Assessment of the Child’s Experience of Stuttering (ACES)

A New Instrument for Assessing the Entire Stuttering Disorder in Child Ages 7 to 18

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One of the *Most Important* Facts about Stuttering

“Stuttering is more than just stuttering”

- In other words…
  - *The child’s experience of stuttering involves more than the just the production of speech disfluencies*
A Problem for Both Clinicians and Researchers

- Although many have discussed the importance of examining the entire disorder in treatment and research

  - The field does not currently have a tool for measuring the full impact of stuttering in school-age kids
A Problem…Compounded

- VERY few treatment outcomes studies have examined changes in the overall impact of stuttering for children in speech therapy
  - This is particularly troubling in the current climate emphasizing “evidence-based practice”
Seeking a Comprehensive Solution

- If we wish to do a better job of...
  - Evaluating the full impact of stuttering in children’s lives AND
  - Documenting treatment outcomes

- We will need a means of describing the true nature of the disorder... and an instrument for evaluating it
Step 1: Describing the True Nature of Stuttering

- The World Health Organization has developed a model for describing the impact of disorders on people’s lives

*The International Classification of Functioning, Disability, and Health* (ICF; WHO 2001)
The ICF describes Health Experience in terms of:

- **Body Function & Structure**: the major physiological and psychological functions of the body

- **Functioning & Disability**: the major areas of people’s daily lives
The ICF Describes When Things Go Wrong

- **Impairments** in Body Function or Structure can lead to...
  - **Limitations** in a person’s ability to perform daily activities or...
  - **Restrictions** in the person’s ability to participate fully in life
The Role of the Speaker’s Reactions to Stuttering

- The link between the impairment and negative consequences is mediated by the speaker’s *reactions* to stuttering
  - Positive/neutral reactions lead to less impact; Negative reactions lead to greater impact
Identifying and Classifying the Child’s Reactions

- **Reactions** (or communication attitudes) can be viewed as:
  - **Affective**: Feelings, emotions
  - **Behavioral**: Tension, struggle
  - **Cognitive**: Self-esteem, self-confidence
It’s Not Just the Child’s Reactions

- The reactions of the people in the child’s environment also affect the child’s experience of stuttering
  - Bullying & teasing, high demands on communication, unrealistic expectations, pressure to be “completely” fluent, etc.
Based on the WHO’s ICF as described by Yaruss (1998), Yaruss & Quesal (2004)
How Does This Help Us With Measurement?

- The model provides a *roadmap* for assessing the entire disorder
  - **Impairment**: Observable stuttering behavior
  - **Reactions**: Affective, Behavioral, Cognitive
  - **Environmental Reactions**: peers, parents
  - **Activity Limitation/Participation Restriction**: Overall Impact of stuttering on the child’s life
Step 2: Developing a Measurement Instrument

- Many instruments for assessing specific aspects of stuttering have been developed (CAT-R, SEA-scale)
  - To date, there is no *single* instrument that examines the entire disorder
  - Such a tool would enhance and simplify measurement, both for clinical and research purposes
Assessment of the Child’s Experience of Stuttering

The ACES is a new instrument for assessing the overall impact of stuttering on the child’s life... from the child’s perspective
Development of the ACES

- The ACES was based on a similar instrument for adults who stutter

Overall Assessment of the Speaker’s Experience of Stuttering (OASES)

Yaruss & Quesal (2004)

For info, ask or see www.StutteringCenter.org
The original OASES underwent extensive testing and validation

- More than 300 people who stutter completed early versions; data were analyzed to ensure reliability/validity

Items in the ACES were adapted from the OASES to ensure that they were appropriate for children
Structure of the ACES

- Four sections examining different aspects of the stuttering disorder
  - General Information about Stuttering
  - Affective, Behavioral, Cognitive Reactions
  - Communication in Daily Situations
  - Impact of Stuttering on Quality of Life
Part I: General Information

- **20 items** examining the child’s…
  - **Perception** of his speech fluency *(impairment)*, speech naturalness, use of speech therapy techniques
  - **Knowledge** about stuttering and factors that affect speech fluency
  - Overall **attitudes** toward speech, stuttering, communication, & therapy
Part II: ABC Reactions

- 30 items about the child’s reactions to the fact that he stutters
  - **Affective**: feelings of fear, anxiety, embarrassment, shame
  - **Behavioral**: physical tension, struggle, avoidance, circumlocution
  - **Cognitive**: low self-esteem, reduced self-confidence
Part III: Communication

- **25 items** about communication in key activities or environments
  - **At school:** talking to kids & teachers, giving presentations, asking questions
  - **In Social Activities:** talking in small groups or one-on-one, telling jokes
  - **At Home:** Using the phone, talking with family members, etc.
Part IV: Quality of Life

- **25 items** about the overall impact of stuttering on Quality of Life
  - How much stuttering interferes with child’s communication, satisfaction with life, ability to participate in life
  - How much stuttering stops child from doing the things he wants to do, saying the things he wants to say
Testing the ACES

- The ACES is still in the *beginning stages* of testing and validation
  - The version presented here is the **THIRD draft version**
    #1: Tested 3-point vs. 5-point scale
    #2: Tested item wording, concepts
    #3: Complete version evaluated with a large group of children age 7-18
Preliminary Data Analyses

- Preliminary data analyses have helped to improve the test
  - Item analysis identified items that needed to be reworded or, in some cases, combined with other items
  - Internal consistency studies verified that items test the same constructs

- Still, more analyses need to be done
You Can Help US!

- YOU can help in our final evaluation of the ACES by administering the instrument to the children you see
  
  - A research version of the ACES (with no identifying information) is included in the handout. Talk to us now (or email jsyaruss@csd.pitt.edu) to learn how you can participate in our study.
The ACES Can Help YOU!

- By focusing on the overall impact of stuttering, you can identify factors that motivate the child to participate more actively in therapy
  
  - Rather than focusing only on techniques the child can learn, try emphasizing **key improvements** the child can experience in his life, as indicated by the ACES
Conclusions (for now)

- Stuttering is a broad-based disorder affecting many aspects of a child’s life
  - If we wish to measure the outcomes of broad-based treatment, we need an instrument that is broad-based
  - The ACES is designed to assess the entire experience of stuttering from the perspective of the child
The Future

- With additional testing of reliability and validity, the ACES may become a tool for measuring stuttering that can be useful not only in treatment but also in the documentation and evaluation of treatment outcomes.