Introduction to Stuttering &
Working with Families of
Children who Stutter

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Contact Amy Natho at anatho@speechpathology.com
This handout is for reference only.
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Stuttering: What Every SLP
Should Know Part 2

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Assistant Professor, Marshall University
Learning Objectives

After this course, participants will be able to:
- Identify the role a parent may play in how a child experiences stuttering.
- Describe how to develop a blueprint for performing the initial interview of parents of children who stutter.
- Describe how to properly educate families on stuttering.
- Identify ways to ensure families are active participants in the treatment of children who stutter.
- Describe obstacles that stand in the way of family participation.

C. Coleman, 2013

Stuttering Causes

Neurophysiology
Genetics
Environment
Demands/Capacities
Temperament/Perssonality
Genetics

It has been consistently proven that genetics play a role in stuttering:
- Independent twin studies
- Adoption studies
- Large families with many cases of stuttering

Pinpointing the exact nature of the genetic link has been more elusive

Genetics: Role in Stuttering

We know that there is a genetic component of stuttering. We do not yet know enough to know exactly what specific genes are consistently altered or if there is a genetic component for everyone
Clinical Implications

- Genetic implications should be discussed
- May ease the burden for some people who think they have caused stuttering
- May increase feelings of guilt for some if their family history is positive for stuttering
- Discussion on genetics has the potential to alter viewpoint on stuttering from a disorder of emotion to a “medical” disorder

Clinical Case

- A 4 y.o. presents with a strong family history of stuttering on mother’s side. Mother is very emotional and worried that her genes have caused her child to stutter
- How do you handle this situation?
Neurophysiology

Neurophysiology also should be routinely discussed, not because we know for sure if that particular child has a certain neurological profile, but to help educate people on causes of stuttering. This can really help families and PWS to see that stuttering is a physiological disorder, not emotional, or voluntary.

Clinical Case

A parent of 3 y.o. you are evaluating is convinced that the child must have a neurological disorder because their stuttering started abruptly. Parent states “Everything was fine and one morning he just woke up and couldn’t get a word out.”
Environment

- Stuttering tends not to be any more prevalent in children who grow up in abusive or neglectful homes.
- While environment likely does not cause a child to start stuttering, it can have a significant impact on the reactions.
- Allergies analogy.

Creating a Positive Environment

- Modeling both targeted speech patterns AND positive reactions to stuttering.
- Reducing demands.
- Reducing time pressure.
- Focus on content, not just manner.
- Turn-taking.
- Let go of perfection!
Clinical Case

A parent states that they are concerned because their child is around another boy who stutters at preschool. Prior to this, their child was not stuttering. They are concerned that their child is learning stuttering from the other child at school.

Temperament

Again, while likely not a cause of stuttering, a child’s personality can play a role in how he responds to stuttering:
- Perfectionism
- High sensitivity
- Intense personality
- Competitive
- Reacts strongly
Resources


Working with Families of Children who Stutter

June 2015

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We won’t have time to cover...

› Involvement of the community
  ◦ Siblings
  ◦ Extended Family
  ◦ Teachers
  ◦ Other service providers (ex. OTs, reading specialists, etc.)
  ◦ Pediatricians
  ◦ Peers
  (Coleman, 2013)

› Treatment approaches
The Buy-in:
Why should we involve parents?
There is a robust evidence base that suggests the importance of parent participation, especially for pre-school aged children (Yaruss, Coleman & Hammer, 2006; Millard SK et. al, 2008; Jones M, et al, 2005, ).

Why is parent participation such an integral part of the therapy process??

1. Parents can be used as a resource for information and helping with the transfer of skills
2. Parents’ reactions have an impact on their child
3. The therapeutic alliance plays a role in treatment outcomes

The Buy-In:
Why should we involve parents?

1. Parents are a resource…use them!
   - We know a lot about *stuttering* and they know a lot about their *children*.
   - Developmental history
   - Temperament
   - Impact of stuttering across a variety of environments
   - etc. etc. etc.

*They can provide us with information that may help us reach our goals in a shorter period of time!*
The Buy-in: Why should we involve parents?

1. Parents are a resource...use them!
   - Generalization and maintenance

2. The role of reactions
   - Parents do NOT cause stuttering
   - However, the way parents respond to stuttering can influence how a child thinks, feels and reacts to stuttering and play a role in how stuttering impacts their quality of life.
The Buy–in: Why should we involve parents?

2. The role of reactions

3. The power of the therapeutic alliance:

- Therapeutic Alliance involves 3 features:
  - Development of bonds
  - Agreement on goals
  - Assignment of tasks

  (Bordin, 1979)
The Buy-in: Why should we involve parents?

3. The power of the therapeutic alliance:

- Common Factors Model: The strength of the relationship between the clinician and the client (child and their family) has been shown to contribute more to treatment outcome than the chosen technique/approach.

![Pie chart showing the distribution of factors affecting treatment outcome.]

- Hope and expectancy (15%)
- Therapeutic Alliance (30%)
- Technique/approach (15%)
- Extra-therapeutic factors (40%)

Lambert & Bergin, 1994
Asay & Lambert, 1999
Bernstein Ratner, 2005
Franken, Kielstra-Van der Schalk & Boelens, 2005

The Parent Interview

- Why do I need to do a parent interview?

  - Set expectations
  - Use the parent as a resource
  - Answer common questions
The Parent Interview

1. Set expectations
   ◦ This is a team approach
   ◦ The presence of BOTH parents is ideal

2. Use parents as a resource:
   ▶ Risk factor questions:
     ◦ Age of onset?
     ◦ Time since onset?
     ◦ Family history? Does family member still stutter?
     ◦ Does your child have any other diagnoses?
   ▶ The basics:
     ◦ What does your child’s stuttering sound like?
     ◦ Does your child do anything with his body while he’s stuttering?
     ◦ When your child started stuttering did it occur suddenly or gradually?
     ◦ Did your child’s stuttering onset coincide with a big change or traumatic event?
     ◦ Has your child’s stuttering changed over time?
The Parent Interview

- **Child’s Reaction Questions:**
  - Do you believe your child is aware of his stuttering? What does your child do when he stutters to show you that he is aware or unaware of his stuttering?
  - What does your child do to help himself when he stutters?
  - Has your child brought up stuttering with you? What did that conversation look like?

- **Parents’/Familys’ Reaction Questions:**
  - On a scale of 1–10 with 10 being very worried, how worried are you about your child stuttering (separate ratings for each parent). Has your rating changed since you first started noticing stuttering?
  - How do you respond to your child when he stutters?
  - How does your child’s siblings respond when he stutters?
  - How do other family members respond when he stutters?
  - If your child continues to stutter, what would you like his life to be like in 5 years?

The Parent Interview

- **Environmental Questions:**
  - What makes your child stutter more? Less?
  - How do you think stuttering impacts your child at school?
  - How do you think stuttering impacts your child socially?
  - Describe what a typical family conversation looks like.
  - Describe what a typical interaction looks like when you’re observing your child with his friends.

- **Temperament Questions:**
  - How would you describe your child’s personality?
  - What happens when your child makes a mistake or gets something wrong?
  - What happens when your child thinks you’re upset or mad with him?

- **Past therapy Questions:**
  - What did you and your child learn with your past clinician?
  - What has worked before? What hasn’t?
The Parent Interview

3. Answer common questions
   ◦ Validate concerns
   ◦ Fight the urge to protect

Initial Sessions–Education

› Education should be ongoing and can be provided by:
   ◦ Parent consult
   ◦ The child
   ◦ Handouts
   ◦ Support groups
Families should know:

1) What is stuttering?
2) What is the cause?
3) Is there a cure?
4) What can I do to help?

1. What is stuttering?

- A disruption in the flow of speech characterized by:
  - repetitions
  - prolongations
  - blocks
- May occur with:
  - Physical tension/struggle
  - Secondary behaviors (i.e. blinking, tongue clicking)
  - *Avoidance of words/situations
  - *Negative reactions (affective, cognitive, behavioral)

*Some components of stuttering are observable and some are not—we need to address both!!
1. What is stuttering?

- Types of stuttering

<table>
<thead>
<tr>
<th>Stuttering–like Disfluencies</th>
<th>Nonstuttered Disfluencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monosyllabic whole word repetitions</td>
<td>Multisyllabic whole word repetitions</td>
</tr>
<tr>
<td>Sound/syllable repetitions</td>
<td>Interjections</td>
</tr>
<tr>
<td>Prolongations</td>
<td>Phrase repetitions</td>
</tr>
<tr>
<td>Blocks</td>
<td>Phrase revisions/abandoned utterances</td>
</tr>
</tbody>
</table>

- Variability

2. What causes stuttering?

[Diagram: Neuro-physiological Factors, Speech/Language Factors, Personal Factors, Environmental Factors]

Kelman & Nicholas, 2008
Initial Sessions–Education

2. What causes stuttering?

- Family history (father)
- Anxious when making mistakes
- Confident
- Receptive/expressive language delay
- Proactive family
  - Talking time competition between siblings

3. Can my child be cured?

For the pre-school aged child (~ 6 years and younger)
- Our goal is to eliminate or greatly reduce the frequency and severity of stuttering

For older children/teens (~7+ years and older)
- We have not identified a cure, however your child can learn ways to manage stuttering so that we can minimize the negative impact it has on their life.
- We are NOT giving up on increasing fluency, however we’re working on fluency AND the other components of the stuttering disorder (i.e. becoming an advocate for themselves, improving overall communication skills, developing positive attitudes towards talking, reducing avoidances, etc.)
Initial Sessions–Education

4. What can I do to help?

- Start with the environment
  - Reduce your own pace
  - Balance comments and questions
  - Reduce talking demands
  - Encourage turn-taking
  - Praise for content
  - Show your child you understood their message
  - Talk openly about stuttering

The answer to this question will be an ongoing theme of therapy and will be taught by both SLP and the child!
Treatment–Active Participants

- Involving parents in therapy sessions
  - Journaling
  - Re-doing session with parent
  - Encouraging parents to share in experiences with child (i.e. voluntary stuttering assignments)
  - “Checking in” sessions (with parent and child)
  - Periodic parent consults (without child present)

Treatment–Active Participants

- Homework
  - Establish “special times”
  - Homework is not JUST practicing speech strategies
  - Use real–life activities
Obstacles

- The Obstacle: Misinformation provided by others
  - Pediatrician
  - Friends
  - Teachers
  - Other SLPs
  - Internet

- The Solution:
  - Ask parents what they already know about stuttering/stuttering treatment
  - Monitoring activities
  - Providing reputable and valuable resources (SFA, NSA, FRIENDS, etc.)

Obstacles

- The Obstacle: Large caseloads/Lack of time

- The Solution:
  - Educate administration from the start (and ongoing)
  - Start a communication journal
  - Have the child complete your daily “update” to be sent home to the parent
  - Send home videos of activities стратегий (keep in mind your school/organization’s regulations and state laws)
Obstacles

› The Obstacle: The busy parent

› The solution
  ◦ Set expectations from the initial phone call
  ◦ Brainstorm with the parent
  ◦ Phone conferencing/Tele-therapy option (keep in mind your school/organization’s regulations and state laws)
  ◦ The all-mighty journal
  ◦ Let parents/children develop home assignments

Obstacles

› The Obstacle: The child who doesn’t want their parents involved

› The solution:
  ◦ Have child identify what parents know/don’t know
  ◦ Develop a hierarchy for including the family
  ◦ Provide child with some control over the information they want to share with their parents
Free Internet Resources

- General Information
  - www.asha.org/Practice-Portal/Clinical-Topics/Childhood-Fluency-Disorders/

- Self Help/Support Groups
  - http://www.stutteringhelp.org/
  - http://www.westutter.org/
  - http://www.friendswhostutter.org/

- Podcasts
  - www.stuttertalk.com

- Handouts/Forms
  - http://www.fluencyfriday.org/index.html
  - http://www.stutteringcenter.org/stuttering-center-forms.html
  - http://www.mnsu.edu/comdis/kuster/

- My Website
  - www.stutteringsource.com

Any Questions?

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References and Resources