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Creating Allies and Developing Advocacy Skills in Stuttering Therapy

Brooke Leiman Edwards, MA, CCC-SLP;
Hope Gerlach, PhD, CCC-SLP

Moderated by:
Amy Hansen, MA, CCC-SLP, Managing Editor, SpeechPathology.com

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continu(ed)

Creating Allies and Developing Advocacy skills in Stuttering Therapy

Brooke Leiman Edwards MA, CCC-SLP, BCS-F
Hope Gerlach Ph.D., CCC-SLP

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CONTINUED

- **Presenter Disclosure:** Brooke Leiman Edwards- Financial: Brooke Leiman Edwards received an honorarium for this presentation. She is Director of the stuttering clinic at National Therapy Center. Nonfinancial: Brooke helped develop the ASHA practice portal on Childhood Fluency Disorders, is a member of the Coordinating Committee for ASHA's Special Interest Group for Fluency Disorders, and is on the Executive Board of the American Board of Fluency and Fluency Disorders. She hosts a blog, www.stutteringsource.com, that is focused on building awareness and knowledge of stuttering and its treatment. Hope Gerlach - Financial: Hope Gerlach was paid an honorarium for this presentation. Nonfinancial: No relevant relationships to disclose.

- **Content Disclosure:** This learning event does not focus exclusively on any specific product or service.

- **Sponsor Disclosure:** This course is presented by SpeechPathology.com.

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Learning Outcomes

After this course, participants will be able to:

- Identify at least 3 reasons why families should be involved in the speech therapy process.

- Identify at least 3 strategies for actively involving families in the speech therapy process.

- Describe similarities and differences between stuttering-related applications of the medical and social models of disability.

- Describe reasons why promoting self-advocacy skills among clients who stutter is within the scope of practice for speech-language pathology, and clinically meaningful.

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I won't have time to cover…

- Involvement of the community
  - (ex. siblings, extended family, teachers, other services providers, pediatricians, peers, etc.) Coleman, 2013

- Common treatment approaches (ex. fluency shaping, stuttering modification, etc.)

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The Buy-In:
Why should we involve parents?

There is a robust evidence base that suggests the importance of parent involvement in therapy (Hughes, et. al, 2011, Yaruss, Coleman & Hammer, 2006; Millard SK et. al, 2008; Jones M, et al, 2005, and more!)

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

1. Parents are a source of information
2. Parents' reactions have an impact on their child
3. The therapeutic alliance plays a role in treatment outcomes

Q1

continuED

continuED

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
        - Changes to stuttering/reaction to stuttering over the course of treatment
        - Etc., etc., etc…
    - **They can provide us with information that may help us reach our goals in a shorter period of time and/or make changes to a treatment plan when necessary!**

    - Generalization and maintenance

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continuED

The Buy-In:
# Why should we involve parents?

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

        - Children who stutter may benefit from support from their family to work through the emotional and attitudinal aspects of stuttering (Hughes, et. al, 2011)

continuED

CONTINUED

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.

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

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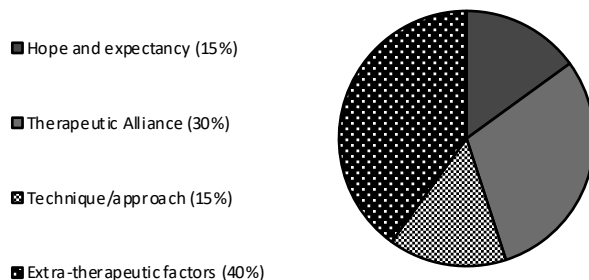
The Assessment: Parent Interview

- Why do I need to do a parent interview?
  - Set expectations
    - This is a team approach
  - Use the parent as a resource
  - To begin education on stuttering
- What format should I use?
  - In-person is best
  - Phone, video conferencing or written questionnaires work as well make sure HIPAA compliant

  *I know that there will be obstacles to involving parents based on your setting, the family, etc. We will problem-solve those things later!

Q2&3

CONTINUED

continuED

The Assessment: Parent Interview

Some information to consider gathering:

- **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?

Q3

continuED

The Assessment: Parent Interview

- **Child's Reaction Questions:**
    - Is your child aware of stuttering? How do you know?
    - 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?

continuED

The Assessment: Parent Interview

- Environmental Questions:
    - What makes your child stutter more? Less?
    - How does stuttering impact your child at school?
    - How does stuttering impact your child socially?
    - Describe what a typical family conversation looks like.
    - Describe what a typical interaction looks like when your child is 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?
- Past therapy Questions:
    - What did you and your child learn with your past clinician?
    - What has worked before? What hasn't?

Initial Sessions:
Education & Shared goals/Desired Outcomes

*Just a reminder: we will discuss overcoming obstacles to parent involvement at the end! We're getting there!

- Treatment planning should involve the SLP, child AND the parent and be ongoing
- Education should also be an ongoing process and can be provided by:
    - The SLP
    - Handouts and other printed resources
    - The child
    - Support organizations
- What format should I use?
    - Parents can be present for the session or for parts of the session
    - Periodic "checking in" sessions with parent and child present
    - Periodic parent consultations (without child present)
    - Journaling
    - Child can "re-do" session with parent for homework
    - Encouraging parents to share in experiences with child (i.e. voluntary stuttering assignments)

Q4

CONTINUED

Initial Sessions - Education

- Families should know:
  - 1) What is stuttering?
  - 2) What do we know about the cause?
  - 3) Is there a cure?
  - 4) What can I do to support my child?

CONTINUED

Initial Sessions - Education

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 parents to buy-in to the idea that we need to address both!!

CONTINUED

CONTINUED

Initial Sessions - Education

- 2. What do we know about the causes of stuttering?
  - Stuttering is thought to occur due to the interaction of a number of different causes or influences. Some factors contribute to the <u>emergence of stuttering</u> and some factors contribute to how the <u>child reacts to stuttering (impact)</u>
    - Neurophysiological factors/genetics (ex. father stutters)
    - Speech/language factors (ex. child has a co-existing receptive/expressive language disorder)
    - Personal factors (ex. child is prone to increased levels of anxiety when he/she makes a mistake)
    - Environmental factors (ex. a lot of talking time competition between siblings)

CONTINUED

Initial Sessions - Shared Goals and Desired Outcomes

3. Can my child be cured?

Through parent education and counseling, our goal is to develop shared goals that are <u>realistic, achievable and beneficial</u> for the child/family:

- For the pre-school aged child (~ 6 years and younger), examples of desired outcomes may include:
  - increasing the chances that the child eliminates or greatly reduces the frequency/severity of stuttering
  - reducing the child's fear and/or discomfort while stuttering
  - ensuring the child continues to enjoy talking and demonstrates a healthy attitude towards communication (whether or not they are stuttering).
- For children ~7+ years and older, examples of desired outcomes may include:
  - guiding their child in becoming an advocate for themselves
  - supporting their child in developing positive attitudes towards talking and reducing avoidances of communication
  - providing their child options for how to effectively respond to and/or manage stuttering moments
  - improving their child's overall communication skills

CONTINUED

CONTINUED

Initial Sessions- Education

4. What can I do to help?

- Supporting the child is not limited to encouraging them to practice "strategies" but **must also** include opening up the lines of communication with regards to the emotional components of stuttering. (Hughes et. al, 2011)

CONTINUED

Beyond the Initial Sessions:

We involved parents in the assessment, we collaborated with them to develop shared goals and desired outcomes, we educated them on stuttering- are we "done" now?

NO!

- We need ongoing collaboration to "keep up with the child." Goals and objectives will change as the child gets older and encounters different speaking situations.

- Parents thoughts, feelings and reactions to stuttering may change as the child gets older as well!

- Parents can assist in generalization of skills and progress to other environments (this includes both the observable stuttering but ALSO their thoughts and feelings related to stuttering)

*OK we made it! – Let's go through some case studies that highlight different obstacles you may face when trying to involve parents!

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Case Study: "Ella"

- "Ella" is a 9-year old girl who is seen with 2 other children in a school setting. She reported that her mother "just doesn't understand what it's like" and that she constantly interrupts her to remind "Ella" to "use your strategies!" Due to speech services occurring during the school day, her mother is not present and can't come observe/join in due to privacy issues related to the other children in her group. There is practically no time during the day for phone calls/meetings with the parent!

CONTINUED

Case Study: "Ella"

- The Obstacle:
  - Mother's reaction is having an impact on the child
  - Large caseloads/Lack of time
- The Solution:
  - Educate IEP team (including the parents) from the start about the importance of parent participation in stuttering therapy. Brainstorm how you will do this at the beginning of the school year/initial IEP meeting.
  - Complete the parent interview via phone or a written intake form
  - Start a communication journal
  - Have the child complete your weekly update to be sent home to the parent/in the communication journal
  - Send home videos of activities/strategies (keep in mind your school/organization's regulations and/or state laws)
  - Keep parents updated on local stuttering support group events

CONTINUED

CONTINUED

Case Study: "Jake"

- Jake is a 7-year-old boy with a single working mother. His nanny usually brings Jake to therapy. During the initial phone intake, Jake's mother appears panicked when talking about the idea of her being a part of the therapy team. She wants the best for her son but is simply unable to take off work every week to bring him.

CONTINUED

Case Study: "Jake"

- The Obstacle: The busy parent
- The Solution:
  - Set expectations from the initial phone call
  - Involve parent when brainstorming ways they can participate in the therapy process
  - Start small— "can you commit to joining us for the last 5 minutes of the session once a month?"
  - Phone conferencing/Tele-therapy option (keep in mind your school/organization's regulations, state laws and insurance restrictions)
  - Use a communication journal
  - Let parents/children develop home assignments to ensure they are realistic and to hold them more accountable

Q5

CONTINUED

CONTINUED

Case Study: "Mason"

- "Mason" is an 11-year-old boy who has never received speech therapy before. His parents reported that Mason's pediatrician has always told them that their son "thinks faster than he can speak" and that it's nothing to be concerned about. His parents have come to you for a "few quick tips to help him become more fluent" and they stated that "it should only take a couple of sessions." They report "he doesn't really stutter- just stammers sometimes." They seem confused and hesitant when they are asked to come in for the parent interview.

CONTINUED

Case study: "Mason"

- The Obstacles:
    - Misinformation provided by pediatrician
    - Parents' expectations of speech therapy do not seem realistic
    - Parents are demonstrating some defensiveness and do not want to make this a "big deal"

- The Solution:
    - Explain the variability of stuttering and let parents know the interview is there to make sure they have a chance to help you individualize treatment to their son
    - Ask parents what they already know about stuttering/stuttering treatment
    - Assign monitoring activities/thought experiments
    - Provide reputable and valuable resources (SFA, NSA, FRIENDS, SAY etc.)
    - Be flexible- the parents may simply not be ready to be active participants but find small ways for them to test the waters and see for themselves the importance of them being involved

CONTINUED

CONTINU**ED**

Case Study: "Max"

- Max is a 14-year-old boy who appears to shut down when his parents join the last 5 minutes of sessions. When asked about his change in demeanor at the end of sessions, he admitted that his parents used to come to sessions when he "was a kid", but he doesn't need them anymore.

CONTINU**ED**

Case Study: "Max"

- 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 of situations for how to include the family
  - Provide child with some control over the information they want to share with their parents
  - Periodic parent-only consultations

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The Role of the Speech-Pathologist in Intervention

As speech-pathologists, it is our role and responsibility to promote "efficient and effective outcomes" for our clients

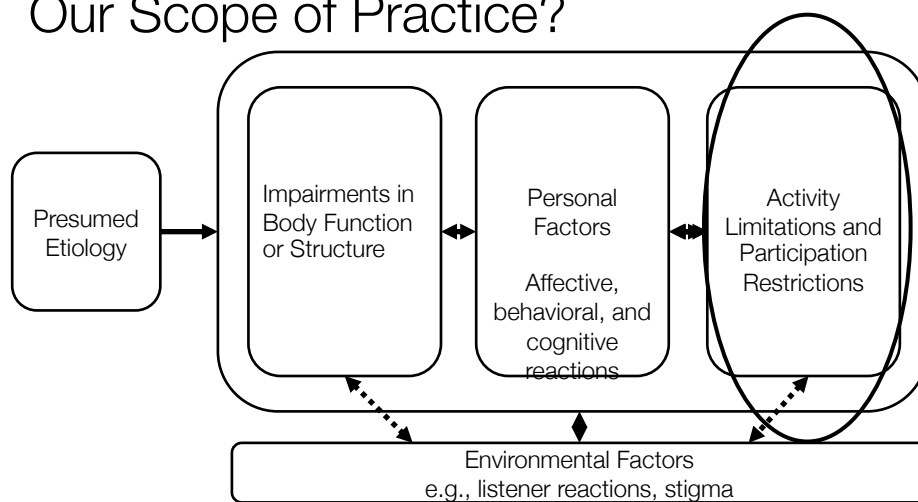But what are efficient and effective outcomes for client who stutter?
- It depends on how we define stuttering as a <u>disability</u>
- Medical versus Social Models of Disability

CONTINUED

Models of Disability

	The Medical Model	The Social Model
What is the root cause of disability?	Abnormalities or deficits in the brain or body	Stigma; Societal barriers
How is stuttering viewed?	Something "wrong" with the person that needs to be fixed	Normal, legitimate expression of neurodiversity
Relationships with professionals?	Clients are recipients of help from experts	Client-driven, collaborative process
Efficient and Effective Outcomes?	Fixing, curing, or preventing the "deficit"	Increasing access and participation in society

Q6

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How does Self-Advocacy relate to Our Scope of Practice?

| Presumed Etiology | → | Impairments in Body Function or Structure | ↔ | Personal Factors

Affective, behavioral, and cognitive reactions | ↔ | Activity Limitations and Participation Restrictions |

Environmental Factors
e.g., listener reactions, stigma

Yaruss & Tichenor (2019)   Q7

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What is Self-Advocacy?

"Effective communication regarding goals and preferences that matter to an individual"[1]

Sub-component of the larger concept of self-determination[2]

Most importantly… a *skill* that can be learned

[1]Test, Fowler, Wood, Brewer, & Eddy, 2005; [2]Field, 1996

continu‍ed

Benefits of Increasing Self-Advocacy

- Gains in…
  - Self-confidence
  - Self-awareness
  - Self-efficacy
  - Feelings of empowerment
  - Leadership skills

- Increased ability to explain…
  - Their disability
  - Goals

Roberts, Ju, & Zhang, 2016

Therapy Activities for Promoting Self-Advocacy Skills for Clients Who Stutter

Promoting Self-Advocacy

- Explore Accommodations
- Write it out
- Learn the Facts
- Foster Connections
- Educate others
- Role-Play
- Advertising
- Disclosure
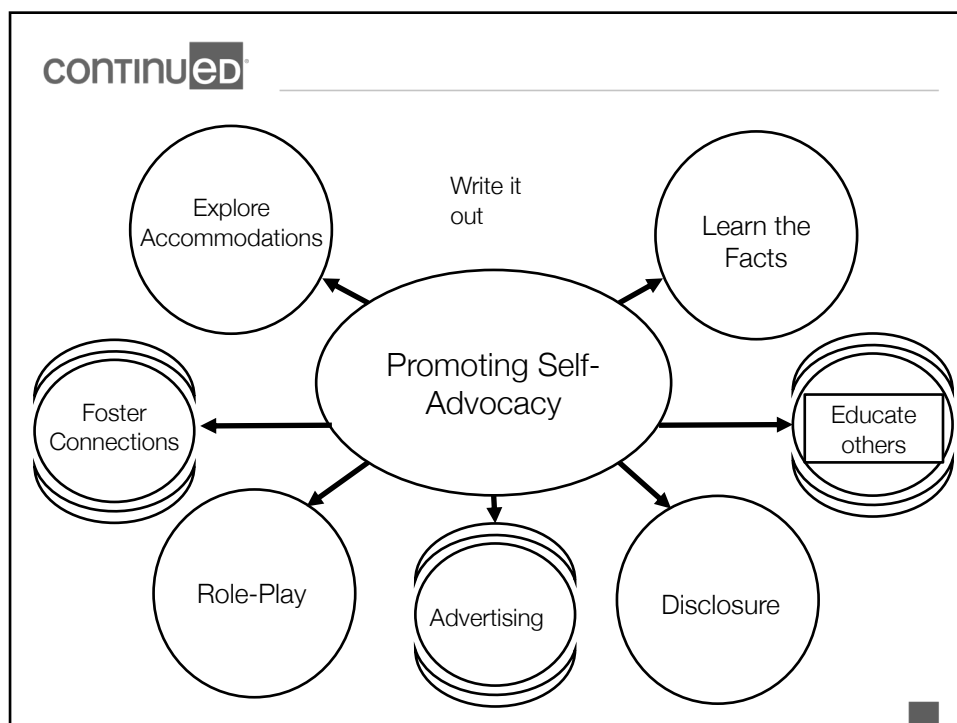
Learning the Facts

Promoting Self-Advocacy → Learn the Facts

What might be helpful for clients to know?
- Speech machine
- Stuttering is no one's fault
- Variability is normal!
- Types of stuttering

Potential outcomes
- Exposing the "magic" of stuttering can increase feelings of empowerment
- Creates solid foundation for more advanced advocacy activities and speech modification, too

continued

Educating Others

Promoting Self-Advocacy → Educate others
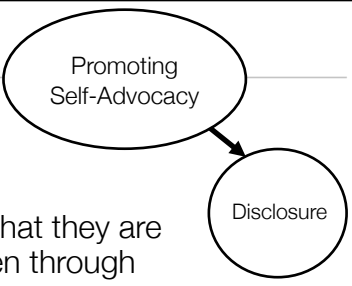
Sample Activities
- Classroom presentation (https://westutter.org/wp-content/uploads/2016/11/Classroom-2015.pdf)
- Stuttering facts booth
- Stuttering brochure
- Educational comics
- Submit letters and drawing to SFA newsletter

Potential outcomes
- Improved ability to explain stuttering to others
- Experience and practice with expressing needs and desires
- Instills from a young age that stuttering does not have to be a taboo topic

Q8

Disclosure
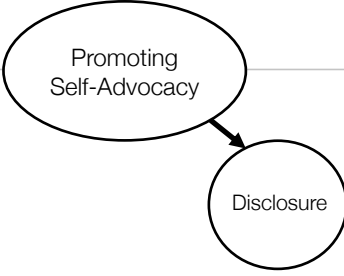
Promoting Self-Advocacy → Disclosure

- Disclosure occurs when clients share that they are a person who stutters with others, often through verbal communication.

- Disclosure should always be a personal choice
  - Individual disclosure decision often involve cost-benefit analyses

- First disclosure experiences are important and can have lasting effects on how people feel about disclosure[3]

[3]Chaudoir & Quinn, 2010

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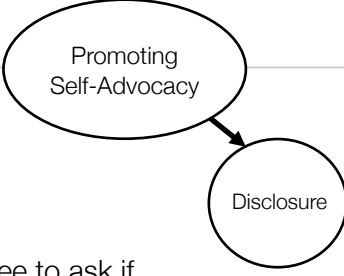
Promoting
Self-Advocacy

Disclosure

Disclosure

Potential benefits of disclosure:

- Reduced worry, fear[4]
- Increased authenticity, self-respect, presence in moments of communication[4]
- Improved communication[4]
- More positive listener perceptions[5]

[4]Boyle & Gabel, 2020; [5]Healey, Gabel, Daniels, & Kawai, 2007

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Promoting
Self-Advocacy

Disclosure

Disclosure

Sample disclosure statements:

- "You might notice that I stutter, feel free to ask if you have any questions about it."

- "I am a person who stutters. You'll get used to it."

- "I stutter, so it's totally normal for me if you hear some pauses in my speech."

   *Disclosures have shown to be more effective when used at the beginning of interactions with informative tones.[5, 6]

[5]Healey, Gabel, Daniels, & Kawai, 2007; [6]Byrd, Croft, Gkalitsiou, & Hampton, 2017

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Promoting Self-Advocacy

Advertising

Advertising

Disclosure is not the only way for clients to be open about their stuttering
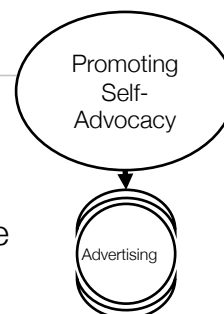
Clients can advertise stuttering in other ways including…
- Wearing a stuttering-related shirt or pin
- Open stuttering
- Pseudostuttering
- Referencing speech therapy or self-help groups

Potential benefits: "deawfulizing" stuttering and reducing shame

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CONTINU ED

Promoting Self-Advocacy

Role-playing

Role-Play

Why role-play and when to do it?
- Allows clients to "try on" advocacy strategies in a safe environment
- Before real-world experiences

Role-play formats
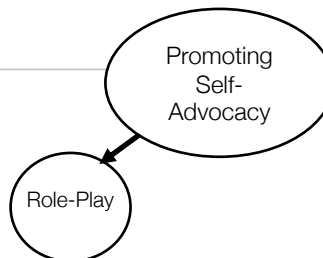- Client can play themselves (the person who stutters) or the communication partner

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Slide 1

continued

Promoting Self-Advocacy
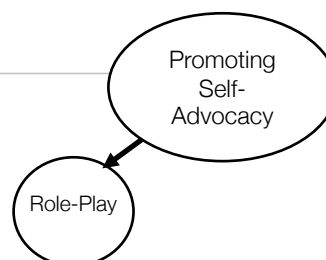
Role-playing

Role-Play

__Difficult questions and scenarios__
- "Why do you talk like that?"
- "What is stuttering?"
- "Can you stop doing that?"

*practice with pseudostuttering if real moments of stuttering aren't present

__Bullying responses__

__Responding to undesired listener reactions__
- Being interrupted
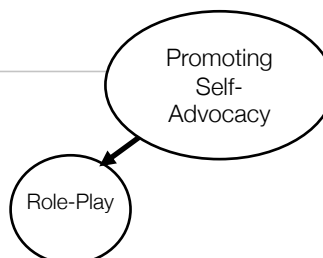- Having sentences finished
- Being looked away from or stared at

Slide 2
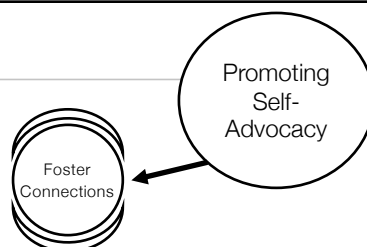
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Promoting Self-Advocacy

Role-playing

Role-Play

Potential benefits

- Increased comfort during moments of real world self-advocacy

- Increased likelihood that the client will self-advocate

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Foster Connections

Foster Connections

Promoting Self-Advocacy

Sample activities
- Group therapy with other kids who stutter
- Mentor/mentee relationships
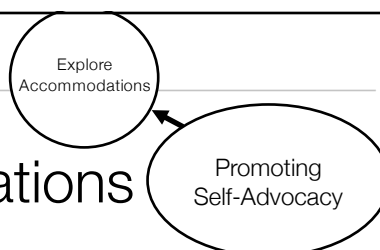- Pen pals/virtual hang outs

Potential benefits of social support among youth who stutter:
- Reduced negative life impact[7]
- Increased self-acceptance[7]
- Normalizes stuttering[7]

[7]Gerlach, Hollister, Caggiano, & Zebrowski, 2019

Q10

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Explore Accommodations

Promoting Self-Advocacy

Explore Accommodations

Accommodations are adjustments that remove barriers and promote accessibility for people with disabilities

Examples of stuttering-related accommodations:
- Called on only when hand is raised
- Extra time for verbal presentations
- No loss of points for disfluency in oral communication
- Alternate presentation arrangements
- Option to choose "order" in presentation line up

Q9

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# Case Study Applications

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Case Study 1: Benny

- Benny is a 3rd grader on your caseload. His mom emailed you and said that she is concerned that Benny "doesn't know how to talk about stuttering at school with his friends and teachers."

- What are some examples of therapy activities that may help Benny develop age-appropriate self-advocacy skills?

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Case Study 1: Benny

Sample goals
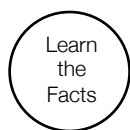
(Learn the Facts)
- Benny will increase his knowledge about stuttering as indicated by obtaining an 80% or higher on 3 quizzes assessing basic facts about stuttering.

(Educate others)
- Benny will educate two friends about stuttering using a format of his choice (e.g., informal conversation, stuttering brochure) and journal about his experiences in his stuttering notebook.

(Role-Play)
- Benny will identify and describe 2 "difficult stuttering situations" and role-play self-advocacy responses with the clinician, provided with verbal prompting as needed.

CONTINUED

Case Study 2: Marquise

- Marquise, a 7th grader, reports that he is experiencing bullying and feels lonely with stuttering.

- What are some examples of therapy activities that may help develop this client's self-advocacy skills?

CONTINUED

CONTINUED

Case Study 2: Marquise

Sample goals

Role-Play

- Marquise will role-play 5 unique self-advocacy responses related to bullying with the clinician, provided with verbal prompting as needed.

Foster Connections

- Marquise will interview an adolescent or adult who stutters and journal about his experience in his stuttering notebook.

- Within the context of stuttering group therapy, Marquise will participate in 3 conversations about stuttering-related thoughts and feelings over the course of the semester.


CONTINUED

Case Study 3: Theresa

- Theresa, a 9th grader, reports that she is "extremely anxious" about starting high school. She reported that she had a hard time paying attention in class in 8th grade because she worried that the teacher would unexpectedly call on her.

- What are some examples of therapy activities that may help develop Theresa's self-advocacy skills?

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Case Study 3: Theresa

Sample goals

Educate others

- With support, Theresa will compose an email draft describing her preferred learning environment to share with teachers.

Explore Accommodations
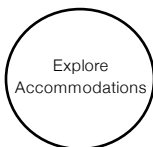
- Theresa will demonstrate the ability to independently describe classroom accommodations related to stuttering.

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Free Online Advocacy Resources

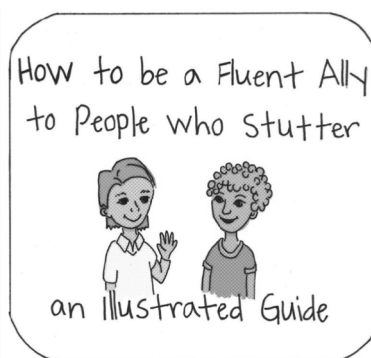https://kids.frontiersin.org/article/10.3389/frym.2019.00153

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contInuED

Free Online Advocacy Resources

http://isad.isastutter.org/isad-2017/papers-presented-by/creative-expression/how-to-be-a-fluent-ally-to-people-who-stutter-an-illustrated-guide/comment-page-1/

How to be a Fluent Ally to People who Stutter

an Illustrated Guide

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contInuED

Any Questions?

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