, but also being willing to experience both joy and hurt with them. An ally is someone who goes above and beyond kindness, they are willing to stand with people who stutter even when it may be difficult.

### THE GOLDEN RULE OF BEING AN ALLY

Let the people who stutter in your life know that you support them on their stuttering journey. Create an open and safe space for them to stutter and talk about stuttering. Remember, if you're unsure about something or how to help - the best thing to do is ask the person who stutters.

## ALLIES:

- 1 DEMONSTRATE INTEREST & ASK OPEN-ENDED QUESTIONS ABOUT STUTTERING, LIKE:**
  - How can I help?
  - How can I support you?
  - If that happens again, is there anything I can do?
- 2 RESPECT THAT EACH PERSON WHO STUTTERS HAS UNIQUE PREFERENCES & PERSPECTIVES REGARDING THEIR STUTTERING.**
  - Allies don't assume that people who stutter want to speak fluently.
  - Allies recognize that people who stutter are the experts on their own stuttering experiences.
  - Allies understand that it is the individual's choice to seek, accept, or decline speech therapy.
- 3 TAKE RESPONSIBILITY FOR PARTICIPATING IN THEIR OWN EDUCATION ABOUT STUTTERING.**
  - The best way to learn about stuttering is to talk with people who stutter.
  - It is not disrespectful for people who stutter if the responsibility to educate others is placed on them.
  - Allies are not expected to be stuttering experts, but they do take some initiative for learning more about stuttering.
- 4 MODEL HOW PEOPLE UNFAMILIAR WITH STUTTERING SHOULD RESPOND TO STUTTERING.**
  - Example: If a person stutter while ordering food at a restaurant with a group of friends, an ally would maintain eye contact until the food is ordered, listening to demonstrate to the server to do the same.
- 5 ARE WILLING TO STEP INTO DISCOMFORT TO SUPPORT PEOPLE WHO STUTTER.**
  - Allies stand up to people who do not understand stuttering.
  - Allies reduce negative stereotypes by educating others.
  - Solidarity means allies do these things with and for people who stutter.

Q5 26

## The Role of the SLP

- Encourage and challenge clients to seek community
- SLPs are the number one referral source for stuttering communities and organization
- Discuss and celebrate stuttering community experiences with clients
- You might be the only person with whom the client can share at length
- Participate as a person, not a professional
- Bring your whole self to allyship

27

## Closing

- Community is not a “bonus” part of successful therapeutic change...it is necessary
- There are many ways to access stuttering community engagement
- These can be broken down into small steps to facilitate client readiness and nice structured goal-writing
- SLPs have an important role in the stuttering community...but it's important to remember what our role is and what our role isn't
- Be yourself!

28



## Questions?

[katie@speechIRL.com](mailto:katie@speechIRL.com)

@speechIRL

[speechIRL.com](http://speechIRL.com)

29

## More resources

- StutterTalk podcast: [stuttertalk.com](http://stuttertalk.com)
- Make Room For The Stuttering: [stutterrockstar.com](http://stutterrockstar.com)
- Blog and podcast, special focus on the experience of women who stutter
- Facebook groups
- [Stuttering Community](#)
- [Stuttering Arena](#)
- [NSA-sponsored FB groups](#) (teens, young adults, parents, etc.)
- Reddit: <https://www.reddit.com/r/Stutter/>
- Includes connections to Discord servers

30

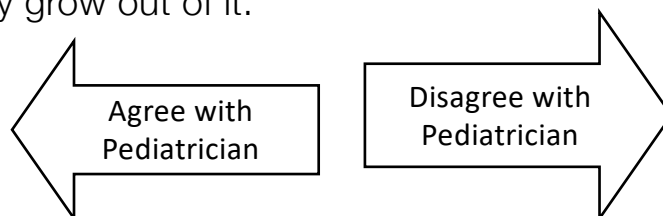
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31

## Case Study: John

- John's parents call you and describe him as a 2 year-old boy with a family history of stuttering (father stutters). John is current showing some signs of early stuttering. John's parents report that the pediatrician has told them to wait for a year or two, as John will likely grow out of it.



## Disagree with Pediatrician

- Age is not a significant factor. John is a boy with a family history. There is need for further evaluation.

Q6

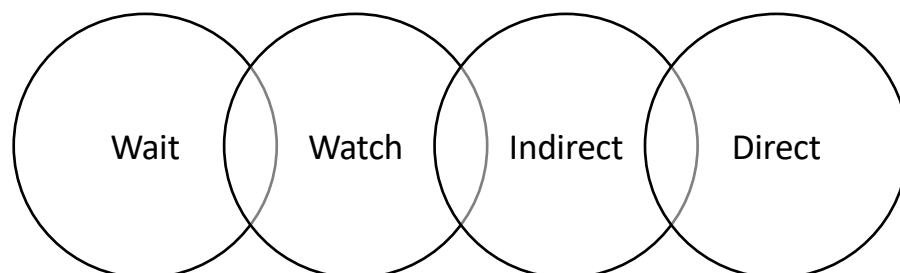
## Completing the Assessment

- Parent Interview / Case History
- Interact with the child
- Observe child's interactions with others (parents, siblings, peers) through live observation or videos
  - Obtain disfluency counts
  - Assess physical tensions and secondary behaviors
  - Administer SSI-4 or Test of Childhood Stuttering (TOCS)
  - Assess risk factors
  - Assess reactions to stuttering

## John's Assessment Data

- Disfluency Rates:
  - Clinician: 4%
  - Parents: 8%
  - Sibling: 16%
- Types of disfluencies: Repetitions with some prolongations. One block was noted. Slight increases in pitch and loudness during stuttering moments.
- Mild physical tension at times, no secondary behaviors
- Stuttering began 4-5 months ago
- Parents are concerned about stuttering
- No other speech and language concerns are present

## Dx Decisions

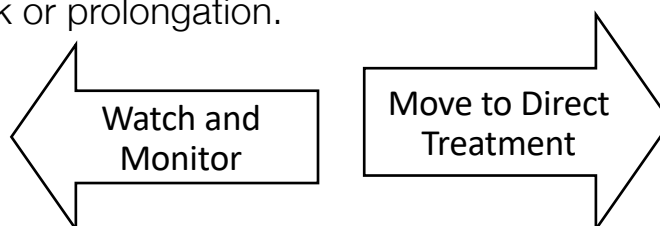


## Choice: Begin with Indirect

- Parent education
  - Speaking demands
  - Time pressure
  - Risk factors
- Modeling
  - Phrased speech
  - Indirect question prompts
  - Recasting / Rephrasing
- Re-evaluate after 4-6 sessions

## Progress

- After 5 sessions:
  - Disfluency rate with the clinician: 8%
  - Parents: 6%
  - Sibling: 9%
- Every so often, clinician notices the child will say “I can’t say it” or get frustrated when in a block or prolongation.



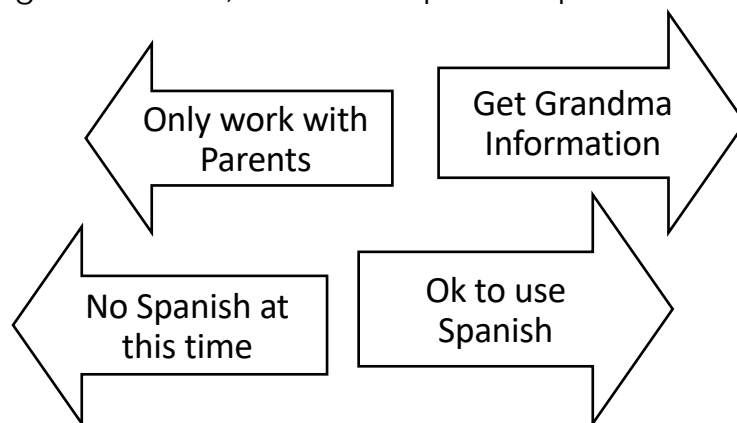
## Move to Direct Treatment

- Now begin to work on:
  - Directly targeting reactions
    - It's ok to have bumpy speech
    - Playing with stuttering
  - Strategies
    - Turtle Talk
    - Easy starts
    - Hard vs. Easy bumps

Q7

## Plot Twist

- John spends a lot of time each day with his grandmother, who also speaks Spanish.



CONTINUED

- Anyone who has a lot of contact with the child should have information about what to do
- No evidence that speaking multiple languages is a negative for fluency development

CONTINUED

## After 6 months of direct treatment...

- Disfluency rate in all settings is less than 3%
- Every so often a block or prolongation will happen
- Reactions of child and parent are positive
- Decision is made to discharge and monitor through
  - Parent contact each month for first three months
  - Re-evaluation if needed

CONTINUED

continued

## After Treatment...

- John's parents check in each month and report no changes. John is doing quite well and all agree further treatment is not necessary right now.

continued

## 8 Years Later...

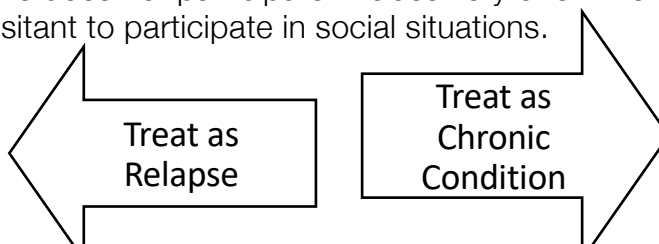
- John's parents call you and express some concerns. John has been doing well until this year. John is now in 5<sup>th</sup> grade (age 10) and has a teacher that tries to "eliminate" the remainder of his stuttering by telling him to "slow down and just think about what you want to say." John is starting to express frustration and is beginning to avoid various situations.

continued



## John's Re-evaluation

- John is re-evaluated with the following results:
  - SSI-4: Mild
  - OASES: Moderate; CCSA moderate
  - Disfluency rate is 6% but with significant blocks at times. John is reporting that he avoids words that he feels he might stutter on and he also reports that he does not participate in class very often. He is hesitant to participate in social situations.



Q9

## John Returns to Treatment

- Focus is now on:
  - Education
  - Support
  - Reducing the impact
  - Overall communication
  - Strategies
  - Counseling
    - Focus on communication and feelings / thoughts associated with stuttering

## Another Piece of the Puzzle

- Focus on Community
  - Teachers!!!!
  - Get John out in the community
  - Summer camps
  - Support groups

## After 3-6 months...

- John's OASES and CCSA scores have improved to a mild level
- John is working with his teacher to develop a good plan for participation
- John is raising his hand in class
- John is participating in social activities and has stopped avoiding words
- John has learned about stuttering and is teaching others. He can use strategies when he wants to.

continued

## Discharge Plan

- Touch base consistently with monthly support group
- Have plan in place for when John needs additional support/treatment
- Work with parents and teachers to monitor progress

Q10

continued

## Changing Roles

- Bring John back at times to teach other children about stuttering / be a model for them.

continued

## John is in College!

- John calls you during his freshman year and needs some guidance. He is doing more presentations now and he is also preparing for summer job interviews.

## Touch-base Sessions

- 4-6 sessions geared toward:
  - Discussing stuttering during presentations and job interviews
  - Maintaining support system in college
  - Helping John identify strategies to choose a career he wants, as a person who stutters

## John Becomes a Teacher

- John begins his career as a teacher. He needs to have a few sessions to consult on:
  - Use of fluency enhancing devices
  - How to talk to children and their parents about his stuttering
  - How to be a leader in the stuttering community

## Closing Themes

- Many times, this is a life-long process
- Support and education are key
- Stuttering is WAY MORE than disfluency
- Treatment needs to be comprehensive
  - So many components
- Education for SLPs is also critical



## Contact!

Craig Coleman: [ccoleman@edinboro.edu](mailto:ccoleman@edinboro.edu)

### More information:

[www.stutteringacademy.com](http://www.stutteringacademy.com)

### Facebook:

<https://www.facebook.com/groups/168290933806220/>



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