Stuttering Treatment Outcomes: Considering the Entire Disorder

J. Scott Yaruss, Ph.D., CCC-SLP, ASHA Fellow
Board-Recognized Specialist and Mentor in Fluency Disorders
Associate Professor, Communication Science and Disorders, University of Pittsburgh
Associate Director, Communication Disorders, Children’s Hospital of Pittsburgh
Co-Director, Stuttering Center of Western Pennsylvania

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Purpose

To describe a means for conducting comprehensive assessment of stuttering intervention from the perspective of the individual who stutters.
Why would we want to consider comprehensive measurement?
Most Important Fact #1

Stuttering is more than just Stuttering!
WHAT specific outcomes should we measure?
Int’l Classification of Functioning, Disability and Health
(World Health Organization, ICF 2001)

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

- **Functioning and Disability**: describes the major areas of people’s daily lives

  ➔ *Impairments in Body Function and Structure can lead to limitations in a person’s ability to perform activities or restrictions in the person’s ability to participate in life*
In stuttering, the link between impairment and the resulting negative consequences is largely mediated by the speaker’s reactions to stuttering:

- **Affective**: Feelings, attitudes, emotions
- **Behavioral**: Actions (Avoidance, tension, struggle)
- **Cognitive**: Thought-processes, self-evaluation

Finally, the reactions of those in the speaker’s environment also play an important role for many.
Considering the Entire Stuttering Disorder

Model for representing the entirety of the stuttering disorder based on the WHO’s ICF (adapted from Yaruss, 1998; Yaruss & Quesal, 2004)
The “Full” ICF Model for Stuttering

**Body Function** (physiological & psychological functions of the body)
- b3300 fluency of speech
- b3301 rhythm of speech
- b3302 speed of speech

**Body Structure** (anatomical parts of the body)
- s110 structure of brain

**Personal Factors** (background of a person’s life, such as coping style, experiences, etc.)
- Affective feelings, emotional reactions, etc.
- Behavioral tension, struggle, avoidance, etc.
- Cognitive thought process, self-esteem, etc.

**Environmental Factors** (external influences on functioning and disability)
- e300s support and relationships
- e355 professionals (e.g., SLPs, teachers)
- e400s attitudes of society and individuals
- e530 communication services
- e555 support organizations
- e585 educational services

**Activity / Participation** (individual’s performance and capacity in various life areas)
- d330 speaking
- d350 conversation
- d355 discussion
- d7200 forming relationships
- d7203 interacting according to social rules
- d810s education
- d840s work
- d850s employment
- d900s community, social, and civic life

**Presumed Etiology** (causal factors not classified in the ICF)
- b152 emotional functions (extreme anxiety or emotional concern)
Model for representing the entirety of the stuttering disorder based on the WHO’s ICF (adapted from Yaruss, 1998; Yaruss & Quesal, 2004)
“The scope of practice in speech-language pathology encompasses all components and factors identified in the WHO framework. That is, speech-language pathologists work to improve quality of life by reducing impairments in body functions and structures, activity limitations, participation restrictions, and environmental barriers...”

-- ASHA (2007) Scope of Practice for Speech-Language Pathologists
How can we possibly hope to measure all that stuff?
Evaluating the *Entire* Disorder

- Since stuttering is broad-based, we must assess multiple aspects during our evaluation

- To do this, we simply “follow the model…”
  - **Impairment**: Observable characteristics of speech
  - **Speaker’s Reactions**: Affective, Behavioral, and Cognitive
  - **Environmental Reactions**: situational difficulties, real or perceived discrimination, etc.
  - **Activity Limitation / Participation Restriction**: Overall Impact of stuttering on speaker’s life
Measuring Impairment (Observable Stuttering Behaviors)

- Most common measures include frequency of disfluencies, type of disfluency, and severity
  - Riley’s Stuttering Severity Instrument may be the most common measure in the field of stuttering

- Stuttering behaviors are highly variable
  - People may not stutter at all in some situations, so we must collect multiple speech samples

- What you see is not always what you get
  - People often try to hide their overt stuttering behaviors because of their embarrassment and anxiety
Numerous tools have been presented over the years aimed at examining the speaker’s “Communication Attitudes”

- S-Scale (Erikson, 1969)
- ICA (Watson, 1988)
- SSS (Riley et al., 2004)
- SPP (Silverman, 1980)
- S-24 (Andrews & Cutler, 1974)
- PSI (Woolf, 1967)
- SSC (Brutten & Shoemaker, 1974)
- SSS (Riley et al., 2004)
- SSC (Brutten & Shoemaker, 1974)
- SPP (Silverman, 1980)
- SESAS (Ornstein & Manning, 1985)

With a few notable exceptions (e.g., Boberg & Kully, 1994), these instruments have not been widely used in treatment outcomes research (or even in daily clinical practice)
Measuring The Rest of the Stuttering Disorder

- Fewer instruments have focused on the role of the environment or the negative impact of stuttering on the speaker’s life
  - WASSP (Wright & Ayer, 2000)
  - Crowe’s Protocols (et al., 2000)
  - (I personally would like to see greater use of these instruments!)

- Many attitudes scales examine environmental factors by considering different situations
  - This has led to criticism (Ulliana & Ingham, 1984) that many “attitudes” inventories simply reflect the speaker’s fluency in different speaking situations
So remind me why we should care about all these other factors?
The speaker’s experiences affect progress in therapy, as well as the ability to communicate, and overall quality of life.
Reason #2: The Personal Identify of Stuttering PERSISTS

- As Manning and others have highlighted, the personal identity (or construct) of being a person who stutters can persist, even after the speaker has tools for “managing” speech
  - “Changes under the surface and over time”

- Personal constructs can change; to support this change requires specific effort in therapy
  - If we are going to address such topics in therapy, we must measure the outcomes of such efforts
The principles of evidence-based practice require that clinicians and researchers collect data about the treatment they provide. Every issue or characteristic that is addressed in treatment must be evaluated. If treatment addresses anything other than fluency, broad-based measurement is required.

Some might argue that the only characteristic that should be addressed in stuttering therapy is the stuttering behavior, but...
The primary complaint (Baer, 1990) is not just the stuttering behavior—it is the stuttering disorder.

Personal histories (Hood, 1998; St. Louis, 2001) & books by people who stutter (e.g., Bobrick, 1995 Jezer, 2003), highlight the broad impact of the disorder.

Census of NSA Members (McClure & Yaruss, 2003)
- Stuttering interferes with school/work (79%) and social/family (64%) interactions
- Many feel embarrassed about stuttering (70%) and avoid speaking situations (82%)

This is true even after treatment!
Reason #5: Treatment Is Not Perfect

- Contrary to the claims of some...
  - Many people who stutter continue to deal with stuttering in some fashion after treatment
    - Studies of “successful” treatment and “recovery” reveal “strategies” people use to avoid stuttering
  - If the stuttering behavior remains at all, then the consequences of the stuttering behavior remain
    - Documenting and evaluating the true outcome of treatment for the stuttering behavior requires that we document those consequences
So what are we supposed to do?
Overall Assessment of the Speaker’s Experience of Stuttering (OASES) (Yaruss & Quesal, 2006, 2008)

- A comprehensive instrument designed to evaluate the experience of the stuttering disorder from the perspective of the speaker.

- Based directly on the WHO’s ICF model so it meaningfully addresses the entirety of the stuttering disorder using terminology and strategies that are consistent with the rest of the field of rehabilitation.
Development of the OASES

- Developed through an iterative process of data collection and analysis with more than 300 adults who stutter to ensure a high degree of reliability and validity.

- Designed to provide an “impact score” and “impact rating” reflecting the severity of the stuttering disorder.

  - The impact score does not simply reflect the observable stuttering behaviors; it reflects the overall experience of stuttering.
Early drafts have been used by colleagues throughout the field for diagnostic evaluations and treatment outcomes studies for several years.

Final version was published in English & Spanish by Pearson Assessments in January 2008.

Additional versions are also in development for school-age children (OASES-S, ages 7-12) and teens (OASES-T, ages 13-17).

OASES-A is currently being translated and validated in 13 countries worldwide.
Structure of the OASES

- 100 items in 4 sections, each on a 5-point scale
- Sections are closely related to the ICF Model

  - **Section I: General Information about Stuttering**
    - Speaker’s perception of the Impairment and general knowledge and perception of the stuttering disorder

  - **Section II: Speaker’s Affective, Behavioral, and Cognitive Reactions**

  - **Section III: Communication in Daily Situations**
    - Activity Limitation / Environmental Factors

  - **Section IV: Impact of Stuttering on Quality of Life**
    - Participation Restriction / Environmental Factors
Administration of the OASES

- Paper-and-pencil administration requires less than 20 minutes to complete and less than 5 minutes to score
  - Computerized administration and scoring is also available through Pearson’s Q-Local
- Can be used in pre/post treatment studies
  - Sensitivity to treatment changes was demonstrated in a study presented at ASHA (2006) and currently being prepared for publication
**Section I: General Information**

- Name:
- ID Number:
- Birth Date:
- Gender: Male/Female
- Are you married or do you have a significant other? Yes/No
- Do you have children? Yes/No
- Are you currently employed or have you been employed in the past three months? Yes/No
- Have you ever received speech therapy? Yes/No
- Are you currently receiving speech therapy? Yes/No

**Section II: Your Reactions to Stuttering**

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td>Depressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Defensive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Amused</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Guilty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Frustrated</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Section III: Communication**

- How difficult is it for you to avoid situations you once avoided?
- How often do you...?
- In general, how do you feel about your stuttering?
- How do you feel about your ability to communicate?

**Section IV: Quality of Life**

- How much does stuttering affect your life negatively?
- How difficult is it for you to deal with general situations?
- In general, how often do you feel anxious about situations at work?
- At home, how often do you feel anxious about situations at work?
- Your relationships with family, friends, and others.
- Ability to function in society.
- Ability to do your job.
- Satisfaction with your job.
- Ability to advance in your career.
- Overall health and physical well-being.
- Overall stress on your life.
- Sense of control over your life.
- Spiritual well-being.
Interpretation of the OASES

- Impact scores and ratings can be calculated for each section or for the test as a whole

<table>
<thead>
<tr>
<th>Impact Scores</th>
<th>Impact Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.00 – 1.45</td>
<td>Mild</td>
</tr>
<tr>
<td>1.50 – 2.24</td>
<td>Mild-to-Moderate</td>
</tr>
<tr>
<td>2.25 – 3.99</td>
<td>Moderate</td>
</tr>
<tr>
<td>3.00 – 3.74</td>
<td>Moderate-to-Severe</td>
</tr>
<tr>
<td>3.75 – 5.00</td>
<td>Severe</td>
</tr>
</tbody>
</table>
So what can we DO with all these data?
Using the OASES to support Daily Clinical Practice

■ To support the understanding of stuttering
  - Because the OASES is based on the experiences of hundreds of people who stutter, clinicians can use the OASES to better understand the nature of the stuttering disorder

■ As a treatment planning & evaluation tool
  - Clinicians can use the OASES to ensure that they work toward meaningful changes in relevant aspects of the speaker’s experience of stuttering
Using the OASES to support Treatment Outcomes Research

From Yaruss & Quesal (2004), International Fluency Association
Is the OASES the only way to do this?
My point is not that you should “use the OASES” – my point is that we should be sure to consider **multiple outcomes** in stuttering treatment outcomes research so we examine the entire disorder.

As noted previously, numerous tools are available for examining various aspects of the disorder, from both the listener’s perspective and the speaker’s perspective.
Conclusion

- Not only it is possible to consider multiple outcomes of stuttering treatment, it is **necessary**, based on the tenets of EBP.
- By basing our measurement upon a widely used framework for understanding human health experience, we ensure **comprehensive documentation** of treatment outcomes.
- Without such information, it is impossible to judge the success of treatment **from the perspective of the individual who stutters**.