



THE VOICE OF ELSA

Newsletter of the European League of Stuttering Associations

Number 5

Winter 1991/1992

Editorial

Dear Readers:

Everybody is talking about Eastern Europe - so are we. The dramatic changes taking place at all levels of political and social life in these countries are only just beginning. One facet of this exciting situation is the increasing interest in self-help, particularly in the health field. For a couple of years, the heavy demand from individuals and groups for information and support will continue to pose a challenge to the established, (mostly) Western self-help associations, many of whom are themselves struggling with various economic and organisational problems. ELSA is extremely grateful to PAPS, the Polish Association for People Who Stutter, for taking the initiative and inviting stutterers and therapists from neighbouring Eastern European countries to the first joint Slavic meeting which was held in June 1991. Lucyna Jankowska, the Polish ELSA delegate, reports on this meeting which was subsidised by ELSA and a couple of national associations.

In the second part of the newsletter you will find a report on the last ELSA meeting in Hamburg/Germany in October 1991. One of the most pleasing items on the agenda was welcoming the Swiss VERSTA who have now officially joined the League.

From the Swiss Alps to the North Sea: On page 6-7, Benedikt Benediktsson from Reykjavik announces the setting up of a stuttering self-help association in Iceland, while Tim O'Callaghan, welcome guest in Hamburg, writes about the situation in the Republic of Ireland.

Last but definitely not least an article on the Dutch model of a Diagnostic Centre which could set new standards in counselling people who stutter and evaluating therapy outcomes.

Thanks to Ellis Griffin from England for 'linguistic support'!

THE EDITORS

The Slavic Summer Feast

Report from the 1st Slavic Congress of People Who Stutter

The 1st Slavic Congress of People Who Stutter was held from 20 to 26 June 1991 (not by chance. It was the time of the annual old feast "Sobótká" (St. John's Day) associated with many time-honoured Slavic customs, the main one being a great bonfire with dances, jumps through a fire and a traditional spectacle of floating wreaths down the Vistula. Elections of "Pure Slavia" (see illustration) have been performed quite spontaneously. These new elements of stutters' meetings were very welcome!

Aims of the Congress

For too long a time East Europe was "a white spot" on the map of stuttering self-help. The first step was made by Poland, so PAPS could boast of being the only such association in the east part of Europe. Now it is high time to change this situation.

The idea of organising a Slavic congress was rather spontaneous. Moreover, it was connected with a special intention: PAPS has not many experiences in the self-help area, but we noticed that it is quite easy to find some people, enthusiasts who would be eager to engage in this activity. We just wanted to meet those enthusiasts among the foreign company and support them in setting up their own self-help groups. The promoting of this new idea among a great number of people causes problems also in Poland. We just hoped we would be able to spark a little light...

Preparations

First of all, a Slavic language was created by us. It is original, consisting of Polish, Ukrainian, Rus-

sian, English and German words, completed by many nonverbal elements (it is estimated that words play an insignificant part in the process of communication, only (%). "Slavic" was a necessary method of answering letters from many countries, and above all, to communicate with each other during the congress.

Apart from this significant activity we sought the financial help from different departments and, surprisingly, we were successful. PAPS got money and moral support from ELSA and National associations as well. It enabled us to cover congress fees for foreign participants.

The invitation and information about the Slavic congress was published in a couple of newspapers in Poland and in other Slavic countries.

Time of meeting

The 1st Slavic Congress of People Who Stutter took place on a beautiful camping site in Kraków. 75 people met there and the main goal those six days was simply to be together. 20 participants from Lithuania, White Russia, Czechoslovakia and Bulgaria, as a special company, were especially welcomed. Above all, stutters, parents with two stuttering children and two students of pedagogics accepted PAPS' invitation to attend the meeting.

The main part of the congress was held during three days, then we had planned a time of social activities. It appeared that all of our activities were similar to a holiday! Workshops took place out of doors, it didn't mean that they were quite loose. Some of the workshops dealt with setting up self-help groups and motivation in stuttering therapy. They were lead by professionals. One of the workshops was particularly in-

tended for the foreign company and it was devoted to answering questions about stuttering and therapy.

Three workshops concerned our work in 'Club J' or self-help groups. They were lead by stutterers or "veterans" in self-help and were devoted to the following problems:

- * How to keep new persons who come to the group for the first time;
- * How to manage difficult situations in our lifes;
- * How to get to know each other better.

Comments from participants

The leading workshop was really an exam for many of us. "Microphone for everybody" was a great conclusion. Oleg from White Russia said that for the first time in his life he had felt as a man of standard value. He considered Club J's workshops as the most attractive part of the congress. Oleg is very interested in setting up a self help group in Grodno.

Tomek from Tchechoslovakia was speaking about his impressions during the congress. At the beginning he had not seen much relevance in our activities to stuttering therapy. He considered it as a nice holiday. Tomek noticed a stuttering therapy as only technical practice. In the latter part of the congress he changed his mind, but yet he thought he was unable to set up a self-help group.

Witek from Grodno told us about stuttering therapy in the Soviet Union which is different from our approach to the problem. Treatment is performed in hospitals and it is connected with many instructions. First, the patient is examined thoroughly, then he undergoes many exercises: massage, baths, hypnosis every day. He takes a lot of medicines and learns to breath correctly and to relax. For two weeks the patient cannot speak at all, then he learns to speak slowly, without stuttering.



Election of Pure Slavia

Witek is successful in this therapy. He was very surprised that we did not learn how to breath properly.

Petar Tonev from Bulgaria is trying to organise a self help group, as yet he has not found a place for meetings. Maybe some day...

Finally, foreign participants received the book "Let's talk about stuttering" by Renée Byrne as gifts.

Piece of news

Television, the radio and the press were interested in PAPS' work. During the first evening of the congress the television broadcast a programme about it. There were also a lot of interviews and a good opportunity to do PR work for ELSA. Two broadcasting stations were engaged in these affairs, four articles were published. Hopefully, we have come out from the background at last.

Around the Congress

Only some of the people who were interested in stuttering self-help were able to attend the meeting. 30 stutterers and parents want to con-

tinue contact with PAPS and get some materials, newsletters etc. One man from Czechoslovakia is eager to form a self help group in Prague. PAPS will try to help them with their expectations and requests.

We have many troubles with parents from the Soviet Union who are asking us to help their stuttering children. PAPS is planning to organise some seminars for them, maybe a summer camp, but I think this is only a dream at the moment.

My reflections

I think our expectations and hopes came true. First of all, 20 people participated in the stutterers' congress. I was aware that it was rather impossible to infect everybody with the "germ of self-help". Only part of them were engaged in our activities, the others admitted that a stay in Poland was a good opportunity to do a little business. However, I was happy that nobody considered the six days as a lost time...

(Lucyna Jankowska)

ELSA in Hamburg

Report on the Third ELSA Meeting

ELSA was once again the guest of the German stammerers. Like the September 1990 Meeting, this year's Autumn Meeting of the European League was held in conjunction with the German Association's AGM. As well as having advantages both organisationally and in terms of atmosphere, this arrangement also has symbolic significance: it underscores the fact that ELSA does not operate in isolation from the national associations, but as part of a European whole. We have now moved another step towards achieving this objective: the Swiss VERSTA has officially joined ELSA as the fourteenth European member.

At the Meeting, the ELSA Officials reported on their activities since the last Meeting in May 1991: Here are some of the highlights:

- ELSA had protested to the Norwegian authorities about the planned closure of Halmrast, a unique special school for stammerers. The Norwegian Stammerers' Association considers that ELSA's intervention contributed to the decision being deferred.
- ELSA is continuing its collaborative efforts within EC organisations and is participating in an initiative by European welfare and self-help associations to set up a European umbrella organisation.

- ELSA's Cologne office is now staffed part time.

Database

The creation of a literature collection and database for stammerer self-help is making initial progress. In our office, the existing material has been sifted through and catalogued; the next step is now to design a system and evaluate the material. An urgent appeal was made to all member organisations to forward all publications as well as any other relevant information (addresses, dates, specialist information) to the Cologne office.

Promoting Self-Help in European Countries

A declared aim of ELSA is to propagate the concept of self-help for stammerers in other countries in Europe, and we can already claim some initial successes: Tim O'Callaghan from Cork/Republic of Ireland reported in Hamburg on the situation in Ireland and his efforts to set up groups and a national association. The Finnish and Swedish delegates were able to report that an organisation had been set up in Iceland. Initial contact has been made with a group in Estonia. Delegates were particularly grateful to the Polish group which has taken their eastern European neighbours under their wing and in June 1991 welcomed stammerers and therapists from Lithuania, Bulgaria, Czechoslovakia and white Russia to a meeting in Cracow.

A further opportunity of promoting self-help may be provided by the 1st European Congress of Speech and Language Pathology in April 1992 in Athens. ELSA is hoping to make a suitable contribution.

Public Relations Work

PR work for ELSA must be directed towards various objectives. It is a means of promoting self-help ideas

among stammerers and therapists alike. Other target groups are international bodies and institutions (e.g. EC, WHO) and the media. This calls for information strategies and materials tailored to the requirements of different target groups. The Italian delegation presented some impressive drafts for a leaflet, a somewhat more comprehensive brochure and a series of TV spots. It was decided to go ahead with leaflet initially.

Self-Help Methods and Concepts

This is the title of a detailed survey to be carried out by all the member associations. It is designed both to collect comparable data and to take stock of the current self-help situation: What do we actually mean by self-help? Which concepts and methods have proved to be useful and effective? The first stage is to compile a questionnaire for the national associations to pass on to the local groups.

Diagnostic Centre

From the Netherlands comes the idea of a diagnostic and counselling centre, an independent institution which could counsel stammerers, recommend therapies and critically evaluate the results. It would thus be able to liaise between patients, therapists and the paying authorities. The Dutch delegates presented the model for such a centre.

Concluding Remarks

ELSA has now completed its first year of existence and can take pride in the structures created. Work at European level requires staying power, and so far the motivation and application of the national associations, and in particular their delegations, have been extremely encouraging!

(Konrad Schäfers)

MALBJÖRG -**A Stuttering Organisation in Iceland**

The 10th of October 1991 was a big day for stutterers in Iceland. That day MALBJÖRG ('Save the Speech'); the Icelandic Stuttering Organisation was born. Some 30 people attended the meeting, including over 20 stutterers. The organisation now has more than 30 stutterers.

We have started a self-help group that meets every other week. Until now we only have talked about our problems and experiences in life, but we are planning speech courses. What we need is information on how these things are done in other countries. It would be interesting to have some information on how you organize your self-therapy groups.

One other thing we have started is the publishing of brochures on stuttering. There have been no small brochures on stuttering in Icelandic and therefore we are planning to publish brochures for stutterers, parents and teachers.

The situation in stuttering therapy in Iceland is not good enough and we are planning action in this area also. There are few speech therapists in schools, so children do not get

the treatment they need. Stuttering treatment for adults receives no government funding. That makes treatment expensive and few adults seek treatment so there are few therapists who have specialized in the treatment of stuttering. The Society of Speech Therapists is also very interested in these problems and in cooperation with them we will try to do something about it.

These are some of the things we are working on at the moment. We are happy that stutterers and their organizations in other countries are interested in us. Hopefully we can participate in ELSA activities in the near future.

Best regards from the stutterers in Iceland.

Benedikt Benediktsson
President of Malbjörg

Address: Malbjörg
pn. 10043
IS-130 Reykjavík
ICELAND

Self-Help in the Republic of Ireland

Self help became a reality in Cork in April 1991 when a group comprising solely of people who stammer organised themselves to meet on a weekly basis with the broad aim of loosening the grip that stammering plays in their lives. I am glad to be part of this group which continues to meet enthusiastically although it must be said that we are still setting foundations and restrained somewhat by lack of finance. However, with each meeting of the group we are helping ourselves and each other and surely, this is what it's all about.

We have been looking at ways of advertising the group and items have appeared in the local press and announcements made on radio. Despite this, our membership has remained fairly static. Indeed, setting foundations and seeking finance and free advertising of our meetings have taken a great deal of time and energy.

There is no other self-help group in the Republic of Ireland and I have no doubt that there are a great many people who would benefit greatly by being involved in such a group. How

we reach these people is the challenge in the months and years ahead. We see our future membership coming mainly from the speech therapy situation and we are maintaining close relationships with the local speech therapy centre who have been very supportive in getting our group underway.

In Ireland, there is great lack of speech therapists. In a recent T.V. programme it was stated that there are only 200 therapists whereas in a country the size of Ireland the requirement is close to 1,200. This shortfall gives some indication of the challenge that lies ahead.

It was very encouraging to meet members of other stuttering associations in Hamburg. I believe a great deal can be achieved by the exchange of information and the sharing of experience between various countries and we, in Ireland, are glad to be able to participate in this. We are now looking forward to the next meeting in Brussels and renewing friendships made in Hamburg.

(Tim O'Callaghan)

The International Association of Organizations For People Who Stutter

John Ahlbach, NSP Director and one of the organizers of the San Francisco Convention, proposes to create an international umbrella organization of stuttering associations similar to ELSA. "This need not be too formal" writes John, "Perhaps we would get someone to volunteer to collect information from the various groups and put out a bi-annual publication. We could all contribute to its cost. We would also be able to speak 'with one voice' when that was necessary." In the next few months, John will draft a statute and send it to all national organizations for discussion and comments.

This issue will also be put on the agenda of the next ELSA meeting in Bruxelles.

Considering a diagnostic centre

WHAT IS THE BEST WAY TO HELP THE STUTTERER?

This article is aimed at discussing the desirability of a diagnostic centre for stutters. Such a regional or national centre would not only be for the benefit of the stutrer but could also be called upon in case of doubt about the normal development of speech and language of individuals. This would provide for the early recognition by professionals of possible problems in this area, and thus any treatment could be started as soon as possible, avoiding the risks of secondary problems.

In the diagnostic centre one could investigate what the problem is and which therapy (therapies) or therapist(s) would be most helpful. Progress could be recorded by means of regular evaluation of the effect of the treatment; and - if necessary - treatments can be adjusted or changed according to the needs of the individual stutrer. This would prevent the unnecessary use of ineffective therapies. The data gathered from the actions and results will provide valuable information for future clients.

Situation

Somebody notices - often from reactions like laughing, teasing, and imitating - that there is something wrong with his way of speaking. Parents (or grandparents) may notice that their (grand)child does not speak with ease. A teacher may recognise that one of his pupils has difficulty talking.

What happens next?

Usually the stutrer will hide away and try everything to hide his stuttering. This leads to the commonly used behavioral pattern of

using synonyms for "difficult" words, expletives, changing the construction of sentences, being silent and avoiding discussion. Everything in life (school, profession, social life) becomes determined by the speech involved. This may even lead to social isolation.

Parents do not normally quite know what to do about it. They start worrying and try to protect their child whenever possible. This concern however may work the wrong way for the child who may get the feeling there is something utterly wrong with his speech or even with himself.

Teachers often do not know how to react to a stuttering pupil. Before long they start

avoiding difficult situations for the pupil, they do not ask him questions and prevent him from having to speak in front of the class. This may leave the child feeling useless, of no importance in the school and thus enhance his feelings of worthlessness.

All these reactions may cause and increase further problems.

Seeking help

Most parents, teachers and stutterers set out to find help. They approach their general practitioner, clinics, school speech therapists, and so on. All these professionals should and will know a certain amount about stuttering but none are specialised. Usually, they do not know about the latest therapies and developments.

It is sad that many parents (and therefore their children) are still silenced with remarks such as: 'Don't worry about it, the stuttering will go away by itself,' or 'He'll grow out of it,' or 'If he talks less, he'll stutter less too.' These remarks not only date back from the sixties, but many professionals are convinced they are true in the nineties.

Therapy

If stutterers are 'lucky' enough to be treated, the selected therapy is often a matter of availability instead of a deliberate choice. There may be a speech therapist in the area, a school speech therapist may be willing to see the child, somebody knows about a successful therapist, a program on television or an article in the newspaper may have mentioned a specific therapy, and so on.

More often than not the treatment is started without knowing what's wrong and what the aim of the therapy is or should be. Neither have criteria been set by which to measure improvements.

Effectivity and results

The therapy often lacks in evaluation of results and in good after-care. Evaluation is often carried out by insurance company doctors or physio-therapists who are expected to determine the effectivity of a given therapy without being hindered by any relevant knowledge about the stutterer and his problems. In some cases the therapist himself comes out with so-called scientific research about his therapy but this, in fact, is the same as a butcher evaluating his own sausages.

It is also possible that a stutterer remains with his therapist for years without any improvement, or that the results deteriorate shortly after finishing the treatment. Frustrated he may start looking for a better therapy but since he does not know how to recognise one he does not know what to look for and ask for. Proceeding by trial and error he has no other option but to ask himself: would the next therapy be better?

Which changes do we need?

In order to prevent situations like these and improve the effectivity of speech therapy and therapists we suggest a different approach. A major role in this approach would be played by one or more diagnostic centres (regional or national). The purpose would be to bring together all available knowledge and

information at regular intervals and to use this for diagnosing, determining methods of treatment and evaluating progress made.

How will this work out?

It is thinkable that in each county or region three specialised professionals meet each week to do a 'clinic' together. All general practitioners, speech therapists, child health clinics, etcetera, send their stutterers and children with speech problems to be diagnosed, to have their problems determined and a desirable course of action chosen. This would imply that all necessary knowledge be available at the centre. The professionals need to have extensive experience within the field and should know their colleagues around the country.

After, say, six months of therapy with the chosen therapist progress would be evaluated at the centre. This involves re-assessment of the used therapy, a decision about whether to continue this therapy or try a different method. The team of specialists would be expected to be capable of doing this properly and to use methods to determine the degree of improvement with great reliability.

In time all this would lead to an insight in useful therapies. The long cherished desire to know more about the effectiveness of therapies for stutterers may then come true.

The crude propaganda for certain unproven therapies (as happens only too often) may then be abolished. Only results will count. Results that will be determined by a small group of professionals and not by therapists themselves or by cost-interested insurance companies.

Within the diagnostic centres incompatibility of interests should be prevented by clear agreements and rules. Any professional can not refer a client to himself and should not get any gain from referring a client to this or that institution such as a hospital or a centre he (incidentally) works for.

Finally

Establishing a diagnostic centre serves many purposes, the most important one being that a fitting, effective therapy may be chosen for a stutterer or stuttering child. The stutterer would not have to try endless and discouraging therapies which are ineffective (for him). Apart from that, it would work out much cheaper for society as well.

(Wim van Alphen)

[ELSA and the Dutch Association 'Demosthenes' are seeking comments on the ideas explained in the above article. Please write to the FISA office or to André Beks, Rijtse Akkers 184, NL-5037 JW Tilburg.]