One Voice

Incorporating *The Voice of ELSA*, the newsletter of the **European League of Stuttering Associations**

FIRST ANNOUNCEMENT

10th World congress for People who Stutter

Lunteren, The Netherlands

Monday 10 – Thursday 13 June 2013

Conference title:

‘Hear no evil, see no evil, speak no evil:
Breaking taboos around stuttering’

Hosted by:

The Netherlands Stuttering Association Demosthenes

Location:

Congresscentre ‘De Werelt’, Lunteren

Hope to see you there...

Michael Sugarman

NEWS FROM ELSA (EUROPEAN LEAGUE OF STUTTERING ASSOCIATIONS)

ELSA ★ THE EUROPEAN LEAGUE OF STUTTERING ASSOCIATIONS registered charity 1074561

One of ELSA's objectives is to bring together and represent the interests of people who stutter in Europe.

Over the last 12 months ELSA was represented at the annual meeting of the European Disability Forum (the European umbrella organization for people with disabilities) in May 2102 and contributed via the presentation of information material at the biannual European Symposium on Fluency Disorders in Antwerp in March 2012. It is important for ELSA to network with other disability organizations, speech and language therapists and other professional bodies to ensure stuttering remains on the agenda and to encourage others to listen and understand the lives and needs of people who stutter.

ELSA continues to focus on the disability model and the latest ELSA disability update document is to be found at: http://www.stuttering.ws/index.php/documents/publications.

We are proud to announce that there are two new member organizations: the new Belgian stuttering association BSV, and the Portuguese stuttering association. We are looking forward to meet and work together with our new colleagues.

The Dutch and the German stuttering associations are working on a declaration on stuttering therapy and together with the ISA we hope to produce a worldwide statement, this is currently work in progress.

We have now had 8 youth meetings since 1995 and it's fantastic to follow the lives of past delegates of the youth meetings and see where they are today. Some of them are now board members, or even chair persons at their national stuttering associations. One of them is new an ambassador! And they use every opportunity to visit each other and meet up. The next occasion is the Nordic stuttering seminar, 31/8-2/9 in Hamar, Norway and we're looking forward to see many of them again.

The next big stuttering occasion is the world congress for people who stutter in Lunteren in the Netherlands, in June 2013. Here ELSA is planning to have a reunion with former ELSA youth meeting delegates. The WC will also be an ELSA mile stone, as the WC organizing committee and most of the members of the WC sub committees are former ELSA youth meeting delegates!

We are also planning for yet another European Youth Meeting. If funding is secured the meeting is planned to take place in July 2013 or 2014. More information will follow.

Regards

Anita S Blom & Edwin J Farr

European League of Stuttering Associations, ELSA

www.elsa.info

www.stuttering.ws

MESSAGE FROM ISA OUTREACH...

Michael our Chair raised a wonderful question at the beginning of the year. What can you do in 2012 to help PWS in your own Country and / or around the world? Some of the upcoming events can be seen at http://www.isastutter.org/.

Have you been able to start something new? If you are on either Board of the ISA, what will you do in the remaining months of 2012 to keep the ISA committees active and progressing for the good of all (http://www.isastutter.org/initiatives/isa-committee-structure-draft-2)? If you are part of your National Association, what will you and your Association, do for ISAD in October 2012? If you are going to volunteer, what will you do to step outside your comfort zones?

I recently attended the International Fluency Association (IFA) Congress in Tours. It was a wonderful place to extend my knowledge, experience and network to meet new friends whilst catching up with current friends. I have written in more detail about this in an article to be found below. As well as meeting new friends from Russia and being invited to their Moscow clinic 'Arlilia' in September, I made new contacts Turkey; Malta; Spain; Persian Department in Voice of America; Vietnam; Portugal; Sweden; Australia; Kuwait.

I have recently reconnected with past friends from South Africa / Senegal to see how we can advance stammering Awareness and help in their countries and elsewhere. We need to talk about Self Help Groups more.

Have you looked at our Facebook site? (http://www.facebook.com/isastutter)

Pay us a visit and tell us what you want.

As often, I will close my contribution by reminding all of us that the ISA exists to help People Who Stutter in any Country of the World. For the ISA to succeed, we need

-volunteers with time;

-volunteers to help with translation between other languages; and

-money.

-volunteers to stand for election on to the next Board of Directors in 2013.
(Do you need information about what is expected?)

If you can give the ISA some of your valuable skills / time / money, please do so. However we are also seeking volunteers to help in fund raising to send PWS to the World Congress in 2013. If you can help, or know of someone else who can help please contact either Michael Sugarman <msugarman1@sbcglobal.net> or Keith Boss <keithmaxkb@yahoo.com>.

I look forward to working with more of you over the next year until the 10th World Congress for People Who Stutter in Holland in 2013 (http://www.demosthenes.nl/wc2013)

Please pass this to all your members.

Keith Boss
ISA Chair of Outreach
Vice Chair and Treasurer
keithmaxkb@yahoo.com

By Adolfo Barrales.
Speech Language Pathologist and Psychotherapist
President of Chilean Stuttering Association: Grupo de Amigos de Personas con Tartamudez Chile.
External Professor and Relator for the Faculty of Sciences, Universidad de Chile
Special Friend of ISA. Member Representative of Chile to the International Cluttering Association..

FROM CHILE, SHARING OUR ACTIVITIES TO OUR GLOBAL COMMUNITY, INTERNATIONAL STUTTERING

Dear friends of our global community, International Stuttering Family, for me is a great pleasure to share with you the multiple activities that I am doing, along with my collaborators, in the association Chilean Stuttering Association (CSA), "Grupo de Amigos de Personas con Tartamudez Chile" (Group of Friend of People Who Stuttering). I am Chair of this Association.

I am applying with great happiness the approach I've been developing for 25 years: Neofonoaudiológico Approach. This Approach applies the current knowledge of the neurosciences to contribute with innovations for helping people who suffer difficulties in their fluency, and sciences that study the human language. The PWS are having good benefits, walking to the meeting with the fluency, quickly and concretely. Also, the approach applies to self-help groups. The approach is in constant improvement and monitoring, in collaboration with Dr. Roberto Gallardo, noted neurophysiologist of the Faculty of Medicine, University of Chile. And this year I'm applying it in a thesis for final year students of the career of Special Education, University Academy of Christian Humanism.

Is a Great honor this year be part of teacher's team to the first "Diplomado en Intervención Fonoaudiológica en Personas con Tartamudez", for Speech-Language Pathologists at San Sebastian University, Santiago, Chile. The interest of the school of my participation has been to teach Speech-Language Pathologists the Neofonoaudiológico Approach.

I have great pride to have worked together with I. Reichel, D.A. Shapiro, B.B. Touzet, A.A. Barrales. I was very pleased our contribution for the 7th World Congress International Fluency Association (IFA) was accepted for a poster presentation: "Emotional intelligence: Implications for Effectiveness in Stuttering Intervention". And be contributing with article to the International Cluttering Association (ICA) newsletter, July 2012 (http://associations.missouristate.edu/ICA/).

Several articles published in the Chilean newspaper "Guardian de la Salud" ("Guardian of Health"). Articles for supporting people who stutter, sensitizing society to understand Stuttering and the life of a PWS, and to contribute to a society accepting the differences of them.

I was honored to be invited by the College of Speech Language Therapists of Chile as speaker at their XXIX Congress, October, 25, 26, 27, 2012: "Introduction to Neofonoaudiológico Approach".

Also, in my compromise of constantly contribute to PWS around the world, in the association which I chair (CSA, GAPTCHILE), together with my collaborators, I am working a full time in others multiple activities:

On July, 13, 2012, we had a Meeting for PWS which are membership to our CSA, GAP CHILE.

Realization of "Seminar-Workshop in Stuttering. Neofonoaudiologico Training. Introductory Level", August, 17, 2012. (http://seminariotartamudez.com/, http://gaptartamudez.com/). Especially for PWS, and open to young people in training as speech and language therapists and also to young people of related fields. The meeting is a place for both groups to meet and exchange ideas. The activity was sponsored by the Career of Education in Special Education, University Academy of Christian Humanism. The article about the Seminar-Workshop was published in the Chilean newspaper "La Cuarta", edition of July, 7.

We are working to acknowledge the International Stuttering Awareness Day of GAPTCHILE, October, 22. Thus, we again accompany this celebration together with the activities of ISA and others Associations around the world. I am very pleased that in the past year our GAPTCHILE celebration of ISAD met to about 100 people (in dependencies of the University of Santo Tomas, Santiago, with the sponsorship of the School of Speech Therapy). The support and help of

Michael Sugarman (ISA Chair), Keith Boss (ISA Vice Chair), and others friends was very important for this achievement (as the support of Daniela Veronica Zackiewicz, Abra Gagueira, Brasil). My warm thanks to each one of them.

A dream that we want meet in this next year is the "First International Stuttering Congress organized by our Chilean Stuttering Association, GAPTCHILE ". We are already working to it.

Also, I am exerting considerable effort to go the next 10th World Congress for People Who Stutter, June 10, 2013, Netherlands.

Dear friends, in all my activities I am always proud and honored to present contributions as a special friend of the ISA.

"In a global world, we live in a country called planet earth"

My warm regards and hugs to all of you.

Adolfo Barrales

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THE 7TH WORLD CONGRESS OF FLUENCY DISORDERS ORGANIZED BY IFA (INTERNATIONAL FLUENCY ASSOCIATION) IN TOURS JULY 2012

I would like to thank the IFA once again for granting me a scholarship to attend their conference in Tours. As part of my agreement I will be sharing with you my experience at the Congress. It was a privilege for a stutterer to be given a scholarship to attend a congress of Professionals and to be given the opportunity to present a workshop about ISA Outreach.

Tours is a very beautiful historical town. I have travelled through it on previous camping holidays. Some of the architecture is very old and will be too costly to replace. A boat trip on the Loire was a very relaxing activity on our one free afternoon. The hotel and food were all very good as I expected, so the only unknown was the congress.

On the very first morning I met and spoke at length with Russians from the Arlilia Stuttering Correction Center in Moscow. They were kind enough to exchange views with me and have invited me to visit their clinic and speak with professionals / adult stutterers / children and others. This visit will be in September 2012. From an excellent 1st day it only got better.

In no specific order I heard about

Telehealth. Some countries are doing it. It could be expanded to happen around the world. We need to find various resources to make this happen. It may be useful to include occasional talks by PWS about their successes / job interviews / relationships / self help groups;

ACT (Acceptance and Commitment Therapy) as offered by the City Lit in London (UK);

Mindfulness as offered in Leeds;

Various treatment techniques for children.

This names but a few of the absorbing workshops / presentations.

I renewed previous contacts and made new contacts with Russia; Turkey; Malta; Spain; Persian Department in Voice of America; Vietnam; Portugal; Sweden; Australia; Kuwait. All these SLPs were interested in what the ISA might be able to do in their countries. It will be good in the future months to explore these possibilities.

Reinventing the wheel, Introduction. Many SLPs from around the world have devised / revised / refined treatments either alone or with a few others. Hearing about their work it was obvious that a lot of hard work had been spent redesigning the wheel. Each being slightly different, but having a number of similarities. Treatments are published in Books / documents / Journals / etc. There are peer reviews and outcome analyses, which are essential before giving treatments, but not essential for the latest ideas to be made available for peer review. All these are not in one place and may not be accessible to all. It will be interesting to see if the IFA / ISA can devise a means to reduce the reinventing of the wheel over and over and.............

My own Local SLT treats clients in a holistic way and helps them to consider what they are thinking about when specific things happen and if there is a way of adjusting this. She considers other aspects of thought as well. Based on discussion with many SLPs at Tours, it would be very good to set up a team to explore the best ways to offer CBT / ACT / mindfulness / etc to PWS around the world.

e.g 'We decide what we think about'; 'We become the product of our thoughts'; 'What we focus on tends to happen'; 'We can chose what we focus on'.

How valuable are concepts like this? How can we refine these techniques and spread them around the world?

I left the congress with many pleasant memories. But I left with more questions.

Could the IFA and ISA work more closely together

-to help SLPs / PWSs / etc around the world?

-to be more proactive linking with WHO / UNESCO / etc?

-to be more effective in suggesting more advances regarding stuttering / cluttering / anxiety disorders in DSM-iv and DSM-v?

It was a very good networking experience. I spoke to many SLPs about treatments and some of the ideas above. I had good chats with Scot Yaruss. about his OASES system. This would be very good material for stammering awareness, but at the moment it must be paid for. He has agreed to help me in any way I ask. I talked to Kate Bridgeman about her preschool Telehealth system. She has also agreed to help me when I know what we want.

I enjoyed the IFA Congress in Tours. I appreciated the scholarship given to me. I appreciated the information I gleaned. I enjoyed networking. I was very pleased to exchange ideas with SLPs / SLTs, and I thank everyone who contributed to making the congress a real success.

Keith Boss

ISA Vice Chair

JOURNEY OF NEPAL STUTTERS' ASSOCIATION (NSA):

Nepal Stutterers Association (NSA) is a non-profit-making, non-governmental organization (NGO), which is registered with the District Administration Office, Kathmandu and affiliated to the Social Welfare Council (SWC) in 2003 with the main objectives of NSA to raise awareness and draw public attention to the living conditions of stutterers in Nepal, and to lobby and advocate for affirmative change in the life of stutterers.

NSA works for the overall welfare and development of the organization; it plans and implements membership activities, awareness raising and advocacy activities; it coordinates the management of resources; it develops linkages with other disability organizations e.g. the National Federation of the Disabled (NFDN), the Stuttering Association in Denmark (FSD) and the International Stuttering Association (ISA)); and it monitors project activities to ensure that they are in accord with the organizational mandate and bylaws of the organization.

Since we were established the FSD financially supports the NSA and helps the NSA in capacity development; for the capacity development 4 persons participated in global line training and in August 2012,one member is going on a 19 weeks organizational development course in Egmont high School Denmark; financially supported by Disabled people organization Denmark DPOD. The NSA got the various projects from DPOD/ FSD, and again the NSA and FSD signed to work as partner in Nepal for 2012 – 2014 with a **Project name** "Towards a sustainable DPO - Rights and Responsibilities of Stutterers in Nepal" and a **Development objective** "NSA consolidated as a strong, well governed and sustainable DPO representing the interest of stutterers in Nepal and contributing effectively to creating affirmative change in their lives"

Due to a strong lobby and the advocacy of NSA, stuttering is recognized by Nepal government and stuttering categorized as a speech disability in 2007 and members are getting a disability card and other facility as other disability group provided by Nepal government also speech disability included in the National census 2011; so we hope to get data about stutterers in Nepal.

NSA has 500+ members, 15 registered district committees and 3 Self-Help-Groups. There are 47 female members out of the total number of about 500.

NSA is the member of the ISA so members of NSA participated 3 times in ISA world congress i.e in Australia, Curiosa and Argentina. From this international platform the NSA learned lot of things. NSA is also a member of NFDN so took the part in executive board member election and I (Sanjay Kr. Jha) was elected to the board membership to form a speech disability group in Feb. 2012.

UNCRPD (United nation convention on rights of persons with disability) has been acknowledged by more than 100 countries in the world and was also acknowledged by the Nepal government (Parliament) on 27 Dec 2009 (5th May 2010 by UN website) and NSA also worked, lobby and advocacy with government for the acknowledgement.

From the NSA, I (Sanjay kr. Jha) got the opportunity to participate in international disability alliance (IDA) workshop "challenges and opportunity of monitoring the UN convention on rights of persons with disability" organized concomitantly with the 7th session of the CRPD committee, in Geneva 15 to 20 April 2012. The main objective of the workshop was to observe how the report presents by the state and the parallel report by civil society and DPOs (Disabled people organizations) and we observed the report from Hongkong, China, Hungary, Peru and Argentina, also we got the opportunity to know from Hungary and Peru the process and technique to prepare parallel reports. Hopefully I will work as a team member to prepare the parallel report from DPOs side.

I feel that most of the disability group (physical, blind, mental, deaf, etc) are very strong in public awareness of CRPD monitoring and implementation and the CRPD committee is also very much aware about these groups. But stuttering (communicational Disorder) is

JOURNEY OF NEPAL STUTTERS' ASSOCIATION (NSA): CONT'D...

somehow far from public awareness. People/ committee members are not very much aware about stuttering in the international platform. I think in most of the countries, stuttering is recognized by the government as a speech disability so in this situation stutters can take more benefit from the state by using CRPD and mainly developing country will get the most benefit. **I request ISA to work for the promotion of CRPD and to bring an awareness raising program to international forums like WHO, IDA, world bank etc.**

Since 2009 NSA started as group therapy; members of NSA comes to the NSA office. They do the self speech practice to improve their stuttering every Saturday and NSA feel it is very important to stutters.

But still the NSA has lot of problems;

Financial problems (only one financially supporting partner FSD)

Running the branch office

No income generating program for members.

To use local resources

No service oriented program for members.

To work as a volunteer etc

The NSA hopes that in future the NSA will able to mobilize local resources and to get other funding partners.

Thank you!!!

Sanjay Kr. Jha
(Nepal Stutters Association)
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email (Official) nepalsa@gmail.com

New proposal developed by NSA and FSD jointly for 2012- 2014
"Towards a sustainable DPO - Rights and Responsibilities of Stutterers in Nepal"

Participants from Nepal, India, Hongkong, Argentina and other countries in IDA Workshop
7th session of UNCRPD committee "Challenges and opportunities of monitoring the UN Convention on Rights of Persons with Disabilities" in Geneva from15th to 20th April 2012.

MALI'S NEWS

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BP E 47 93

January 5, 2012, Overcoming Stuttering Association in Mali (Mali-AVB) became a member of the Malian Federation of Disabled People of Mali (FEMAPH).

Since that day, our association has participated in several training sessions organized by the FEMAPH.

Organizationally, the AVB is actively preparing for the establishment of a new office to manage the destiny of our association for the next three years.

Some International News, Mr. Camara Zan Association has just participated in the 7 th World Congress of fluency disorders organized by IFA in Tours, France.

TRANSITION TO NARRATIVE APPROACHES FROM COGNITIVE BEHAVIORAL THERAPY FOR STUTTERING

The Japan Stuttering Project does not aim to cure, improve or to control stuttering. Going through various transitions over the years, we are now focusing on narrative approaches to address stuttering.

In Japan, the history of therapy for stuttering began in 1903. The approaches then employed are quite similar to the four techniques for fluency enhancement in the integrated approach that Dr. Barry Guitar proposed. I myself received this form of therapy in 1965 and worked very hard to cure my stuttering without success. Some people claimed their stuttering was cured but in fact they were only able to speak slowly or to control stuttering to a certain extent, and in four months after therapy, virtually almost everyone experienced a relapse. I therefore gave up treatment or improving stuttering behavior, and instead organized a self-help group of people who stutter in 1965.

Through our self-help activities we recognized the need to differentiate stuttering symptoms from the problems of stuttering. Stuttering problems are developed by negative awareness of the people who stutter toward stuttering. They are negative behaviors, such as hiding stuttering, avoiding speaking situations or maintaining negative attitudes; negative thoughts that stuttering is bad, inferior and embarrassing; and negative emotions such as anticipatory anxiety or the fear about stuttering, misery or a sense of guilt after the incidence of stuttering

We learned later on that what we found about stuttering coincided mostly with the ‘iceberg theory’ proposed by Dr. Joseph G. Sheehan. Stuttering symptoms may change naturally over time but it is difficult to cure and control it by therapy, which has been proved by many experiences of people who stutter. My stutter has changed a lot from the early onset, but this is not the result of therapy. Based on the premise that stuttering cannot be cured, I have simply continued to work on my negative behavior, thoughts and emotions, which were hidden under the water. These are the negative effects of stuttering underneath the iceberg, which can be changed.

At our annual workshop, we have invited Japan’s leading psychiatrist, clinical psychologist, social psychologist, theatrical people, etc., and learned a lot from them, focusing on our behavior, thoughts and emotions. The approaches we have learned are interpersonal transactional analysis, assertiveness training and cognitive behavioral therapy to work on our behavior; rational emotive therapy, cognitive therapy/cognitive behavioral therapy to deal with our thoughts; and person-centered approach, psychodrama, and Gestalt therapy focusing on our emotions.

Such efforts have been published in books by major publishers, including “Stuttering and Cognitive Behavioral Approach” co-authored by Dr. Yutaka Ono, a psychiatrist and the Japan’s leading authority in the field of cognitive-behavioral therapy.

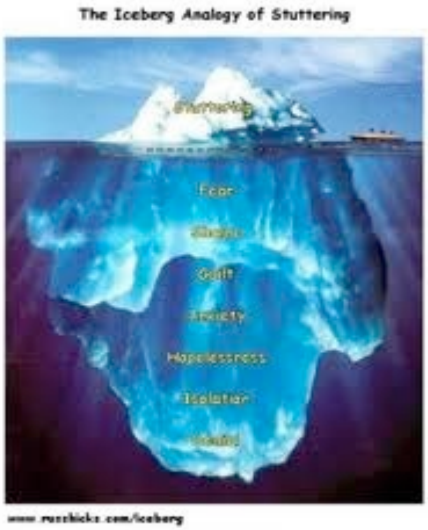
Our recent workshop which was held last autumn featured narrative approaches which have drawn a great deal of attention in the field of family therapy in recent years. In place of the evidence-based approach, we are now learning narrative approaches. However, rational emotive therapy, cognitive-behavioral therapy and interpersonal transactional analysis that we have practiced for many years are an integral part of the narrative approaches. I am going to publish a new book next spring, “Stuttering and Narrative Approaches.”

Thus, our longtime efforts we have made to deal with stuttering since 1965 are now leading us to the final phase. We shifted from therapy which was negative about stuttering to the approach which accepts stuttering, and now we are collecting our stories of stuttering experiences. This August, we will hold a workshop for parents of children who stutter, speech therapists working at hospitals and school and other professionals to propose a clinical approach to stuttering, which focuses on the acceptance of stuttering.

The members of the Japan Stuttering Project are now weaving the threads of stories together, departing from old stories of denying stuttering that had been in place for so many years. Let us have the courage to face the fact that treatment methods remain unchanged for over a hundred years and that stuttering is still incurable. It should be a mission for people who stutter and have been struggling with it to move forward with more positive outlook on stuttering.

Shinji Ito
Executive director
Japan Stuttering Project

THE STUTTERING ICEBERG MEETS THE ICEBREAKER



The Iceberg theory was proposed by Joseph G. Sheehan. It is used by many as an Analogy of stuttering.

In our stuttering analogy

- above the surface is the unusual facial distortions and any secondary characteristics;
- below the surface is the fear, shame, guilt, anxiety, hopelessness, isolation and denial.

I had convinced myself during 60+ years that everything that had gone wrong in my life was due to my stutter. I learned about the stuttering iceberg in 2006 and it very neatly confirmed what I 'knew' in my heart of hearts. Sheehan knew his subject and gave a very good visual aid to explain it. Many SLPs / SLTs / PWS (People Who Stutter) have discussed this in detail.

I joined the local Toastmasters International group near the end of 2007. At the first meeting on 9th October 2007 the Inspiration of the evening was 'Feel the fear, but do it anyway'. This made me question many thoughts / beliefs I had about non stuttering people. I decided to explore this for my first speech, known as the Icebreaker speech which has the objective of telling the audience a little about the speaker. I did some research and entitled my speech 'The Stuttering Iceberg meets the Icebreaker'.

I came to the conclusion that there was a **Communication Iceberg**.
(remember 93% of Communication is mainly non-verbal body language plus some percentage for tone and only 7 % relates to the words we speak. So 93% of communication is nothing to do with words.) This Communication Iceberg potentially impacts the lives of the majority of people in this world.

THE STUTTERING ICEBERG MEETS THE ICEBREAKER CONT'D..

In the Communication Iceberg there is
- fear of speaking to people you do not know;
- fear of speaking to groups;
- fear of speaking in public:
- shame about some aspect of our lives;
- guilt about past actions / behaviour;
- anxiety about the unknown as well as some anticipated events;
- hopelessness when we have to face the unknown alone;
- isolation when we are on our own and negative / raw emotions flood to our minds;
- denial of things about ourselves we do not wish to think about;
- also we can add embarrassment, negativity, lack of self confidence, avoidance, nervousness, low self esteem, reactive, passive, full of emotions and at times emotionless, comfort zones, tense, intimidated, inferior, shy, withdrawn, victim, poor eye contact, poor socialising, softly spoken, poor breathing, uncertain, to name but a few.

Acceptance of the above made me realise that
- my belief that 'everything that had gone wrong in my life was due to my stutter' was just a false belief and should be discarded;
- I could improve my communication skills in many ways which had nothing to do with stuttering treatment therapy;
- modern stuttering treatments / therapies from SLPs / SLTs are invaluable to help to initially 'get the words out of our mouths', if this is still a difficulty;
- More and more SLTs / SLPs are using a variety of holistic approaches to get clients to take control of their communication; their thinking; their attitudes; their behaviour; their emotions; their self assessment; their approach to life etc.
- SLTs / SLPs have listened and have modified their approach to clients in so many ways since the pioneer therapists many, many decades ago.

I offer one specific example.
After I decided to join Toastmasters International and before the first meeting. I felt fear, anxiety, nervousness etc. I put all these emotions down to my stutter.
Now, with hindsight I know this was a poor negative way to think about my stutter. Most people would have the same emotions before a first meeting like that. Those emotions were nothing to do with my stutter.
I have also learned that I can chose how to interpret any event and chose what I want to think about. So currently, I can chose how I deal with what is going on in my mind and switch thoughts fairly easily. It gets easier, the more I do.

If you want to discuss any of the above with me, please get in touch.

If you have read and accept the above, let me ask you to think about:-
Is it sensible to continue to use the Stuttering Iceberg as a stuttering analogy?

Turn all your negative thoughts into positive ones,

Keith Boss

WHO'S AFRAID OF STUTTERING TREATMENT? A REVIEW OF THE TOP STUTTERING WEBSITES

Of Google's top stuttering websites, only a few include information about stuttering treatment: Wikipedia, the Stuttering Home Page, and speech clinics such as the National Center for Stuttering, Hollins Communications Research Institute, and the Mayo Clinic.

From looking at their websites it appears that the stuttering organizations are afraid to talk about treatments. These include the Stuttering Foundation of America (SFA), the National Stuttering Association (NSA), and Friends Who Stutter.

Additionally, organizations that provide medical information appear to be afraid to talk about stuttering treatment: the National Institutes of Health (NIH) PubMed Health and Medline Plus, the Nemours Foundation (KidsHealth), and MedicineNet.com.

The American Speech-Language Hearing Association (ASHA) website has only a few sentences about prolonged speech (fluency shaping) stuttering therapy. The NIH National Institute on Deafness and Other Communication Disorders (NIDCD) has a little more information on other stuttering treatments but it is neither accurate nor up-to-date.

Who's Afraid of EBP?

I went to a convention of a stuttering organization. I met many people who stuttered severely, and I asked whether they'd done any stuttering treatments. Oh yes, they all said, and told me that they have wonderful SLPs they have gone to several times a week for years to do "bouncing," "phrasing," and playing Uno. The adult son of a SLP stood up at a group discussion and said, while stuttering moderately to severely, that he highly recommended speech therapy. He'd been in speech therapy for more than twenty years and he loved it! He tried to tell us the name of his favorite stuttering therapy program but he couldn't say it. A young man stood up and said that "not all speech therapists are bad," that there are some good ones out there, but it's "hit or miss" whether you get a good one or a bad one so you have to keep trying until you find a good one. I stood up and said that it's not "hit or miss," that there is a field called Evidence-Based Practice (EBP) that quantifies and measures the outcomes of stuttering treatments, and says which stuttering treatments are effective or ineffective. The convention organizer (who is a SLP) stopped me there and told me to sit down.

In 2006 the American Journal of Speech-Language Pathology (AJSLP) and the Journal of Fluency Disorders (JFD) published three systematic reviews of 31 studies of pharmaceuticals [1], 17 studies of altered auditory feedback (AAF) devices [2], and 162 studies of "behavioral, cognitive, and related approaches" [3].

The treatment outcomes set in the AJSLP systematic reviews were less than 5% stuttering, and/or improved social, emotional, or cognitive (SEC) measures, and these fluency and SEC measures had to be maintained for at least six months post-treatment. Only five effective stuttering treatments were found. This isn't rocket science: a lay reader can become an expert on what stuttering treatments are effective in an afternoon. Of the top stuttering websites, only Wikipedia supports EBP.

WHO'S AFRAID OF STUTTERING TREATMENT? A REVIEW OF THE TOP STUTTERING WEBSITES CONT'D...

The opposite of EBP is the view that different stuttering treatments have different intended outcomes,e.g., fluent speech, less tense or effortful stuttering, or increased speaking confidence regardless of stuttering. Some outcomes can be quantified but others can't. The SFA website expresses this view ("there is disagreement about acceptable treatment outcomes from stuttering therapy") and doesn't recommend or even describe any stuttering treatment (except indirect therapy).

A study found that the Successful Stuttering Management Program (SSMP) was not effective for either reducing stuttering or changing stutterers' SEC measures [6]. An exchange of letters in the journal [7] followed the study, debating whether increased stuttering can be a desirable treatment outcome, vs. the view that SLPs start out intending to reduce stuttering and the ones that fail come up with intangible treatment outcomes that their therapy programs are allegedly effective for.

Indirect Therapy

The NIH, SFA, KidsHealth, and MedicineNet.com websites recommend one stuttering treatment: indirect therapy for preschool-age stutterers. This treatment alters parents' speech and behaviors, such as speaking slower, and pausing after a child speaks and before the parent responds. A 1995 systematic review of a dozen studies [4] found indirect therapy to be ineffective. ore recent studies Several studies have suggested that indirect therapy makes stuttering worse!

Who's Afraid of Consumer Reviews?

Before I buy anything now, I read the reviews on the Internet. My website has reviews of stuttering treatments written by consumers. None of the top stuttering websites include reviews of stuttering treatments written by consumers. Again, this shows that stuttering organizations are afraid to talk about stuttering treatment.

Who's Afraid of Stuttering Treatment Research?

Researchers are afraid to investigate stuttering treatments. Almost all stuttering research is etiology (the nature and origins of stuttering) or stutterers' life experiences such "listeners' attitudes about stuttering." Treatment subjects are difficult to find. Collecting and analyzing speech samples is time-consuming. No guidelines are available about designing a study (how to measure stuttering, where to take speech samples, how long the follow-up should be). Applying for grants takes years, and you have to compete against large, professional teams from other fields that do nothing but apply for grants, making most stuttering researchers look like amateurs. A researcher needing to get published is more likely to do an etiology or "listeners' attitudes about stutterers" study.

The quality of stuttering treatment research is poor. The AJSLP systematic reviews rated 193 studies on a 5-point scientific quality scale, and found that the average score was 2.5. Many studies lacked speech samples taken outside of speech clinics, lacked follow-ups, etc.

The SFA and other stuttering organizations regularly publicize etiology research but infrequently publicize treatment research. For example, a 2001 study in JSLHR [5] showed Modifying Phonated Intervals (MPI) stuttering therapy to be effective. The National Institute for Deafness and Other Communication Disorders (NIDCD) is spending $3 million on a 6-year study of MPI stuttering therapy. This is the biggest study ever of a stuttering treatment. You'd think that an effective new treatment with a large government-funded study would be news, yet none of the stuttering organizations have published articles about MPI stuttering therapy and few people have heard of it. (Disclaimer: my company makes an iPhone app to support MPI stuttering therapy.)

WHO'S AFRAID OF STUTTERING TREATMENT? A REVIEW OF THE TOP STUTTERING WEBSITES CONT'D...

We could change this by making stuttering treatment research so cheap and easy that researchers won't need grants. First, we need a database where stutterers can volunteer as subjects in studies. Second, we need a website where volunteers can learn to analyze speech samples, and researchers can upload speech samples for volunteers to analyze. Third, this website could have guidelines explaining how to design and budget a stuttering treatment study. Such a website would cut the cost of stuttering research to a fraction, as well as standardizing procedures.

What You Can Do To Improve Stuttering Websites

1. Wikipedia is the best of the top stuttering websites. The short, readable, factual article covers all the main points about stuttering and its treatments. If you see a mistake, correct it. If new research comes out, add it. Wikipedia is in dozens of languages; edit the Wikipedia article in your language.
2. If you have a stuttering website, add EBP stuttering treatment information.
3. If you have a website for a national stuttering self-help organization, add an area for stutterers to write reviews of therapy programs in your country. If you need technical help with this, ask me.
4. If you have a blog, write about new studies of stuttering treatments.
5. Send e-mails asking the SFA, the NIH, KidsHealth, and MedicineNet.com to add EBP stuttering treatment information.
6. Send an e-mail asking the NSA and Friends to add consumer reviews of stuttering treatments.
7. Send an e-mail asking ASHA to add a stuttering treatment research volunteer center.
8. Link your website to stuttering websites you like. If you don't have a website, "like" websites on Facebook, Twitter, etc. Your links and likes will help these websites get into the top ten. Be sure to "like" my website!
9. Help me to start an organization to advance stuttering treatment research and provide EBP information about stuttering treatments, i.e., to inform consumers and SLPs what stuttering treatments are effective. We can't expect the SFA, NSA, Friends, NIH, or ASHA to do this. We can update the AJSLP and JFD systematic reviews with studies published after 2005. We can identify which programs are effective, e.g., the AJSLP systematic reviews found that prolonged speech (fluency shaping) is effective because ISTAR has been proven effective in several studies; however, Hollins has not been proven effective. If reading journal articles is your idea of fun, e-mail me!

Thomas David Kehoe

Disclaimer- The views reflected in this article are solely those of the author and not necessarily the views of the ISA Board

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India.

A 7 year old stammering child asked to leave school.

The Times of India newspaper gave a brief report on a child of 7 who stammered, being asked to leave the school. This shows that lack of awareness of stammering by some Teachers, can lead to a world of grief for young children.

Ed Feuer (Canada) told me that this had been discussed in an online group Stutt-L. He posted on this group..........

Kids who stammer have 'higher IQs': Experts

Terming the incident "unfortunate", Chembur speech therapist Dr C Daryani called for more awareness. He said over the years he has observed that children who stammer have higher IQs, compared to normal children. "It is not documented but I have seen an overwhelming number of cases where children who stammer are more intelligent. Schools should try to integrate and facilitate their education, rather than shun them," he said.

I know of no study about the IQ of stuttering children. But I can say I know of many people who stammer work with computers.

I asked the coordinator of TISA (The Indian Stammering Association) if he had more information. Apparently Jasbir Sandhu had seen the article in the Times of India, research some details and wrote to the school. His letter said

Dear Sir/Madame,
St. Xavier's Pre-Primary School
Pune.

At the outset I am extremely grateful for showing your concern and giving a very prompt reply to my mail. I convey my sincere thanks for the same. I would like to add that we are certainly not being carried away by media reports. I being from legal background, I well understand the role of Media. Our only concern is that Shaun Santamaria should not in any way be penalized for no fault of his. He is too young to understand the communication skills and what speech blocks are. When I read the news in Times of India on 7th morning it pained and shocked me a lot. I can well understand how a PWS suffers because of no fault of his despite having all the abilities. Though approximately 1% people worldwide suffer from this handicap but it has remained a neglected area. The idea was giving support to the young child.

On perusal of term 1 and term 2 reports it is observed that though it has not been mentioned anywhere that Shaun stutters but as per our experience the following remarks in report give indication that the child may be a developing stammering:

INDIA CONT'D..

READING : He is unable to read even the right words.
SPELLING : He is able to spell only a few words.
NURSERY RHYMES & JINGLES : He needs to learn the rhymes is unable to recite any rhymes.
DRAMATICS : He is hesitant to act in class.
GENERAL REMARKS : Shaun is a quiet and well mannered child. He must participate in class activities. He lacks self-confidence. He must make an effort to improve in his overall performance.

The above indications requires immediate help to the child to recover so that he may not develop confirm stammering. TISA is an association of Indian people who stammers . Its purpose is to collect and disseminate relevant, correct and unbiased information for people who stammer and their families, friends and society in general. It is promoting self help group movement where PWS learn to help each other and themselves. After Parents I have greatest regard towards Teachers because they only tell us what is good & what is bad.

Do you know what is common amongst following?

(i) King George VI England
(ii) Aristotle, Great thinker
(iii) Winston Churchill.
(iv) Marlyn Monroe
(v) Ed Ball - British Minister for Labour
(vi) Rowan Etkinson (Mr.Bean)
(vii) Issac Newton
(viii) Charles Darwin
(ix) EMS Namboodripad
(x) Hritik Roshan

They all had speech problems.

Stammering is involuntary repetition of part of a word (syllable) while speaking. It is caused by a rare neuro – physical disorder of the speech nerves in the brain. It is important to understand its "involuntary" and "variable" nature. It may not be present while singing, whispering, reading with others, talking to pets, friends and under a variety of other conditions.

About 1% adults are expected to be PWS. It is more common among men than women by 4 to 1. About half of PWS may have a close relative with the same disorder.

INDIA CONT'D..

For Teachers here are a few tips to help a child who may be developing stammering QUIETLY:

(1) Identify the children who are shy in class like Shaun.
(2) Talk to their parents about their behavior.
(3) Talk to child – how he feels. Talk about it openly.
(4) Encourage the child to speak and take part in school activities.
(5) Don't give any special treatment to such child.
(6) Praise their qualities.
(7) Take care of Teasers in school.
(8) Talk to class about stuttering.
(9) Do not call students in specific order.
(10) Invite a therapist in school.
(11) Talk to child in slow relaxed way
(12) Never interrupt when he is saying something
(13) Encourage to speak loud.
(14) Never fill in words during childs speech.
(15) To gain confidence encourage for some hobby – singing, painting, social activities.
(16) Never interrupt to say : slow down, first think what you want to say, take a deep breath etc.
(17) If you do not understand, say sorry, what did you say? But do not react negatively, either in words or through facial expression and body language.
(18) Increase the situation in which the child is most fluent. Success in one situation builds confidence and leads to success in more situations.
(19) Keep natural eye contact.
(20) Treat the person who stutters with the same level of dignity and respect as you treat other people.

I have all respect and full faith in Law of Land which will certainly do justice. Meanwhile if you need any help in this regard TISA will be too happy to HELP.

Sincerely yours,
Jasbir sandhu,
Chandigarh,
Cell 099150 06377.

It is examples like this that highlight the need for the ISA to work with the IFA, ASHA and others to raise more awareness in schools and Universities around the world. We need to link to other worldwide bodies like the WHO / UNESCO / etc and all National and International disability organisations . e.g. UNCRPD (United nation convention on rights of persons with disability) and IDA (International Disability Allience). How many more years should this ignorance by teachers in some countries be allowed to continue?.

Keith

Thanks to the Times of India / Ed Feuer / Jasbir Sandhu

10th World Congress for People who Stutter (10-13th June 2013)

The year 2013 is the year in which the 10th World congress for People who Stutter takes place! Just two years after the congress in beautiful Buenos Aires it is time to move to Europe again. The congress takes place in the Netherlands, in a small town at the geographical centre of the country.

Since the congress of 2007 in Croatia, a small group of active members of the Dutch Stuttering Association Demosthenes has been planning on this event to take place in their country. At the annual general meeting prior to the congress in Argentina, the ISA members voted for the Netherlands and since then a lot of work has been done. The location for the congress has been confirmed, fund-raising has started, committees set up and the website gained on content.

The congress will take place in conference centre 'De Werelt' located in the small town Lunteren, surrounded by a forest, on the edge of the largest national park of the Netherlands, the Veluwe. The centre has a double function: in summertime it is a holiday resort for less fortunate families, funded by church and profits from congresses and events which are being held during the rest of the year. From Amsterdam airport Schiphol it only takes little more than an hour to reach the conference centre by car or train. Other airports like Eindhoven and Düsseldorf Weeze are options to fly on. Information about the location and access is available on the website www.stuttering2013.com.

For a few weeks the list of six already known keynote speakers is online and spread through social networks like Facebook and Twitter. On this list are: Anita Blom (Sweden), David Shapiro (USA), Shinji Ito (Japan), David Mitchell (Ireland), Marie-Christine Franken (Netherlands) and Michael O'Shea (Ireland).
Objectives of the congress:

to connect people from all over the world who share the same speech impediment

to share knowledge, scientific and other, about stuttering with each other

to share this knowledge with the world, to help others who don't have any resources

Themes / sessions:

New developments & research, personal stories, communication, treatment & therapy, education & work, taboo-breakers, parents, children and school.

This congress is for:

people who stutter themselves

their families and friends

therapists and students in speech pathology

People who wish to give a presentation or want to organise a workshop can send in an abstract. Information about the format and procedure can be found on the website.

Also, the organisation would like to know how candidate participants would like the congress to be. On the website there is a form named 'Questionnaire'. Please check it out if you are interested in visiting the congress, please.

WWW.STUTTERING2013.COM

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Seminario

Taller en Tartamudez

NNEI

Nivel Neofonoaudiológico
Entrenamiento Introductorio

> “Especialmente dirigido a Amigos con Tartamudez.
> Abierto a Estudiantes de Fonoaudiología, Educación Diferencial, Profesionales Afines.”

- ✓ Conocerás tu primer nivel de entrenamiento aplicando enfoque distintivo Neofonoaudiológico de GAPTCHILE, en un Nivel Introductorio, en el conocimiento de la tartamudez y su aplicación para beneficiar la fluidez con experiencias prácticas.
- ✓ Conocerás GAPTCHILE., estando inserto en el proceso mundial de la Tartamudez.
- ✓ Ponencias de invitado Neurofisiólogo, de Personas con Tartamudez, de estudiantes de Fonoaudiología.
- ✓ Conocerás los siguientes Niveles de Entrenamiento (Terapia) Neofonoaudiológico.
- ✓ Espacios de esparcimiento para conocernos, compartir nuestras vivencias positivas, establecer vínculos sociales.

17 DE AGOSTO

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