

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

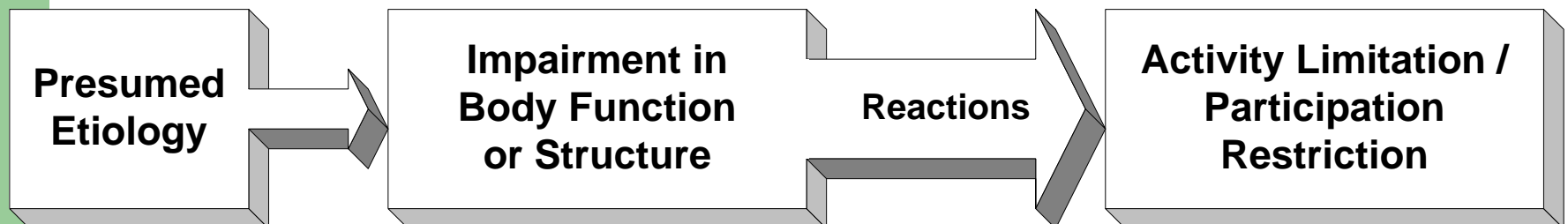
The ICF Describes When Things Go Wrong

- ***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



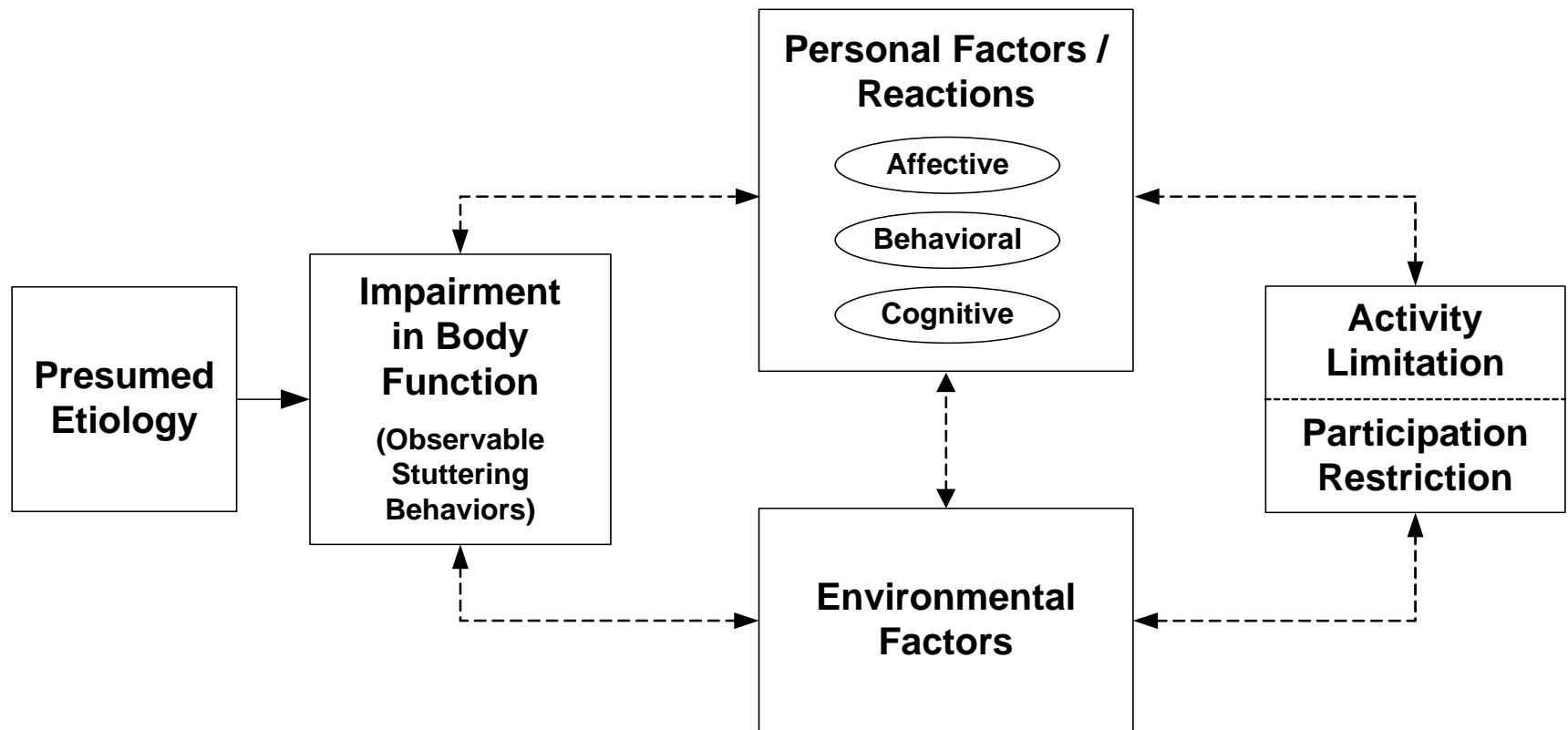
Identifying and Classifying the Child's Reactions

- **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.

A Model for Describing the Entire Disorder



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

Development (cont.)

- 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.