

One Voice



International
Stuttering
Association

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



Joseph Lukong, Convenor of First African Conference on Stuttering with street banner



Summer Camp for Stuttering Children by Japan Stuttering Project



AFRICAN CONFERENCE and INTERNATIONAL SPEECH PROJECT

*Mark Irwin
ISA Board Chair
October 27, 2005*

History

In February 2004 at the World Congress of PWS held in Perth Australia, David Shapiro and Peggy Wahlhaus discussed with me their idea of collaboration with the ISA to develop a programme for bringing stuttering therapy to the developing world. A model for this initiative was the internationally recognized “Medicines Sans Frontieres” (Doctors Without Borders). Stefan Hoffman as ISA Outreach Committee chair was later involved in these discussions and it was decided to pursue this idea further.

There was a meeting in Perth and later group email discussions where it was decided to name the programme –International Speech Project –Stuttering (ISP-S). The rationale was if funding was to be secured and recognition achieved then the project had to have a broader appeal than simply stuttering therapy. It was decided it would be more likely to be favourably received by potential donors if the programme related to provision of general speech therapy services.

Once this decision was made other issues were its structure and where and how to launch the project. Stefan Hoffmann, Moussa Dao, Joseph Lukong and I collaborated to initiate an inaugural African Stuttering Conference in Douala Cameroon from 6th-8th October 2005, thinking that this conference would provide an opportunity to gain insights into needs and fund raising possibilities. This background information would enable effective future planning and make Douala the obvious place to launch ISP –S.

Conference Organization

Joseph Lukong as Conference Convenor and Coordinator General of the Speak Clear Association of Cameroon was responsible for conference management. Guidance was provided by the ISA through involvement of me, Stefan Hoffman and Moussa Dao.

Attendees

From inside Africa there were delegates from 14 different African countries. Of course the main group came from Cameroon.

From outside Africa the conference was supported by speech pathologists Anne-Marie Simon from France, experienced in work in Africa, two of her colleagues Sylvie Brignone and Cecile Couvignou, as well as David Shapiro (USA) and Suzanna Rosenberger (Germany). In addition psychologist Peter Howell (England), geneticist Radha Upphala (India) and teacher

Isobel Quick (Australia) also made conference presentations.

Promotion

Anne Marie Simon was a key person in promotion of the event throughout Africa. She had many contacts as a result of previous work there. In addition others heard of it through her interviews on Radio France Internationale. Joseph Lukong liaised with me to produce a conference brochure and later worked tirelessly communicating via email with potential delegates from all over Africa, as well as creating media awareness in Cameroon. The ISA and BSA published details of the conference on their websites.

Finance

The ISA took up the challenge to financially manage the event. It sought funds from recognized aid agencies, embassies and churches without success but was successful in obtaining private donations directly and through affiliated member associations. Originally it was hoped that fund raising could be arranged to fully support travel, accommodation and meals for one delegate from each African country. In the end budgetary constraints meant we could only offer 50% air fare while fully supporting accommodation and meals. Delegates from 21 African countries were involved in discussions about attendance. Of these, delegates from 14 countries attended. Distribution of scholarship money raised by the ISA was managed in Douala by me, Joseph Lukong and Moussa Dao, after telephone and email links to ISA treasurer Hermann Christmann of Denmark.

Aims of Conference

- Give information about stuttering
- Give stuttering therapy
- Give information about development of self-help groups
- Gain information about situation for PWS in Africa
- Gain information about situation for therapists in Africa
- Gain information for fund raising possibilities
- Launch International Speech Project –Stuttering

Information Given

- Information was given to delegates via conference presentations by all the speech pathologists and by psychologist Peter Howell, geneticist Radha Upphala and teacher Isobel Quick. The general public was informed through numerous radio and

television interviews. Credit must go to Joseph Lukong for publicizing the event so widely in Douala and ensuring such widespread media coverage.

Anytime I was interviewed, including a segment on the 7:00 TV news, my message was for the general public to understand stuttering is a disability that can be managed to varying levels depending on age, severity and support. The message for PWS was to come out, not to be anxious, embarrassed or ashamed of their stuttering and join a support group as a means of helping themselves.

- Stuttering therapy was provided to the delegates in pre-conference work shops conducted by Anne Marie Simon and David Shapiro.
- I gave a presentation on stuttering self-help groups –how to make them work to ensure they remain dynamic and open.

Information gained

- Generally the situation in Africa for PWS is poor due to a lack of understanding and use of ineffective and physically harmful treatment techniques. Examples included a report from Salad from Kenya on how he was beaten vigorously on the back with a sheep's lung as a treatment method. Joseph Nsubuga from Uganda reported incidents where children who stuttered had been killed in the belief they were possessed by evil spirits.
- Belief in witchcraft is still prominent in Africa and the local witchdoctor/ faith healer is used as a therapy source. Western style therapy exists to varying extents. Recognized speech therapy qualifications are available in South Africa and Togo. The Togo training institution has received funding from Handicap International and students receive specialist training in stuttering therapy from Anne Marie Simon. Other people have done what can best be described as auxiliary training either in France or in South Africa. Elsewhere psychologists treat stuttering. Sami Yasin from Sudan reported that speech therapists are unknown in his country.
- There are many international aid organizations, churches and embassies providing assistance in Africa. Unfortunately none of those approached by the ISA or by the Clear Speech Association of Cameroon were able to help.

Launch of International Speech Project –Stuttering

After consideration of input from numerous sources the ISP –S was launched with a general concept of developing self-help groups to liaise with specialist speech pathologists to provide information to PWS and the general public. In addition the specialist SLP's

would provide postgraduate education to African "speech pathologists" and psychologists. Another priority was to lobby African governments to provide training for French and English speaking students in the established facilities in Togo and South Africa respectively. Later perhaps, when enough speech therapists in various African countries had been trained it might be possible to develop local education facilities staffed by people previously trained in Togo or South Africa. A development board will be established to manage practical implementation of these ideas.



Mark Irwin and Moussa Dao giving press interviews

Summary

The delegates indicated that they very much valued the opportunity to build networks with other PWS and experts from within their own countries, from Africa, and from other countries in the world. Judging by the number of contact details exchanged this will be only the start of the ongoing development of a supportive network of people with a commitment to improving the situation for PWS in Africa.

Expert information was shared in a two way process and knowledge deepened. From this we can expect the development of more self-help groups in Africa plus the provision of more effective therapy and training services. In addition a foundation has been set for ISP-S so that essential information and effective stuttering therapy might soon be brought to all people of the developing world.

Thanks are due to everyone involved in this historic event. A huge splash was made in the pond of stuttering awareness and understanding. The ripple effect from this splash will further develop the ISA mission of a world that understands stuttering.

Finally as a visitor to Africa I found the hospitality shown by the local delegates to be outstanding, and would encourage others to participate in any future conferences.

Editorial for VOICE OF ELSA

This year has been a busy one for the European League of Stuttering Associations (ELSA). 2005 saw us prepare for the 5th Youth Meeting (held in July), give presentations across Europe on the scope of our work, attend and participate at European Disability Forum (EDF) meetings, (particularly their Annual General Assembly), culminating in the significant “ELSA Cocktail Reception” where we met with Members of the European Parliament for recognition of International Stuttering Awareness Day (ISAD).

Raising awareness of stuttering is an all-important facet of ELSA’s work. My feeling is that when information on stuttering filters through to as many stakeholders as possible, it provides the foundation for help and services that will ultimately come our way from many quarters. I believe that the work of the national stuttering associations across the world, umbrella associations like ELSA and ISA, and the speech therapy profession will one day ensure that there is adequate,

plentiful and quality help for people who stutter. However, we have to be patient.

Representation at the highest level is of paramount importance and is one of ELSA’s key objectives. The successful ELSA reception at Strasbourg for the ISAD is an example of such representation, and is detailed here in this edition of One Voice, and on ELSA’s website.

I am always inspired by the dedication of many people across the world who give their free time to promoting the rights of people who stutter, both young and old. To all of you - please do continue, you are the lifeblood of the stuttering community.

I wish you all a successful 2006.

Edwin J. Farr MBE

Statement on Stuttering and The International Stuttering Awareness Day (ISAD) signed at the European Parliament

An important step towards greater awareness of stuttering at political level was taken in Strasbourg on 25 October 2005. All Members of European Parliament (MEP) had been invited to a reception on the occasion of the International Stuttering Awareness Day. The event was jointly organised by ELSA and the Spanish Stuttering Association (TTM Espana), and supported by the European Disability Forum. Special emphasis had been given to inviting the members of the Disability Inter-group which is an inter-party working group of Members of the European Parliament (MEPs) engaged in disability politics. More than 30 MEPs accepted the invitation which – according to insiders at the European

Parliament – can be regarded as a success. Also, representatives of several National Stuttering Associations attended the reception. Short speeches were given by Adolfo Garcia, President of TTM Espana, Richard Howitt MEP, Chair of the EP Disability Inter-group, and Edwin J. Farr MBE, Chair of ELSA. In the course of the reception MEPs were asked to sign a “Written Statement” on “Stuttering and the International Stuttering Awareness Day” that states important needs and demands of people who stutter and calls upon European Parliament to officially recognise International Stuttering Awareness Day. (For the full text of the statement see below)

ELSA presents at the EDF Annual General Assembly

The European Disability Forum (EDF), the representative organisation of 50 million disabled people in Europe, held its Annual General Assembly in Barcelona on 28-29 May 2005. More than 150 leaders of the European disability movement from 29 countries (including ELSA) participated in this key meeting. The meeting also consisted of a presentation by ELSA’s Gina Waggott who is a member of the EDF Youth Committee. Picture shows EDF President Yannis Vardakastanis with Gina Waggott of ELSA. For more details see www.elsa.info



ELSA's 5th Youth Meeting a Success

July 2005 saw ELSA's 5th Youth Meeting take place in Nijmegen, the Netherlands. The meeting was part funded by the Council of Europe and the feedback has been overwhelmingly positive. The theme, "Educating and Empowering Young People to Work with the Media" has already been realised with international press coverage. Young people who stutter from 15

countries gathered to learn more about the media and discussed and produced a media campaign. But the week was also about meeting, sharing and letting go. For more details see www.elsa.info



Anita Blom of ELSA speaks in Croatia

Outreach and contacts with Speech Therapists are two of ELSA's key objectives, and we are happy that Vice Chair Anita Blom was invited to Dubrovnik to speak and give a workshop at the 3rd Congress Of Croatian Speech And Language Pathologists (28th of September

to 1st of October 2005). Around 250 SLPs learned more about the life of a person who stutters, the work of ELSA and the need for cooperation between ELSA as well as National Stuttering Associations with SLPs.

Anita Blom of ELSA speaks in Czech Republic

Anita has also been invited to the prominent speech clinic LOGO in Brno, Czech Republic, to celebrate the ISAD by giving a workshop about stuttering and by being the keynote speaker at a conference in the City Hall of Brno where the audience, consisting of PWS,

SLPs, politicians and other people working with or interested in stuttering, could learn more about ELSA, the ISA and the ISAD as well as stuttering. More about the clinic at <http://www.logoped.cz/>

Africa in the lead

Stefan Hoffmann
ISA Outreach Working Group

As you can see from various articles in this issue of One Voice, the big event this year has been the African Stuttering Conference in Douala, Cameroon. From an Outreach Point of view, this was a huge success. Delegates from various African countries came to the event and could feel, quite a few of them for the first time, the benefit of the self help concept for stutterers. Reactions now 2 months after the meeting show that something has started rolling there: the nicely made website of the Nigerian Stuttering Association, plans for events in Uganda and the willingness to contribute to future ISA projects by Sudan show the immediate effect of the inspiration the delegates got in Douala. For me who could not be there it was joyful to witness from afar that this event was organized and conducted in a very professional manner. Thanks for all who made that possible.

For me as one who is always eager to add more countries to the contact list of ISA, this year 2005 was very fruitful. During the run up to the Cameroon meeting I was able to get in touch with stutterers from Mauritania and Mauritius. Some have been briefly confused and thought this is one and the same place, but actually those countries represent the far west and the

far east of Africa, so symbolically spreading the ISA flag over the continent.

It is with great joy to see that Brazil became an ISA member now. I consider this being a major step forward in Latin America. I know of the solid ground work that (now former) ISA Special Friend Daniela Veronica Zackiewicz has laid in Sao Paulo and other cities and we expect to hear from Brazil soon about their first events as ISA members.

Further on I want to inform you that new contacts have been made with people from Philippines, Iraq and Mexico. From this list of countries you can see how widespread the message about ISA has already become and on the other hand how diverse the challenge is to add contacts to ISA's list.

As usual, I want to invite the readers to consider joining the ISA Outreach Working Group. By doing so, you help directly with spreading news and information about stuttering to places still far away from ISA. Apart from helping ISA, you also have a chance to grow personally in the process. Welcome!!

COMMUNITY VISION FOR GLOBAL ACTION

Judith Maginnis Kuster, Professor at Minnesota State University, Mankato

Michael G. Sugarman, MSW

The 8th annual International Stuttering Awareness Day--October 22nd activities were held around the world. You can read about ISAD 2005 activities sponsored by people living with stuttering and the professionals as well as the European League of Stuttering Association's statement to recognize ISAD in this newsletter or by going to www.stutteringhomepage.com and clicking "announcements of ISAD activities around the world."

The 8th On-line conference was held October 1 –22nd, 2005 and over 101 different individuals representing 19 different countries were involved in the conference presentations. Several professionals served as experts for the "Professor is In" and the "Researcher is In". The conference was divided into sections: People who stutter tell their own stories (16 papers), support group activities (2 papers), research about stuttering (7 papers), treatment information and issues (9 papers) and programs and power points (6 papers). Special features included power points, downloadable software programs, and an audio file. Statistics for the month of the conference indicate the entire site had 571,218 requests for information. 2,724,830,591 Bytes were transmitted during the summary period. At the time of this writing, individuals in 83 different countries have

checked into the conference. During the month of October, papers were read by an average of 385 people with a range of 189 – 644. One paper was translated in Spanish (200 hits) and Italian (149 hits), which was not included in the summary of how often a single paper was read.

In November 2005 Judith Kuster and Michael Sugarman presented a poster session at the American Speech Hearing Association (ASHA) conference in San Diego, California, USA. One hundred summaries of eight ISAD online conferences, 500 ISAD and Bill of Rights and Responsibility for People who Stutter posters, and 100 ISAD buttons were distributed. Nine professionals who coordinated ISAD activities not previously reported shared what they did for ISAD. Probably more activities occurred during the month of October that go unreported.

ISAD continues to be a mainstay to our continued outreach efforts in making the "WORLD UNDERSTAND STUTTERING"—thank you for helping to change the attitudes of people living with stuttering about themselves as well as how the general public views stuttering.

Editorial

"No one dies from stuttering", said Tom Weidig, Research Committee member of British Stammering Association, in explaining obstacles people who stutter have to live with (thestutteringbrain.blogspot.com). Now we know this might not be true, as ISA Chair Mark Irwin quoted (Page 2, OV 20), Joseph Nsubuga from Uganda reported incidents where children who stuttered had been killed in the belief they were possessed by evil spirits.

What a bitter knowledge!

And this is why I am proud of what ISA has done in Africa. These names should be remembered by African PWS by their great work in pushing the first African conference on stuttering. Editing those articles from representativess from Benin, Chad, Congo, Ghana, Mali, Nigeria, Sudan, etc., I was surprised at the huge obstacles they have conquered – all the governments, NGOs and Embassies, even churches, would not give financial help, many even did not reply!

Oh we live in a world with discriminations toward stuttering! Because of the characteristic of this disorder,

we have difficulties letting others know what we have suffered, and hence, in the old time, we used to refrain ourselves from the outer world.

Now the world seems to be a little bit different! And we know, some of these changes should be contributed to the very existence of our groups, to the one voice from 60 million people in the world – it is really a great power!

Merry Christmas and Happy New Year!

Jianliang Zhang
(You may call me Albert ☺)
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FIRST AFRICAN CONFERENCE ON STUTTERING

Joseph Lukong

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THE International Stuttering Association (ISA) in collaboration with the SPEAK CLEAR ASSOCIATION OF CAMEROON (SCAC), organized in Douala Cameroon, is the first ever African Conference on stuttering. This conference took place from the 6th to the 8th of October 2005, brought together people who stutter (PWS) from some African countries, prominent member of the ISA, speech TREATMENT Pathologists, psychologists, researchers and educationalists from Australia, North America, Europe and Asia. The conference had a theme “UNDERSTANDING STUTTERING AND ITS TREATMENT”.

It should be pointed out here that about 17 million Africans are affected by stuttering. The situation of this people who stutter in Africa is quite difficult due to the absence of adequate information on the causes, prevention and treatment of this disorder. In the absence of modern health care for stutterers in Africa; PWS often go for the available traditional and at times very crude methods of prevention and treatment for stuttering. It was to remedy this situation that some speech pathologists in collaboration with the ISA and SCAC decided to organize this conference as the first step to helping stutterers in Africa. Attendees to this conference came from 15 different African countries and the following non African countries: Germany, France, India, Australia, England, and the USA.

Before the start of the conference, some speech pathologists attending this conference, organized in collaboration with the SCAC a series of free speech therapy sessions for stutterers, and training sessions for the medical corps, teachers, social workers and parents of children who stutter. These specialists equally used socio-cultural, religious and the mass media to pass over useful information on stuttering

to the public.

During the conference itself key note presentations and workshops were done and valuable information on stuttering treatment, research and self help were passed out. African delegates equally are testimonies in relation to the state of stuttering in their respective countries.

Before the conference rounded up an important project called INTERNATIONAL SPEECH PROJECT STUTTERING was launched. This project aims at developing the concept of self help groups in many

African countries, whose groups will liaise with specialists to provide adequate information to PWS and the general public. The project also aims at helping to train local speech professionals that could help to fill the existing vacuum. It was also decided that for this project to be successful, some funding bodies and African countries should be lobbied to support it.

This conference would not have been organized without the

support of the International Stuttering Association that obtained private donations from her affiliated member associations and some private donors to help fund part of the travel cost, feeding and lodging of African delegates who accepted our invitation and attended the conference and those other people who help to support it in one way or the other. Michael Sugarman and Amy Johnson of the USA sent some hundred of copies of the ISAD posters and the bill of rights and responsibilities of people who stutter that were shared out to conference delegates who took them back to their respective countries to help and spread stuttering awareness there. Example of Cameroon is shown on the picture that follows where SCAC members dressed in their T-shirts went out to the streets of Douala Cameroon on October 22nd 2005 which is ISAD to sensitize the public.



AFTER TWO YEARS ATTEMPTS SUCCESS STARTs

A message sent from Moussa Dao (Burkina Faso) to Joseph Lukong

Dear Joseph,

As promised I send you our project which was granted by France embassy. Another project was funded by Handicap International (French association related to disability)

The general idea of those projects is the fact that by sensitizing teachers we may improve the school year children who stutter and by that we may contribute to prevent the worsening of their stuttering.

Our challenge was to convince eventual sponsors. It was an exhausting task. As you know, government just congratulates and says that they have no means. After setting up our association, we sent a message to all NGOs and Embassies to explain the purpose of our association and ask partnerships. Obviously many of them didn't reply, others replied by telling that stuttering is not in their priorities.

Our attempts were negative.

I expected such reactions because there are a lot of associations who send this kind of requests. People didn't have enough time to read carefully all the requests. More important, Sponsors are sometimes disappointed by associations. For example there are more than 1,000 associations in the field of AIDS. Only few of them really successfully work for people who live with AIDS.

Our failure did not prevent us to start activities. Our thought was: we have to demonstrate that we are able to achieve small activities with our own little means and without any supports.

We met some headmasters and they were really enjoyed by us to come and sensitize their teachers. During workshops we took pictures and teachers' reactions.

We used to invite the Embassies and NGOs. Of course they didn't come. Every year we built a document which contains all activities achieved and our upcoming projects. We sent these documents to Embassies and NGOs.

It was simply to inform them about the result of our activities and particularly to show them our commitment and dynamism.

Later, we decided not simply send letters for just partnership but ask for appointment. The majority didn't reply, some once again replied that stuttering is not in their program, but at least some responded positively.

Wow! After about 2 years' attempts success starts.

When we met them, we did our best to explain the importance of the theme of stuttering. I'm sure that, nobody could be insensitive to the theme of stuttering if this theme is well presented.

You may have all the elements, but the manner to present them in a good

order and convincing way is essential to attract attention and get partnership.

Slowly but surely we will convince all the NGOs and Embassies.

During our meetings with teachers, our program was:

- First questionnaires to know general ideas on stuttering, their attitudes in classrooms, folk ideas on stuttering
- Presentation (if possible with PowerPoint) on what stuttering is and what teachers could do to help children who stutter in classroom
- Testimonies of members of ACB who tell their difficult situations in classrooms
- Projection of the film: To speak
- Questions and debate
- Questionnaire to evaluate the knowledge

I would like to say that the CD of ISA was very helpful to develop our program.

It's important, according to the situation in each country, to develop project to spread the information contained in the CD.



Teachers are really enjoyed to get information on how to handle with children who stutter. An old ladies said “For many years I have been teaching, I participated at many workshops, but none touched me like this. You

Now, in Handicap International and France Embassy, the persons who manage the cooperation department are practically my friends.

This week, my wife and I are invited for a dinner in the house of the charged in cooperation department of France Embassy (the third personality in the Embassy). You are aware of how it is difficult to approach embassies staff in Africa, but thanks to stuttering I have friends there. Now I enter easily in the embassy of France.

In Cameroon, you have many assets. You have done many activities and the success of African conference is a good point. You already started contacts with NGOs and Embassies. The little problem will be the fact that embassies and NGOs are in Yaoundé (the capital). But I think you will find a solution to overcome this challenge. I’m sure that you will succeed. You have the essential means for this task: your

commitment and courage.

Best wishes

Your brother Moussa

AFRICAN DELEGATES TESTIMONIES

Dr Elie Nazaire MBan
Congo Brazzaville (Central Africa)

The African conference was a great event for me. It was an opportunity for African delegates to break their loneliness. In Africa many things are told about stuttering. We thought that stuttering was an insurmountable challenge. Thanks to studies and researches in USA, Australia and Europe, this challenge could be overcome now. What hope!!!

For many years my grief due to stuttering makes me think that I was inferior to fluent persons.

During the conference I learnt so much with scientists and many personalities who share their interesting experiences on how they successfully managed it.

I’m from Congo Brazzaville. In my country there is only one speech language pathologist who is not specialized in the field of stuttering. That reveals the important need of help in my country. It’s proved that if a child who is 6 gets therapy early there is a 95 % of chance to treat his stuttering.

Due to the situation in my country, I am willing to set up a self help group in order to help people who stutter. I would like to finish by thanking the chairman of ISA (Marc Irwin), Joseph Lukong, Anne Marie and her team and all sponsors for that African conference

Edith occhoumaré
Benin (West Africa)

The first ever African conference on stuttering which was the first stone of the edifice was a great success. As a speech language pathologist, this conference allows me to reinforce my knowledge on stuttering and learn new therapies approaches.

Thanks to this conference, I met eminent SLP, psychologists, researchers, leaders of associations, parents of children who stutter.

These meetings already help me to improve my way to take care of PWS.



Like all organizations and enterprises in their beginning, the organization of this conference had its weakness. I hope that for upcoming conferences those problems should be solved.

I couldn't finish without thanking all the team of SCAC in Cameroon for their initiative and the success of this conference.

I would also thank ISA which make my dream a reality. At last, my thanks to all participants for the richness of our exchanges and the good time we had in Douala. This event is deeply engraved into my heart. I hope that many others meetings in Africa, Europe be organized.

Thanks to SCAC, ISA and all

Diallo Oumou SIDIBE
Mali (West Africa)

It was a real pleasure for me to participate in the African conference. First of all I would like to thank the Lord who allows me to be in Douala. I would like to thank my family for their financial support. I would also like to thank all donators for African conference. Thanks also to Stefan who send pens and ISA for ISAD poster. This conference was an opportunity to touch many PWS and parents of Child who stutter. Thanks to this kind of meeting the ignorance and taboo related to stuttering will be overcome. I would like to thanks the minister of social development of DRC for his message. My dream is that this minister transmits the voice of stuturer to African countries leaders. I would also like to thank Anne Marie, thanks to her broadcast in France Radio. I was encouraged to start an association in Mali.

This conference was an opportunity for many stutters from different countries of Africa to meet. I hope PWS in Chad will follow the step of Mali and set up their association.

For me it's important to help us to create stuttering centers in African countries. They would be places for treatment centre and meeting places for PWS.

PWS in Africa must create their umbrella association. It would be in relation with ISA and would be a means to do pressure on governments.

I would like to finish by telling that much must be done to help PWS, particularly in countries like mine where stuttering is considered as a curse.

We must work together to help PWS.

Long live to ISA

Akintunde Adeyemi
Stuttering Association of Nigeria

I represented Nigeria at the First African Stuttering Conference Douala, Cameroon, on October 6 to 8, organized by Joseph Lukong (Speak Clear Association of Cameroon), where I delivered a paper workshop titled "Absence of Modern Speech in Nigeria". The conference was nice that it brought people from most African countries together to share ideas on stuttering on the theme "Understanding Stuttering and its treatments". Most especially, people from Australia, France, Germany, Switzerland and more countries came to the conference.

Thanks to Joseph Lukong who came about this great idea of the conference. Special thanks to Stefan Hoffmann (Germany) who donated free pens to us during the conference and Michael Sugarman who donated free posters during the conference. Most thanks to International Stuttering Association board's chair Mark Irwin, who reimbursed all African delegates who came to the conference.

Ousmane Issa Bourkou Santa,
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First of all, I want to thank the International Stuttering Association and the donors who helped me attend the first African Stuttering Conference held in Douala, Cameroon, Africa, from October 6-8, 2005.

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Watson Kelemogile Lekalake
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The group that met to discuss ISP-S -representatives from 7 countries

Finally, the long-awaited event for the people of Africa with special attention to speech took place in Douala, Cameroon.

Africans who stutter are usually stripped of their leadership qualities. Verbal communication is our everyday activity in Africa. Ma'yibuye fluency (Zulu word for "let it come back").

I would like to thank the International Stuttering Association (ISA), Mrs Judith Eckardt and her husband George, from Tucson, Arizona, USA, and my parents Darius and Suzan Lekalake for sponsoring me to the tune of more than half a million francs to attend this conference.

I was representing Speak Easy South Africa (SESA). This is one of the organizations in South Africa which is a good measure that really South Africans are creating a new dawn in our young democracy. The SESA Johannesburg branch, of which I am a member, meets once a month, and is led by speech therapists and some successfully recovered people who stutter.

After four days of adapting in the tropical equatorial region of the continent, Dr. Mark Irwin, chair of the board of the ISA, from Australia, opened the first African Stuttering Conference with a testimony.

The message "Think Globally – Act Locally" was well received. The message, given by Stefan Hoffmann and read by Dr. Moussa Dao, encouraged national stuttering

conferences. Just imagine when each African country can start hosting an annual national stuttering conference, just as they all host at least one annual national soccer competition in their respective countries.

Ma' yibuye iAfrica, before those of us who stutter perish like kids in silence inside the wrapping blanket on the mother's back.

I hope we, as Africans, can sustain the wealth of information we discovered from the workshops presented at this conference. I attended the English-language workshops, where Professor David Shapiro, from the USA, illustrated gentleness and evenness of the rate of speech and naturalness of speech; where Dr. Sami Awad Yasin, of Sudan, played mind games with us, where Dr. Uppala Radhakrishna looked microscopically into our cells, taking us way back in time then telling us what the future holds for us; and where Suzanne Rosenberger illustrated how she plays with the kids in the stuttering summer camp in Germany.

All of these presentations helped me realize the pain I cause to myself by trying hard to achieve fluency. I remembered the Japanese philosophy which highlights that one can achieve a huge impact by applying a light force.

I am looking forward to witnessing how the Western scientific approach and the traditional African approach will integrate to cure stuttering.

I realized that everybody was happy to meet me as much as I was to meet them. The language barrier between French and English could not stop us from engaging in conversations and going out at night as comrades in what appeared, to this tourist, to be the crime-free city of Douala.

I made a lot of friends and this was enough evidence that the initiative for a single African Stuttering Association will succeed.

Last, but not least, I would like to thank Joseph Lukong and the Speak Clear Association of Cameroon for a job well done.

Let's keep talking.

Comments About African Stuttering Conference

SAMI AWAD YASIN

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Founder and Director of Sudanese Stuttering Organization (SUDASO)
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There are some people who are dedicated to help others, and sometimes there are some problems in someone's lives that work as an incentive: first to overcome or live with it successfully, second to help others who are suffering from the same problem and be their guidance for better life. Both these are very human, BUT what is more than just human is what Dr. Mark Irwin (ISA Chairperson) and others have done for Our African Persons Who Stutter (PWS) - they brought more than 20 delegates from all over Africa, with some famous Speech Therapists from outside Africa, to Douala in Cameroon from 6th – 8th Oct. 2005, with the theme: Understanding Stuttering and Its Treatment. It was most successful, because it brought all stuttering sufferers in Africa for the 1st time together, and now they are planning many good projects for themselves, of course with the amazing hospitality of the Africans.

About Sudan, only because of this magnificent conference idea, we were motivated to establish our national Sudanese Stuttering Organization (SUDASO) which aims at bringing together psychologists who are

trained in stuttering therapy, with PWS who will benefit from therapy services and the forming of self-help groups. Now we are trying hard to have a therapeutic center for PWS, which can also be used as a club for PWS social interaction activities; another thing is that we have good links with schools and Ministry of Education, and updated and simplified therapy programs trying to make it available and usable by teachers and parents of PWS. For the time being we don't have specialized speech therapists hoping to have experts to come to Sudan and train our care-providers in short-courses and later use them as trainers for others.

Till that happens, we have a message to say: Who ever you are; a PWS or not, professional or not, educated or not, you can do a lot for the child or PWS by accepting him and the way he speaks. He is a very normal person who deserves full respect and has all the rights like you. For the teachers make the schools good time places for students who stutter, and for parents make your child who stutter feels the joy and respect being talking to his most lovable persons.



Joseph Lukong, Mark Irwin and Moussa Dao with recipients from ISA scholarship fund

STUTTERING AND REVERSE MADNESS

Akintunde Adeyemi

Stuttering Association of Nigeria

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This article aims to explore if there is any significant interaction between the stuttering condition in individuals and the degree to which it is defined as a psychotic condition.

This article will draw theoretical inspiration from the dramaturgical idea of society as proposed by American sociologist Erving Goffman. Goffman's basic assertion is that society and the meaning that are exchanged within it are farce, like the goings-on on the drama stage.

Hence it can be concluded a significant degree of the discrimination suffered by stutterers comes from a naive and primordial conception of their condition as a mild psychosis. In the drama of life, the stutterer is the lisping fool whose words are not clear and are highly theatrical, provoking amusement.

Having made this curious discovery, debunking this myth is of so much importance. The stutterers' condition is by no measure a reflection of psychotic disturbances. And stutterers have as much intellectual capability as a person who does not stutter. However, the onset of stuttering might hark back to some turbulent emotional distress which, if still retained in the mental hold of a person, might accentuate the stuttering condition. Hence, therapeutic attention should be directed towards detecting and measuring the degree to which past emotional events interact with a stutterer's view of the world.

PERSONAL EXPERIENCE of a journalist stammerer

Anass Mohammed

*P.O.Box AN 11076, Accra-North,
Ghana, West Africa*

It is indeed hard to be a journalist and stammerer at the same time. This is because people expect you to be very fluent. And I happen to be a journalist who stammers and I wish to share some of my experience with you.

I must point out that these experiences only relate to my practice as a journalist and are very recent. For those of you readers who are conversant with happenings in Ghana, you must have heard of the Committee for Joint Action or CJA for short. This committee was formed as a pressure group early in the year after the government

increased the prices of petroleum products by about 50%. I happened to be the reporter assigned by the Ghana Broadcasting Corporation (GBC) Radio to cover the first demonstration of the CJA on March 1, 2005. While on location, I fed the newsroom about happenings as the demonstration or the protest match proceeded. But when it was time to put whatever information I gave into a news item, which required that my voice is heard on air, those in charge thought there were breaks in my voice and that even though in my voice they had all the facts they needed, they concluded that my voice be not used. A colleague who was on leave and joined the procession as a mere observer was called and his voice was used on air. The reason for me being assigned, which I suspect was because I could be impartial, was relegated to the background.

I encountered the same "embarrassment" when this year's Senior Secondary School Certificate Examination began. Among three of us who reported from location, I was the number two in terms of ranking. And in our newsroom tradition, the senior's name is always mentioned first when two or more people are on the same assignment. But when it came to arrange our tapes after the 12-hours bulletins had been aired, my tape was the last. That was done basically to ease dropping the tape should the producer had hard press for time. When the time came for a bye election on the August 30, 2005, at the Ododiodio constituency, I was not named as one of the reporters because those assigned were to report from location. In effect, I am no more assigned to cover any assignment that will require me reporting from location.

Again was the embarrassment in May 20, 2005, when I was to read my own report of the Annual Humanities Lecture of the Ghana Academy of Arts and Sciences I covered the night before. The lecture was delivered by the Chief Justice of Ghana, Mr. Justice George Kingsley Acquah and it was on Parliamentary Vetting and Ghana's Constitutional Democracy. The topic and the personality were important to us as state broadcasters and so we could not do without the story. After I read my report which to me hardly showed any traces of my stammering, the Chief Controller of Programme of GBC Radio questioned why I went on air with my voice. Believe me I have never read my story ever since. I write for others to voice for me.

It has now clearly drawn on me that broadcasting is not for the stammerer. And though Ghana is bedevilled with unemployment, I have inwardly resolved to leave GBC even if there will be no employment for me.

I do not think my superiors are aware of the fact that their actions sometimes hurt me. So are many other Ghanaians. *(Continued on page 13)*

LETTER FROM UGANDA

NSUBUGA JOSEPH
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DEAR BROTHERS AND SISTERS IN THE STRUGGLE,

I have the pleasure to thank all those persons who worked tirelessly financially, materially and physically to make the African conference a success. Special gratitude goes to Mr Mark Irwin the Chairman, Mr. Steffan Hoffmann, Joseph Lukong and all language experts like Susanne, Sylvie Anne Marie and others who sacrificed their time to grace the occasion and the hospitality of the host country.

In my view and evaluation of the African Conference I have this to say to the stutterers worldwide:

- a) THE WAY IS LONG
LET US GO TOGETHER.
- b) THE WAY IS DIFFICULT
LET US HELP EACH OTHER.
- c) THE WAY IS JOYFUL
LET US SHARE IT.
- d) THE WAY IS OURS
LET US GO IN LOVE
- e) THE WAY GROWS BEFORE US
LET US BEGIN.
- f) THE SHAPE OF THE HEAD DETERMINES THE
HAIRSTYLE SO NEVER GIVE UP.

Easy Speak association has been strengthened further by the recent African conference and I am now busy organizing a one day peaceful demonstration by students who are in holidays along the streets to make our voice heard. The final aim is to make our voice heard and create a public awareness of the co-existence and equal treatment of all people with various disabilities.

DREAM MISSION

OUR ABJECTIVE IS TO PAVE THE WAY FOR AN ALL INCLUSIVE ACT WHICH RECOGNISES ALL FORMS OF NATURAL DISABILILTIES IN UGANDA AND THE WHOLE WORLD IN GENERAL.

MAY GOD BLESS YOU ALL

From page 9

The conference, that brought together people from different countries and cultures of the world because of stuttering, was a success apart from some lapses notified here and there. It was wonderful that stuttering, which we use different words to call (French “bégaiement”, British “stammer”, Sara my mother tongue “tamaï”, and so on), brings us from all parts of the world to meet, discuss and find solutions according to our area. I hope this conference will open the way for us to fight ignorance and discrimination that stammerers suffer for a long time in Africa and will help us to take our destiny into consideration.

This conference helped me understand better my situation and gives me "tonus" (energy) to speak in front of people. I will dare to do things which I haven't done before because of stuttering.

In order to help other people in the same situation as me, I'm about to create a self-help group to let stammering people know their rights. Together we will fight this taboo that we undergo everyday and everywhere.

From page 12

I have therefore thought it wise to start an organisation that will take it as a responsibility to sensitise normal speakers to understand the plight of the stammerers. Though the organisation has not taken off yet, I am seriously contacting people and in no time Ghana will have an organization or association of stammerers.

NATIONAL STUTTERING ASSOCIATION UPDATE

*Lou Madonna
Philadelphia NSA Chapter, USA
NSA News Online Team*

Since our last report in the Volume 19 issue of *ONE VOICE* in May, 2005, the National Stuttering Association (NSA), in the United States, continues to make great strides in improving its financial condition and overall outreach to the community-at-large.

We held our 22nd Annual Conference in downtown Chicago, Illinois, from July 13th to 17th, at the Westin Michigan Avenue Hotel. This conference set a record for the highest attendance ever at 602. Our beloved longtime member, Marty Jezer, who passed away in June, was inducted into the NSA Hall of Fame.

The conference was dedicated to the children and teenagers in the organization and the occasion was observed with the kick-off of the NSA Kids Program. This new initiative integrates all of the services in the NSA and provides help and support to young people who stutter, from age 3 on up, and their families. These programs include Youth Days; C.A.R.E. (Connection, Advocacy, Resources and Education) Groups for children who stutter and their parents; TWST (Teens Who Stutter) Chapters; Internet Yahoo Groups; and newsletters. We have established only a handful of CARE and TWST chapters throughout the US at this time, so we still have quite a challenge ahead of us in growing new chapters and striving to adequately meet the needs of young people who stutter in America and their families.

We continue to emphasize our outreach programs that target speech-language pathologists. Recently at the annual convention of the American Speech-Language Hearing Association (ASHA) in San Diego, California in November, NSA hosted a large booth in the Exhibit Area where many of our materials were marketed. Approximately 12,000 Speech/Language Pathologists attended this convention. In addition, three NSA members were recognized with awards. Lee Reeves

received the Distinguished Service Award for his years of hard work and dedication to the NSA and people who stutter. Speech-language pathologists Scott Yaruss and Charlie Diggs were honored with the Fellows Award, which is one of ASHA's highest accolades, and the Fellow status is retained for life.

The NSA website (at www.westutter.org) is updated weekly with important news relevant to everyone in the stuttering community, and, of course, we continue to publish our bi-monthly newsletter *Letting GO*, which is now distributed online to contributing members who wish to receive it in this format. We have also recently initiated broadcast e-mail messages to all members in our database, and have distributed welcoming kits to the leaders of our adult chapters to aid in outreach and increased membership in 75 chapters nationwide.

Our "Change For The Better" automatic monthly donation program has shown a slight upward trend in participation, and we have implemented an e-mail membership renewal reminder program for those who renew on an annual basis.

In 2006, we are looking forward to our 23rd Annual Conference, to be held from June 28th to July 1st at the Westin Long Beach Hotel in Long Beach, California. As is usually the case, the NSA Board will hold its winter meeting in February at the Westin Long Beach Hotel, in preparation for, and anticipation of, the conference in the summer.

The NSA will continue on a path forward in the new year that will maintain our growth and ensure that we will continue to be America's premier organization of support for all people who stutter, their families, and the professionals who treat them.

Happy New Year and best wishes to all of you in 2006.

NEWS FROM BRAZIL

*Daniela Veronica Zackiewicz
Vice-president of ABRA GAGUEIRA
(The Brazilian Stuttering Association)*

It is with a great pleasure that we inform the results of the National Campaign "Gagueira não tem graça. Tem tratamento" (Stuttering does not have fun. It has treatment):

16 Brazilian states have actively participated on the campaign.

35 cities have promoted public actions in squares malls, universities, hospitals, nurseries, schools and places surrounded by people, by distributing informative flips, banners, informative sheets and so on. In addition, the promoted speeches, scientific conference, talks and meetings with professionals and with stuttering people and finally, press release.

43 speech and hearing pathologists have worked as regional coordinators together with Graduated schools from several states.

10 stuttering people were directly involved with the campaign coordination.

12 texts, from notable authors, have been published on online forum concerning the different practices and treatment for stuttering.

84 questions, addressed from states, were sent to the online forum.

70 people participated on the Presidential Forum in CEFAC- São Paulo, on October 12.

16 interviews were done on radios, papers and TVs.

1 30 seconds TV ads was produced and released by TV Globo, on national chain.

Brazilian Stuttering Association counted 200 internet-visitors access daily, during the campaign.

Although impressive, numbers may not truly indicate the impact of the National Campaign, especially to stuttering people. Considering the participation of the stuttering people, some of them have to be mentioned: Stuttering people lecturing, soliciting speech on school class, being live intertwined, divulging and assuming an important role as a stutterer and as a society active-changing.

I am very proud to participate in the Campaign Organization Group, together with Sandra Merlo, Eliana Nigro e Ignes Maia, and observe how people (speech and hearing pathologists and stutters) have involved in their own places and cities to get this remarkable result.

I invite everybody to visit
<http://www.abragagueira.org.br/diainternacional.html>,
know the campaign details, and prestigiate those people whose actions showed to be an important step to a better life fro stuttering people.

In the name of the Campaign Organization Group, I also would like to thank all the institutions and groups which have supported the Campaign:

Splash Publicidade, Laboratório de Investigação Fonoaudiológica da Fluência e Processamento Motor da Fala do Curso de Fonoaudiologia da USP, Sociedade Brasileira de Fonoaudiologia, Comitê Nacional de Fluência, Internacional Stuttering Association, Linguagem Direta Fonoaudiologia, Hospital Israelita Albert Einstein Unidade Avançada Alphaville, TecMac Engenharia e Construção, Pró Fono produtos Especializados para Fonoaudiologia e Thot Comunicação e Linguagem.

ARGENTINA

Lic. Claudia L. Díaz.

The Argentinian Stuttering Association works hard with the aim to spread the information about this difficulty and aware people about it.

The A.A.T. organizes two meetings every year, held in May and October. We always try to take over every aspect related to stuttering. Our important aspect is the stuttering in children. The A.C.T.'s newsletter is quite necessary and the role of the people who stutter is meaningful. The meetings between people who stutter and therapists of language are permanent in the A.A.T.

We have achieved some support for the next year to afford treatments for families under low social status. The A.A.T. knows that prevention is something of paramount importance. This support comes from the Buenos Aires government. The free meetings in the A.A.T. take place every fortnight and that is how we get more involved in our work day after day. The A.A.T. participates in different Congresses and meetings about other specialties related to stuttering, and this is something really convenient. That's how the A.A.T. keeps on helping to spread the Information regarding this difficulty all over the country. At present, we are looking for our own head office in order to carry on with our activities in a more comfortable way. We are trying as well to search for companies that may be interested in supporting us.

All the themes mentioned before are not simple but we know that all this means a great contribution to the institutional role and it expresses at some time, the vast importance of people who stutter.

We started to search about some aspects related to stuttering for example: the school and the child: teasing and bullying. This way, we try to help teachers in the classroom to facilitate integration and to prevent negative attitudes in connection with our social reality.

We continue contributing to spread the stuttering and the new concepts about this problem.

"The strength does not stem from our physical capacity but from an unshakable will" (Mahatma Gandhi).

We believe that it is possible together.

Austria

Monika Schuster
Secretary of OESIS



The Austrian Self Help-Organisation for stuttering people called ÖSIS would like to inform you about our activities and projects in 2005.

This year the ÖSIS has celebrated its 15th year since the foundation of our group together with the Awareness Day on October 22. Like every year we held an open day in our office in Innsbruck and managed to be mentioned in some newspaper articles and were visited by quite some people.

We have edited different information folders and an actual version of our TIB (Therapy Information Brochure) which is frequently asked for by our members, institutions, teachers, speech-therapists and parents of stuttering kids.

We also offer information kits for various groups like stuttering adults, parents of stuttering pre-school kids and kindergarteners, parents and educators of stuttering school-kids and teen-agers, teachers and speech-therapists.

Additionally once or twice a year groups of future teachers come to our office and get a lecture about the problem of stuttering.

Regarding our project “Summer-camp for Stuttering Children” which ended last year we offered three follow-up weekends and a one follow-up week for all the children which had taken part in this project over the past 5 years. The theme was “Europe –united in stuttering? We speak about Europe” and ended with a visit of the European Parliament and European Council in Strassburg. There the whole group was invited by two Austrian EU-parliamentarians to talk about stuttering and raise awareness for the problem of stuttering people.

Another new project is a “Therapy-Camp” for children from the age of 6 up to 14 years in Salzburg.

During the whole year we have also offered different seminars and one encounter-weekend

France

Alain PAUTE
alain.paute@wanadoo.fr

The Self help group (13th district of Paris) has existed till now for two years. What a distance have we covered!

We meet once or twice a month and everyone can express himself without fear of being judged or sized up in regard to the other's fluency.

It is also a place to exchange ideas, to tell stories and individual experiences. We can also share our knowledge on stuttering.

The curious thing is that we no longer are searching for miraculous methods which could alleviate us from this millstone, but that we look just for is to be listened to, and to find a way to improve the quality of our communication.

Most of us believe that our intimate stuttering has settled itself in us for life, so why should we struggle against an invincible enemy?

Obviously the other side of the coin is that we are no longer working on our speech fluency, out of spite for some, by discouragement for others, or because of the secondary benefits one can take out of the disorder for a few others.

However, assiduous work, with strictness and courage, enhance without contest the quality of our communication and consequently the stutterers' lives. For us, in this Paris Group, the respect to the other's speech, and conviviality, are essential and seem to us more important than a rehabilitative work.

Letter from Sweden

Dear friends and colleagues,

2005 has been an innovating year for the SSR. We are working on an evaluation of our work, our material and our future. An example is our whole new website (www.stamning.se), as the internet is today's most important way of spreading and finding information, with an internal and external forum to initiate debate and participation. A meeting with all chairpersons from the local chapters was held to discuss the workings and future plans of the SSR.

The SSR is also working to write down the history of the SSR, from the time it started as a local group, to

today's national association with 16 independent local chapters with almost 1000 members and high political, national and international activities.

The ISAD was celebrated all over the country with a national, political statement, a governmental motion, activities all over the country and an interview with our talented golf player Sophie Gustafsson for the ISAD online conference (www.stutteringhomepage.com).

Also this year's children's and youth camps have been a great success with more attendants than ever before. It's so important to have young people to not see their stuttering as a problem, but as a push forward to develop their personality and other skills. They are our future and we need to give them the self esteem and confidence to love and accept themselves and to be their own spokespersons and hopefully the future spokespersons of our associations. Also many parents have become active after the children camps, as they found there is hope and that they CAN make a difference for their child by working together and being the spokespersons for their children.

Stuttering has become more interesting in Sweden. This is shown by the fact that stuttering has been in

the media a lot, not in the least thanks to a very devoted non-stutterer (!), who acts as the link between the SSR and the media, and also by the huge interest of the delegates of the two days' annual congress for speech therapists, SFFL, where the SSR had an information table. A big part of the new attention is because our very own Per Alm, a person who stutters himself, who has received his Doctor degree in February this year with his theses "Stuttering and the brain: fluency skills from a neuroscience perspective" and we hope to read more from him in his hard work to solve the stuttering puzzle.

All the best wishes for 2006 and let's join hands to make the world understand what stuttering is all about.

Warmly,

Anita S. Blom
International contact
Swedish Stuttering Association, SSR
anitablom@telia.com

The Patmar Programme for Adults Who Stammer

*Lead Therapists: Patrick Kelly and Maria McDonnell
Ireland*

Stammering affects 1 per cent of the adult population. Many people have had years of individual therapy which has failed to address their needs. Many feel that they have been failed by speech and language therapy, and believe that there is not further help available to them. Most people feel that they have been restricted by their stammer, and that it has impacted negatively on many aspects of their lives (family, socially, and work). In many cases, stammering is never talked about at home, and people have no opportunities to meet others who stammer, resulting in feelings of isolation and despair. Meeting people, ordering in restaurants, interviews, public speaking and making phone calls can be sources of constant struggle and frustrations.

Background of the Course

This course was conceived by Patrick Kelly in 1997 following an Irish Stammering Association (ISA) open day in Galway which he chaired. Feedback from the open day and personal experiences from working in Ireland highlighted for him the totally inadequate service that existed for adults who stammer, and this convinced him that a radical new approach was needed. In Ireland, half of the health boards do not treat adults

who stammer, and many speech and language therapists have little experience working with this client group.

It was decided to run an intensive, residential course in All Hallows, Dublin, for members of the ISA, an organisation which funded 50% of the course. It was decided to run an eight-day course with a three-day follow up course one month later. A residential course was planned in order to accommodate people from all around the country. Feedback after the course was extremely positive. The residential nature of the course was considered to be essential for such success, as:

1. Family member involvement was valuable.
2. Group cohesion provided an environment in which rapid, lasting change could be made.
3. Therapy could continue outside the clinic setting and skills could be generalised socially.

The aims of the course were:

1. To provide the foundations of long term change.
2. To help the persons who stammers become their own therapist.
3. To enable the participants to cope with their stammer by understanding how they stammer.
4. Coming to terms with their stammer.

5. Reducing avoidance.
6. Stammering more easily.
7. Working on all aspects of stammering - behaviour, attitudes, feelings, thoughts, strategies, reactions and social disadvantage.
8. Working within the context of the whole person.
9. Gaining appropriate support from family, friends and work colleagues.
10. Providing in-service training in stammering therapy for therapists.

The therapists running the courses have years of experience working intensively with this client group. One of the lead therapists who stammer can draw on personal experiences to which clients relate.

Due to the success of this course in 1998 it was decided to run the course annually. Four further courses were run, two in All Hallows and two in Enniscrone, County Sligo.

Approach

The course follows an eclectic approach, drawing on Sheehan's desensitisation and "Iceberg" and Van Riper's Phases of Therapy (Identification, Desensitisation and Modification). In addition to this, the residential setting allows for daily intensive practice of speech techniques outside the clinic setting (e.g. shops, bar, telephone). A qualified health board counsellor visits the group. Integral to the success of the course are follow-up supports which include the following: daily telephone rota, follow-up courses and referral to counselling where required: clients are also encouraged to form self-help groups in their localities after the course.

Two therapists are invited to attend to gain experience and to help and two previous group members help during the entire course. A one-day meeting is arranged with these people prior to the course. Names of prospective clients are obtained from the ISA by media coverage, by word of mouth and from other speech and language therapists. Every client is interviewed to assess their suitability for the course. The interviews are videotaped. Ten clients are chosen.

The course runs for eight days. From the outset, it is made clear that no hierarchical structure between clients, therapists and helpers exists. Group sessions are conducted in a circle with therapists and helpers seated among the clients. The importance of respect for each other and confidentiality is stressed. Family member(s) or friend(s) attend on the first and last day of the course.

Individuals view their own video (interview) in small groups to identify their stammering behaviours. Rating scales (WASSP, S24, Iceberg, and Tree People) are completed at the beginning and end of the week for the

purpose of monitoring change. Large group discussions and brainstorming and small group and individual therapy is carried out. Video-recordings of Van Riper, Sheehan and the British Stammering Association (BSA) video "A Chance to Speak" are shown and discussed. Outside assignments take place. Speech and non-speech games are conducted intermittently. There are visits during the week from any former group members who wish to share their experiences and a health board counsellor.

Rationale

While this course adheres generally to the Sheehan and Van Riper principles, fluency is not the goal of this therapeutic intervention. The ethos of this course is that success in the long term is dependent on (1) the person learning to accept him/herself as a person with a stammer, (2) stammering openly in a controlled way, (3) continuing the desensitisation process by not avoiding words and situations and by establishing speech goals and setting challenges.

Techniques are practised in the settings which cause the major difficulties for the individuals (e.g. ordering in restaurants, at the bar, asking strangers for directions, telephoning; sometimes, if they wish, going into their workplace). A questionnaire on stammering is devised by the clients and presented to the public. These exercises are for the purpose of desensitisation and to practice controlled stammering.

Involving family members is considered an essential component of the course. The necessity to deal with the whole person, and to view the person within the context of the family unit is recognised. The people participating in the course need the support of the family, they need to be accepted by their family as a person with a stammer and to feel able to stammer openly and for this to happen the family need to fully understand the problem.

Experience running these courses has highlighted the fact that there are certain individuals whose childhood experiences have been so traumatic that significant long-term progress with their speech cannot be achieved without first addressing these issues. Many of these clients recognise during the course that this is an essential step in their recovery and choose to be referred for professional counselling after the course.

Two follow-up weekend residential courses currently take place, one two months after the course and the second one six months after the course. It is inevitable for most that relapse will occur. At the end of the week's course clients are largely desensitised and quite fluent, but once they leave the safety of the cohesive group and return to the real world, it is difficult to maintain progress. The two-month break allows them to experience real-life situations and to reflect on these.

Most clients find the follow-up weekend very beneficial and for some it can be the turning-point. The six-month follow-up is arranged as it is recognised that these people are changing habits of a lifetime and long-term support and guidance is necessary.

The clients devise a phone rota and keep in contact with each other and with therapists on a regular basis in order to support each other and practise the techniques. Clients are encouraged to set up support groups locally with support from the speech and language therapists in the initial stages with the aim that no further speech and language therapy will be required.

Conclusions and recommendations

Outcome measures provide convincing evidence that this approach offers long-term benefits for clients who stammer. Life changes are made, which include accepting themselves as people who stammer and being able to control their speech instead of their speech controlling them. It must be acknowledged that these are people who have other issues in their lives apart from their stammer and when interpreting outcome measures, these factors must be taken into account (for example, intelligence, family situation, degree of bullying and abuse).

These courses are constantly being modified in response to feedback received from the clients. Components of the course which have been found to be essential are:

1. Family involvement – should be strongly encouraged.
2. Self help groups – speech and language therapists should assist clients in setting these up after the course.
3. Follow up weekends – clients should be encouraged to meet twice yearly.

Broader recommendations include:

1. Speech and language therapists should receive more specialised training with adults who stammer.
2. Individual and group therapy should be available for adults who stammer in all health boards.
3. A centre of excellence should be set up to address the needs of children, adolescents and adults who stammer.

It is acknowledged that this approach is not the whole answer to this complex disorder but it is a model for therapists to modify and build upon.

From Passing Twice

*Barry Yeoman,
United States of America*

Passing Twice, an international organization of lesbian, gay, bisexual and transgendered (LGBT) people who stutter, is gearing up for a busy 2006.

This year, we are expecting to overhaul our website (www.passingtwice.com) with a contemporary look; sponsor workshops at the National Stuttering Association's convention in Long Beach and the British Stammering Association's conference in Telford; begin a conversation about our presence at the 2007 world congress in Dubrovnik, Croatia; and host a number of local social gatherings for our members to meet.

In October, Passing Twice sponsored a New York screening of "Spit It Out", Jeff Shames' bold new documentary about his own journey as a stutterer.

Appearing on a panel discussion afterward were both the filmmaker himself and Passing Twice co-founder Elizabeth Kapstein, who drew parallels between stutterers' self-disclosure and the coming-out process of LGBT people. We are proud that the film features several Passing Twice members.

More information about "Spit It Out" is available at www.mintleafproductions.com/sio.html

Passing Twice would also like to serve more people outside the United States, and we urge self-help organizations throughout the world to direct their LGBT members to our website or email address (passing_twice@hotmail.com).

From the New Zealand Speak Easy Association

Warren Brown
New Zealand



New Zealand Speak Easy member Quentin Brown, left, and Stuttering Treatment and Research Trust (START) speech-language therapist Shelley Williams hand out free sausages in Auckland to attract attention for International Stuttering Awareness Day on October 22. One per cent of Kiwis stutter.

New Zealand Speak Easy members took to the streets and shopping malls to publicise International Stuttering Awareness Day, on October 22.

In Auckland, free chocolates and flyers were handed out, then a free barbecue was held outside the Stuttering Treatment and Research Trust (START) offices to attract attention. Later a display was set up in a south Auckland shopping mall. Those who took part all wore

red T-shirts with the stuttering message “1% of Kiwis do it . . .”

In Christchurch, members also publicised Speak Easy at a mall.

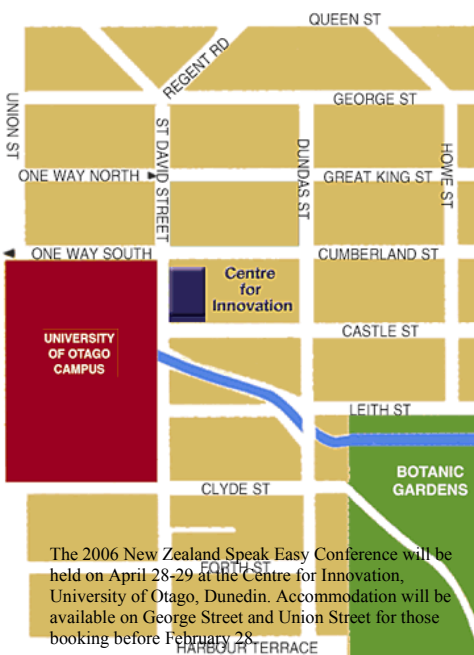
Full-colour Speak Easy posters were printed in advance of the awareness day, to further spread the stuttering self-help message.

The 2006 New Zealand Speak Easy Conference will be held on April 28 and 29 at the Centre for Innovation, St David Street, Dunedin.

The theme of the conference is “The Inner Me”.

The keynote speaker will be Professor Ross Menzies, Associate Professor of Psychology in the School of Behavioural and Community Health Sciences at the University of Sydney, Australia. Professor Menzies specialises in treating obsessive-compulsive disorder, in addition to phobias, generalised anxiety disorder, post-traumatic stress, performance anxiety, panic disorder, depression and relationship problems. He is also known for his research and treatment work in adult stuttering.

Those from overseas and round New Zealand who want to attend need to contact Ngaire Renton at 74 McDonald Street, Mosgiel, New Zealand, or rentonnn@ihug.co.nz before March 1 if they want motel accommodation in Dunedin with other members of Speak Easy.



The 2006 New Zealand Speak Easy Conference will be held on April 28-29 at the Centre for Innovation, University of Otago, Dunedin. Accommodation will be available on George Street and Union Street for those booking before February 28.



New Zealand Speak Easy members Phillip Khouri and Quentin Brown, and speech-language therapists Rachel Dobbin and Shelley Williams promote Speak Easy and stuttering therapy at Manukau Westfield Shopping Mall, South Auckland.

“Stuttering is Not an Issue of Complete Recovery but How We Live” --JSP’s Statement Broadcast on Japanese TV--

*Shinji Ito
Executive Director
Japan Stuttering Project*

We realized that we were not alone as persons who stuttered through meeting with many people like us. We also studied stuttering and found that recovery from it was difficult, which eventually led us to explore ways to live with this problem. Through our self-help activities we learned to accept who we are and to live our lives to the fullest.

As we wanted to share what we have learned from self-help group activities with children who stuttered, we organized our first summer camp for such children and their parents sixteen years ago. This summer camp, which invites children from age five to eighteen, recently had more than 140 participants from all over Japan. Such a big camp organized by a team of adults who stutter, teachers from special speech classes in public school systems, professional speech therapists and volunteers must be unique in the world.

This camp and JSP’s weekly meetings were recently televised as a documentary for 40 minutes by the TBS Broadcasting Corporation, one of the most prominent TV broadcasting corporations in Japan, and was highly received by the viewers.

The program featured our summer camp in detail with the narrative of our statement: “The challenge for those who stutter is how to deal with the negative image of stuttering which the general public and those who stutter themselves have.” The first part of the program showed how we deal with our stuttering; with discussions on stuttering (two 90 minute sessions and one 60 minute session) plus a 90-minute session in between for writing essays on stuttering experience and memories. The second part of the program featured a children’s drama performance. They survived many rehearsals before performing in front of the entire group on the last day of the camp. This was really a great source of encouragement for them.



During interviews of children by the TV program producer, elementary school children talked about the experience of their stuttering being imitated and teased by other children, and discussed how they could handle such situations among themselves. High school students discussed their future jobs, and one of the middle high school students said, “When I was in the third grade of elementary school I was so much affected by my stuttering and wanted to be fluent by all means, but this

camp changed me. I now accept the way I am.” Another middle high school girl student said, “Stuttering is part of my personality. It suits me, so I don’t think I must cure it.” One of the staff members, a school teacher who also stutters, said, “In fact, I have no other personal appealing points except for stuttering. I am grateful to my stuttering since I can appreciate what I am experiencing now just because stuttering helped me to grow.”

The TV program director had to edit and clip the video tapes of the three-day summer camp and the weekly meetings into a 30 minute program. He said, “Every clip shows how lively and delightful the participants are and because of that I found it really hard to show that they actually experienced difficult days.”

The TV documentary was really significant since it vividly showed viewers how children and adults who stutter are accepting and enjoying themselves, in contrast to the approach of many Japanese researchers and clinicians, who consider that stuttering is disgraceful and inferior and that it must be cured.

The JSP plans to make this documentary into a DVD as teaching material to promote better understanding of stuttering through the voices of children who stutter and distribute it to their parents, researchers and clinicians. We are also planning to make English subtitles so that we can share our experience with the international stuttering community.

First Stuttering Research and Treatment Seminar of China

Ning Ning & Danling Peng

*Institute of Cognitive Neuroscience and Learning
Beijing Normal University, China*



The first Stuttering Research and Treatment Seminar of China (SRTSC), sponsored by the Institute of Cognitive Neuroscience and Learning of Beijing Normal University and co-hosted by China Rehabilitation Research Centre and Chinese Stuttering Association, was held in Beijing Normal University in October 15-16, 2005.

This seminar was the first meeting about stuttering research and treatment in China. It offered a platform to share experiences with experts and people who are affected by or interested in stuttering. The theme of this SRT seminar was "Caring for the stuttering group; and pushing forward the research of stuttering". With the intention of open understanding and equal communication, famous experts and therapists involved with stuttering research and treatment in China, as well as the Chair of Outreach Working Group of International Stuttering Association, Stefan Hoffmann, were invited to discuss developments of stuttering research and treatment. In addition, Dong Qi, vice president of Beijing Normal University, Luo Yuejia, director of national Laboratory for Cognitive Neuroscience and Learning, and Jin Zhen, director of MRI center in 306 hospital of PLA (People's Liberation Army of China), were invited to attend the opening session.

During the 1 1/2 day seminar, experts reviewed the history and status of stuttering research, and then introduced their research and treatment programs. In a cooperative and respectful atmosphere, experts carried out extensive and in-depth discussions on the

definition and evaluation of stuttering, the problem of inheritance and environment, structure and function, psychotherapy and speech production training, the choice of training program and relapse of stuttering. It was generally agreed that the results of stuttering research should be interpreted cautiously. Integrated therapies were suggested for treatment of stuttering.

In addition, members of the Chinese Stuttering Association exchanged their experiences with Mr. Hoffmann on how to build a self-help group. They called on society to respect people who stutter.

Finally, many participants shared suggestions on the further development of stuttering research and treatment in China. They hope to combine research and treatment with the goal of developing a research and treatment team. In China, there are about 13 million people who stutter, a large proportion of the world's stutterers. This could afford extensive samples for stuttering research.

Although stuttering research began much late in China, in this seminar, we shared information about many excellent research projects and effective treatment programs, with the promise that the future will be even better. Our hope is that this seminar will produce more caring for people who stutter and more support for stuttering research and treatment.



From the Fluency Club, India

*J. C. Nigam, Speech and language pathologist
Fluency Club, India*

The Fluency Club has entered its 12th year. We want to share our real experience with the stammering group of the whole world regarding successful achievement in fluent speech behaviour through a very simple and quick method to achieve the best results.

We do not believe in any conventional method like slowing down and prolonging your speech, voluntary stammering, using a metronome or speaking on each beat, using delayed auditory feedback and so on. What we do is teach the person to observe carefully, concentrating on the breath stream when he is not speaking, and tell us what is happening in their mind about breathing normally. We ask the person to count as fast as he can, in one breath, up to 30, 40 or 50. If he fails to do this, we do and ask him to observe carefully. He should learn to breathe in and speak in the most normal manner while he has the breath. During this process of letting out the breath, the person should concentrate and speak in a normal way. As soon as he

understands the method of using normal breath function while speaking, he accepts it very easily and uses it outside the clinic.

Counselling and other confidence-building procedures are used according to the need of the person. During seven to 10 days of speech therapy, these procedures help the person in changing his total attitude about his speech behaviour.

The club is also creating an awareness programme for parents and their kids, information sheets for school teachers and small Hindi-language books for parents. Parent meetings and workshops with school teachers are some of the activities we do in vacations.

I hope our friends will use this method and get fluent speech in a short time. People may contact me for further details at 22751605 (Delhi) or 9810380921 (mobile).

Venezuela: New Book in Spanish - "Stutterers Speak"

Last June, the book "Stutterers speak", written by Dr. Pedro R. Rodriguez Carrillo (stutterer and coordinator of the Virtual Support Group TTM-L), was published.

In his book, written in Spanish, the author gathers and analyzes the living experiences of a group of native Spanish-speaking stutterers who, by using the Internet, discuss what stammering means for them and its consequences, both socially and psychologically.

In the back cover of the book, it can be read: "The stammering speech is a great stranger for both, the one who stammers and, those professionals who are in charge of its treatment. A stranger to which, those who are affected fear deeply, and they prefer not to speak about. The professionals that treat it, in most cases, do not reach the desired results. It is, in synthesis,

knowledge to be built. Part of that construction process should be based on the knowledge and analysis of how much the stutterers have to say about their own stammering condition. *Stutterers speak* is the beginning of the construction of that knowledge, it is a place where their souls are naked. They speak about their fears, frustrations and, how their lives have been submitted by their stammering condition. The book highlights the therapeutic importance of their shared experience, the influence of sharing as a way of changing beliefs and attitudes toward the problem and, the emergence of new perspectives in viewing and cohabiting with such a complex dysfunction, as the stammering condition is".

We congratulate Dr. Rodriguez for his publication, and invite you to read it.

Viewers might see something of themselves on TV screen

SPIT IT OUT

Produced by Jonathan Skurnik and Jeff Shames
(Mint Leaf Productions, New York)
Reviewed by Warren Brown

There's a delicious moment at the start of *Spit It Out*, Jeff Shames' video documentary on stuttering.

Jeff is standing on a largely deserted beach, reciting a poem, *The Charge of the Light Brigade*, with pebbles in his mouth. He is trying to imitate Demosthenes, an orator in ancient Greece who believed that putting pebbles in his mouth and speaking over the sound of the sea might cure his stuttering.

After letting the pebbles fall from his mouth onto the sand, Jeff speaks directly to the camera to explain his

experience. As he speaks — fairly fluently, I would have to say — his brow furrows. Then he spits out another pebble, flashes an impish grin and carries on talking.

I guess the reason why the incident is so memorable for me is that we live in a world where so much of what we see on television is manufactured and rehearsed. TV emotions are stylised and homogenised. TV speech is smoothed to a steady and relentless fluency. Tears are used only for dramatic effect. Flashes of humanity are so often edited out.

The fact is life is often quirky. People who stutter are not always aware of what is happening in their mouth. I felt a great sense of relief seeing someone on screen talking with a pebble in his mouth that he didn't know was there. Jeff's on-camera blunder gives him warmth as a human being.

It is a warmth that he manages to sustain throughout his 55-minute documentary, filmed with the help of Mint Leaf Productions.

It would be true to say that Jeff has rather more problems than most people and only some of those problems are related to his stuttering. He had a difficult relationship with his father, his parents split up when he was a teenager, he married a woman who developed a drinking problem and he has battled his own addiction to cannabis.

Perhaps it's something to do with his competitive New York environment but he just keeps trying to pick himself up and turn his life around. He comes across like a middle-aged character from a Woody Allen movie — full of turmoil but searching relentlessly for solutions.

His quest leads him to a FRIENDS convention, where he helps a nine-year-old boy deal with his feelings towards stuttering; to a National Stuttering Association convention, where he feels accepted as a human being; to a couple of gestalt therapists, who deal with his marriage problems; to Mel Tillis, a country and western

singer who stutters; and to a New York theatre group for people who stutter, where he acts the role of a father whose son stutters.

What is perhaps unique about this documentary is that it looks at stuttering in terms of the relationships that people have with each other.

Stuttering is a communication difficulty. Relationships are built on communication. If someone stutters in a relationship then that will have some effect on the way that that relationship develops.

How Jeff relates to his family plays a big part in this documentary. It left me thinking whether Jeff's life would have been dramatically different if he had never begun stuttering.

Parts of the documentary evoke strong feelings of recognition and empathy. The most fraught part is when Jeff's wife, Elisa DeCarlo, is talking on camera about her relationship with Jeff's father, Bill, and she casually lets slip that Bill tried unsuccessfully to seduce her when she was dating Jeff many years ago. Bill's come-on line was that there was something not quite good enough about Jeff but that he was the man she needed. Jeff, who it seems had never suspected that such a thing had happened, becomes angry and upset, leading to an unscripted sequence in which Jeff repels his wife's attempts to soothe him and splutters about how humiliated he feels because of his stuttering.

Perhaps it's a good thing to witness someone else's setbacks and their valiant attempts to overcome them. To see another person who stutters in those situations can be instructive, ennobling, embarrassing or cathartic. I guess what I'm trying to say is that people should get hold of the video and watch it. It's not light entertainment. They might see something of themselves on screen and gain insights from it.

Information about ordering the video documentary Spit It Out is available from New Day Films at: www.newday.com/films/SpitItOut.html For overseas orders, add \$US20 for shipping.

Sound advice given on how to turn your life around

BELIEVE IN YOURSELF

By Nick Tunbridge
Reviewed by Warren Brown

Nick Tunbridge, author of *The Stutterer's Survival Guide*, has launched a new aid to help people who stutter. He has released an audio CD, called *Believe In Yourself*.

The CD's cover notes say the hour-long monologue is "designed to leave you with practical advice as to how to get your life back on track and help you reach your true potential".

Nick says on the CD that education rarely teaches people living skills. People pick up tips on the way. While books provide plenty of useful information, often it is difficult to apply what has been read.

He says what he needed was a checklist to keep him on track. That led him to devise what he calls “the four keys” of successful living.

The first key is: “Not to let other people define who you are as a person and what you are capable of achieving.” He says many people who stutter see their stuttering as a sign of inadequacy and incompetence. They base their worth as a human being on feedback from others about their stuttering. This, he believes, is a vicious circle. He urges people to break the pattern of needing to rely on others for approval. Instead, he wants people to surround themselves with positive reinforcement.

The second key is: “The importance of having role models in your life.” He urges stutterers to seek out others who stutter but who are successful in life. He tells of two people, Greg and Ted, who both run their own businesses and have been successful, despite their stuttering. Their common trait was that they never let their stuttering stop them or restrict them from achieving their goals in life.

The third key is: “Really understand the motivators for your actions.” He says on the CD that his motivation

was to accept who he was. He had learned that to speak up as a stutterer was no longer a failure. He found he no longer needed the approval of others.

The fourth key is: “Learn how to manage and reduce anxiety.” Anxiety could be caused by hereditary, by chemicals in the brain, by personality or by life experiences. He says he used cognitive therapy to value himself and love himself.

On the CD, he says he began stuttering at age four. By the time he reached his 30s, his life was “at a desperate stage”. He contemplated suicide.

But he turned his life around. Now married with two children, he works in Melbourne, Australia, as an executive search consultant for an employment agency.

For me, the four keys are things that I have worked out myself in my long journey towards fluency. I recommend Nick’s CD.

Those wanting to buy the CD should contact Nick Tunbridge at 28 Eighth Street, Parkdale, VIC 3195, Australia, or at align@dodo.com.au

DISABILITY OR NOT?

*Mark Irwin
ISA Board Chair*

ABSTRACT

Stuttering is a legally defined disability in many countries of the world. Even so to call stuttering a disability can provoke a strong negative reaction in both SLP’s and people who stutter (PWS). Why would this be so?

Objections to describing stuttering as a disability involve one or more of the following arguments:

1. Disability is not the right word.
2. Some people who stutter do not choose/want to see themselves as disabled.
3. The label disability encourages the victim mentality.

The International Stuttering Association, the umbrella organization for national self-help and support groups throughout the world, recently debated this question, confirming its recognition of stuttering as a disability. The rationale for this decision will be discussed.

SUMMARY

1. Is disability the right word?

This issue relates to the episodic nature of stuttering, its situational specificity, differences in how its life impact is perceived by sufferers, as well to the fact it can be ameliorated by therapy. Consideration of this leads to the question: is there another word that better describes stuttering? Traditionally there have been two other words associated with disability –impairment and handicap. The distinction between them has been described by American SLPs Scott Yarus and Bob Quesal, among others, in the following manner: Impairment refers to the stuttered speech patterns, disability describes the communication difficulties, and handicap describes the impact the communication difficulties have on achieving life goals.

With stuttering, of course, the extent of the communication difficulty can be more than just the observable speech. The communication difficulty is also affected by the speaker’s anticipation of, and/or reaction to, the stuttering behaviour. So disability can still exist in spite of only a minor observable impairment and minimal handicap. However these distinctions are obviously subtle and confusing. The same issue affects accurate descriptions of many other disorders besides stuttering. In 2001 the World Health Organization

responded to this by re-evaluating its previous International Classification of Impairments, Disabilities, and Handicaps, in favour of a new framework known as the International Classification of Functioning, Disability and Health. Without going into a full description of the impact of this change, (see Yarus and Quesal, Journal of Communication Disorders 37, 2004), one obvious implication as seen by the change in title, is that the words impairment and handicap have been devalued leaving disability as the general descriptor.

In addition to this it is necessary to consider the use of the word disability when applied to what is known as the “disability movement”. This movement is becoming very powerful as previously disadvantaged members of society seek attitudinal and legislative change. There is no question that some PWS have been disadvantaged by their stuttering, (e.g. unable to obtain a job because of an inability to speak well under the stress of an interview), and need these matters to be brought to the attention of authorities. Again disability is the right word to describe stuttering if stuttering is to be supported by the disability movement.

2. Some PWS do not choose/want to see themselves as disabled.

A survey was recently reported on the response of PWS to the question “Is stuttering a disability.” The majority responded negatively to this statement. As a result it was argued that “whether a person is disabled by stuttering or wants to be recognized as having a disability/ being disabled, is an individual choice.”

A response to this statement leads to a debate on the semantics of the previously discussed impairment, disability, handicap definitions. It could also be argued that the same people who are not happy to see themselves as having a disability are also not happy about seeing themselves as people who stutter. In other words there is a lot of shame, embarrassment and denial for PWS. Dealing with this is the major role of self help groups, and of course is regarded by many as a foundation stone for successful therapy. As expressed on related matters by popular TV psychologist Dr. Phil McGraw, “you can’t change what you don’t acknowledge.”

3. Labelling stuttering a disability may encourage a victim mentality.

This of course relates to the issue discussed above. But it goes further. That is because PWS have a legally defined disability they may be entitled to concessions that encourage them to stay disfluent. They may also fall into the trap of using their stuttering to receive sympathy and support they feel they would not

otherwise get. In other words there is a disincentive for PWS to seek therapy or respond positively to it.

Most commentators would agree this is a possibility, but this position also assumes therapy could be effective for everyone who stutters. Clearly this is not the case. Many PWS have had years of therapy and still remain relatively disfluent. Another question raised here is “just how hard should one have to try to become fluent?” An analogy is to expect everyone who joins a golf club to keep on practicing until they can play like Tiger Woods. This is obviously an unrealistic position. Some may have the talent, capability and luck as well as access to the right coach to do very well, but most of these golfers are going to remain players of modest skill.

Indeed this raises another question: “What expectations should therapists have of their clients?” The ISA has also looked at this question and ratified a Bill of Rights and Responsibilities for People Who Stutter. The general concept is one of individual rights for the person who stutters. In other words some may choose to live with their stuttering while others may work at overcoming it –the path is for each individual to decide. But with either path the word disability remains. **Stuttering can be seen as a disability to be lived with, or as a disability to be overcome.**

A World That Understands Stuttering



**WRITTEN STATEMENT ON STUTTERING
AND THE
INTERNATIONAL STUTTERING AWARENESS DAY (ISAD)**

This Statement is to mark 22nd October as International Stuttering Awareness Day (ISAD), raise public understanding about stuttering and to reduce negative stereotypes and discrimination which people who stutter face daily.

International Stuttering Awareness Day

International Stuttering Awareness Day recognises the growing alliance between people who stutter, speech-language professionals and other clinicians who are now, more than ever, learning from each other and working together to share, give support, and educate one another and the general public on the impact that stuttering has on individuals' lives.

Stuttering

More than 4.5 million persons in the enlarged European Union are affected by the speech impediment of stuttering. It is widely accepted that 5% of children under the age of five will go through a phase of stuttering. Without pre-school intervention up to 20% of these children are at serious risk of developing chronic stuttering which may persist into adulthood. In children under five years, twice as many boys stutter as girls but in adulthood four times as many men as women stutter;

Stuttering still remains a relatively unknown, misunderstood and misinterpreted disorder to the detriment of those afflicted by it. Research and the provision of information on stuttering still have low priority Europe-wide. This can result in social exclusion, bullying and lack of full access to the labour market. Yet all research indicates that the stuttering and non-stuttering populations are identical in terms of intelligence, mental state and behaviour;

Today's Europe is marked by growing unification and co-operation. This must therefore be reflected in an adequate, unified representation of the interests of people who stutter throughout Europe and their respective national associations;

People who stutter have the right to be informed fully about therapy programs and technical aids including estimates of the likelihood of success, failure or relapse;

People who stutter have the right to receive therapy, appropriate for one's unique needs, concerns, and characteristics, from professionals adequately trained to treat stuttering and its related problems;

People who stutter have the right to choose whether or not to participate in therapy or to change therapy or clinician without prejudice or penalty;

People who stutter have the right to stutter, or to be fluent to the extent one is able, and have the right to communicate and be listened to;

People who stutter should be accorded all rights mandated by laws or regulations for all citizens regardless of one's degree of stuttering, and have a right to the redress of grievances for documented evidence of failure to be treated fairly and lawfully.

ELSA, with the support of the Disability Intergroup, calls on the European Parliament, the European Commission and Council to:

Ensure that people who stutter have the right to be treated with dignity and respect by individuals, groups, institutions and the media regardless of one's degree of stuttering;

Ensure increased resources for the early screening, detection and diagnosis of stuttering in children;

Ensure better access to, and information dissemination of, different speech therapy options and communication aids across the EU for children and adults who stutter;

That research in the field of stuttering and other speech impairments are recognized and supported by the EU's 7th Research programme;

Strengthen disability non-discrimination legislation through a specific EU Disability Directive and for people who stutter to be recognised as discriminated persons under the terms of such legislation;

Recognise the International Stuttering Awareness Day - 22nd October

This Statement was presented on 25 October 2005 by the European League of Stuttering Associations (ELSA) with the support of Fundación Española de la Tartamudez - (TTM-España) and the European Disability Forum (EDF)



TTM / fundación española
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