

# Newsletter of the European League of Stuttering Associations

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## **Editorial**

*Bonvenon at la Vocho de ELSA. Ni opinias, ke nun vere estas la tempo, ke Europaj balbut-asocioj utiligu la universalan lingvon Esperanto. Espereble iuj el vi sukcesis legi ghin?*

*En tiu chi eldono de VdE, ni enkondukas du novajn rubrikojn: "Intenaciaj Novajhoj", kunmetajho de agoj tra niaj landaj asocioj, kaj "Elstarajhoj", en kiu ni chefskribas kelkajn plej interesajn ajhojn el naciaj revuoj. En tin chi eldono ni focusas al artikoloj de Germans "Kieselstein" (intervjuo kun Turka parolterapiisto) kaj Brita "Speaking Out" (projecto Pendleton pri flueco).*

*Kompreneble, ni esperas ke vi ghuos VdE kaj trovos la artikolojn interesaj. Sed ni ankaŭ esperas ke vi sentos vin instigitaj al kunlaboro kun la agado de ELSA, chu per reago al la imagoplana propono de Italio, chu per aligho al la "korespondamika" reto, chu per oferto de artikolo au novajho por venonta eldono. Ni plezure atendas viajn vortojn!*

*La redakcio.*

Welcome to the **Voice of ELSA**. We thought it was really time that Europe's stuttering associations utilised the universal language, Esperanto. Hopefully some of you were able to read it?

In this edition of **VoE**, we introduce two new features: "International News", a composite of activity across our member organizations, and "Highlights" in which we feature a couple of the most interesting items from national magazines. In this edition we focus on articles from Germany's Kieselstein (an interview with a Turkish speech therapist) and the United Kingdom's Speaking Out (The Pendleton Fluency Project).

Of course, we hope you enjoy the VoE and find the articles interesting. But we hope, too, that you will feel moved to involve yourself in what ELSA is trying to do, wether by responding to the imaginative proposal from Italy, joining the "pen-pals" network, or .submitting an article or news for a future edition. We look forward to hearing from you!

The Editorial Board

## ***"Self-Help: simply not enough people know about it..."***

An interview with Figen Unsai, a Turkish speech therapist in Berlin

*Almost two million Turkish people live and work in Germany, 400.000 of them in Berlin (which incidentally makes Berlin the second largest Turkish city). The following conversation with Figen Ünsal, a Turkish speech therapist who works with Turkish stutterers in Berlin, was recorded by BV-member Harald Strätz:.. The interview not only examines the situation of Turkish stutterers in Germany but also gives us some impressions of a Nation which until now has not figured in an ELSA context. A third aspect is what stutterers' associations can do for people in ethnic minorities who stutter . We will pursue these questions in future issues of "Voice of fil.SA". Our thanks to Figen Ünsal and Harald Strätz for their permission to translate and publish the interview.*

THE EDITORS

Q Figen, you are the first and - so far - the only Turkish-speaking speech therapist in Germany?

A As far as I know, yes. At any rate in Berlin. I don't know about the situation in the rest of Germany. I haven't heard anything from the speech therapists' association, and I couldn't find anyone in the directory.

Q News would get around?

A Absolutely.

Q In Berlin you specialize in Turkish people with speech difficulties?'

A Like all speech therapists I am trained to treat people with voice and speech disorders. Since Turkish is my mother tongue I have particular access to Turkish people who stutter.

Q You work in a public health centre in the district of Berlin-Kreuzberg. What is your job?

A At present I work alone in the health advisory service, and my functions are to provide diagnosis, counselling and treatment related to speech problems in Turkish people. Actually, it was originally planned that I should work in conjunction with a social worker, but as she does not work here any more I have to cope on my own. Her post has been cancelled, so it's up to me now. Due to their migration history Turkish people have a lot of problems here in Germany. I adopt an holistic approach which takes the social problems into account. But it is difficult to get a complete picture when you are all on your own.

Q What are the most common speech problems?

A In the health centre I can only treat children and adolescents, but as I am (the only Turkish-speaking speech therapist I also provide diagnosis and counselling for adults. Most frequently I come across speech development disorders, but stuttering is also very common.

Q In adults, too?'

A Yes. It is striking that Turkish stutterers hope for a miracle, a miracle healer who will cure their stutter with injections or drugs. This attitude is prevalent even among well-educated people, for them it is difficult to understand how their own stutter came into being. Many of them cannot imagine at all. Advising these people basically means to make it clear to them that their stuttering changes as soon as they start changing themselves. When they go out more often, are prepared to take more risks and thus learn how to deal with their stutter in a better way, e.g. by dissolving blocks and putting something in their place. It is a problem to explain it to them because they think all this is all so "intellectual" and that people would notice when they prolong the words. For one of my clients the big problem was that he did not want to stutter voluntarily. After all, he came to therapy in order not to stutter, so why should he stutter then?

Q Do you see any difference between German and Turkish stutterers in terms of their willingness

to join self-help activities?

A Most stutterers want their stutter to go away as soon as possible. For the Turks, this has more to do with Orientalism, fanaiasy and the belief in miracle cures, yet sometimes they realize they must deal with their stuttering. In Turkish society people who stutter have a very hard time. People will often ridicule them, as they do in other societies.

Q American society, for instance, is more relaxed and generous when it comes to so-called deviations from normality.

A That's possible. In my experience, many Turkish stutterers have the attitude that stuttering is a gift of God, something which came over them sometime and about which they can't do anything. That's the way it is!

Q Do these people come to you?

A No, they don't come to me. It surprises them that you can do something about stuttering. One mother I know does not believe that her daughter will ever overcome her stutter. With this girl I have a lot of problems; she first had to develop a positive attitude towards stuttering therapy. She said it did not really make any sense; if it did, she would not stutter any more. On the one hand there is the attitude "I want to get rid of my stutter, I don't want it", but on the other hand people think "That's the way it is, you can't do anything about it".

Q Do the adolescents come on their own accord or are they brought by their parents?

A It varies. It's more the adults who come on their own accord. They are highly motivated -almost too highly, as this is linked to very high expectations.

Q What about self-help?

A I think they don't know about it. The idea of self-help is strange and remote to them. Two years ago I organised a seminar in Dortmund with Turkish and German adolescents who stutter. It was there that I heard some of my people say, "We never stutter like the Germans". I found this amazing because the Turkish teenagers stuttered in just the same way. They simply didn't want to be among people who stutter.

Q And when you hold up a mirror to them?

A It shocks them.

Q Is it a healthy shock?

A Well, either they stay away, or it hits them very hard. You then have to be able to break their fall. One teenager who has been coming to me for advice for quite a time began to stutter worse than before. For him it was not a therapeutic success. I have never known anyone to stutter more severely during therapy. He had terribly strong avoidance behaviour, though. He spoke very fast, as if he wanted to gallop away from his stuttering, and in doing so he stuttered very severely and noticeably.

Q Are there any professions except speech therapists who treat stuttering in Turkish people?

A I don't know of any. There is a need for more Turkish-speaking experts. One Turkish neurologist once told a stutterer: "Go to Mrs. Unsal, and you will be cured within six months." That's really bad!

Q Do you know any Turkish speech therapists in Berlin?

A No, I don't. One trainee speech pathologist who did her practical training at our health centre was very interested. Unfortunately, - she didn't know any Turkish.

Q Do you think that Turkish stutterers have inhibitions about attending a self-help group and that they are afraid of not being taken seriously by the Germans?

A That may be justified. They've got enough problems to worry about in their society, so they can't do much about other things. Women, by the way, tend to be more active, more motivated and more interested. They have always achieved something for themselves. There was one young woman in particular who got on really well and who was very receptive to everything I

offered her.

Q Do your Turkish clients readily adopt new ways of speaking and speech techniques?

A Unfortunately not, in most cases. They want to speak correctly right from the beginning. One important point, by the way, is how to meet other people. We practice this in role playing. Two of my Turkish girls demonstrated to the Turkish boys how to get to know girls.

Q German women or girls?

A The Turkish boys like to meet German girls but they prefer to marry Turkish women.

Q What can be done to make stuttering self-help palatable to Turks who stutter?

A imply not enough people know about it. One young woman attends self-help seminars regularly, and she always talks very enthusiastically about it. But she is something of an exception. The problem is one of public relations. In the health centre the leaflets are on display, but unfortunately they are in German only. I haven't got time to translate them into Turkish. This would be a first step.

Q Thank you very much, I think that's enough for today...

(From "De Kieselstein" (D), 7/1993)



A round-up of what's happening in Europe from ELSA's member associations:

In **Bulgaria**, Peter Tonev and Mikhail Kayabashev continue to spread information about stuttering through publications and local radio. With a logopedist, Peter has arranged week-long speech improvement courses. Mikhail says: «We would like to share experiences with our colleagues in Europe by post».

OSIS, the association in **Austria** has staged two successful seminars titled "To live together - to learn from each other" and "Fear kills speech - ways out of stuttering", OSIS vice-chairwoman, Andrea has become a (art-time worker in the office; the office now opens to the public one evening a week and a library is being established. OSIS is symbolized by a pair of walnuts on their logo ("problems to crack") and in July a walnut tree was planted in an Innsbruck park... no news yet of any walnuts harvested!!

In **Finland**, the magazine "Painokas" has reached 15 years of age, the anniversary being celebrated with an "even thicker and more closely-printed issue than normal"! The issue featured reviews of past issues, writings and poems from readers, competitions and many items on international contacts, particularly with Estonia. Painokas is doing well nowadays - it's a pity so few people elsewhere can read and understand such a universal language as Finnish!

Like many other charities and voluntary organizations, the Bundesvereinigung Stotterer-Selbsthilfe (**Germany**) is threatened by serious cuts in funding as a result of drastic economic measures due to the recession. Luckily, the series of five videos produced for specific target groups (adults, parents, teachers) was completed as planned in 1993.

Malbjorg, the **Iceland** group, are happy to report some summer sun in the south, with temperatures around 15 degrees Celsius, "quite warm for us". The 1994 Nordic conference is to be held in Iceland for the first time, hopefully this will give Malbjorg a boost and inspire increased activity. This winter plans include activating a self-helpgroup in Reykjavik.

In the **Netherlands**, host of the most recent ELSA meeting, Demosthenes is considering establishing a professional enquiry office, thinking about changing its name, and working on a new leaflet. There is work to prepare a "Stuttering Awareness Week" in early 1994.

In the **United Kingdom**, AFS too have been involved with a "Stuttering Awareness Week" which for the first time has actively involved members of the parliament in helping to raise awareness of stuttering. There are now 3 full-time workers in the AFS office and many other people help out at different times. A "review day" was held to begin the important process of planning for the next few years.

The annual meeting of NIFS (*Norway*) took place in the mountains. A "Stuttering Camp" was held in the summer in Tromsø and was a great success. Tromsø is the "country of the midnight sun"! NIFS has also established links with stutterers and therapists in Latvia.

In *Poland*, helped by public funding, PAPS has increased its activity. Wilder and summer camps were held, enabling 100 members to improve their social abilities through entertainments as well as professional therapy. Several European friends took part in a convention at Gdansk in October.

The FSD in *Denmark* staged the Nordic Meeting in September, on theme of "The stutter and the environment". Work with parents of children who stutter is taking shape: 3 parents are now part of the FSD board/committee, and they are trying to establish self-help groups of parents in some areas. Interestingly, this is also happening in the U.K., where the AFS held an Open Day on child stammering for the first time in Leicester, where the first parent support group for people with children who stutter has been running for several months.

In *Sweden*, SSR have shown the way for all ELSA countries, with their ambitious and practical attempt to promote self-help in Estonia (see also "The Estonian Visit in Stockholm"). The SSR is also working hard to organise the 4th International Convention for people who stutter which will take place 26-30. July 1995 in Linköping. The two main topics will be: Research and therapies for children and adults. If you have any ideas that will be useful for the organizers, please send them to Ake Bystrom, Högskolegatan 27, S-582 63 Linköping. The SSR says; «You are all very welcome to Sweden in 1995!»

So, the stutterers of Europe are alive and well! Please send in your national news for the next issue of VoE so we can keep you informed of what's happening across the countries.

Send to:

Tim Powell, 7 The Avenue, Herxlett, Co. Wick, Ireland. Tel: 01 434 4111.

## Let's Get Together!!

*An invitation from Italy: Milena Michele writes...*

As a spokeswoman of the self-help group of Perugia (Italy) I'll try to assert here the importance of inter-personal relations among people who stutter of different countries, and to suggest a proposal to help realize this,

- 1) The existence of an "umbrella" of the national associations like ELSA has to be taken as a means and not as a goal (see K. Schal'ers, VoE No.6): this means too that we shouldn't confine ourselves to a bureaucratic concept of the association for the self-help groups; Personal contacts among the groups with direct exchange of experiences can be enriching and stimulating as regards the consciousness of psychological and environmental aspects of stammering, as well as the relations between stutterers and society, and can therefore offer creative starting-points for our common studies and activities.
- 2) Inter-personal contacts among groups would give us better insight into the range of effects of stuttering, of our needs for active associations and of their potential, and can lead the groups to stimulate each other (M. van Eekcten, personal message. VoE 6) into activity and to encourage solidarity for each group, and for ELSA.
- 3) Stutterers' concepts of self-help could maybe be developed through inter-personal contacts with fellow stutterers from different countries. For example, opportunities for travel, making new friends, learning foreign languages could help many stutterers to better fulfil themselves, and can help us all to tackle the-tendency towards isolation - harmful in our present world, where approach to contacts and relations abroad is increasingly important.

A proper concept of self-help, in our opinion, is to act in such a way that each one of us can achieve full expression of his/her personality.

This applies, of course, on a wider basis than human relations; but we feel that relations between stutterers are an essential pre-condition to any further achievement.

I think too that direct contact to people perhaps very different from us in many aspects except in their relationship with language can strengthen our sense of the universality and humanity of stutterers, and our sense of identity and of the care we must take of ourselves.

Assuming a more or less general agreement with the above, our point is that meetings and similar opportunities to exchange views and experiences that have been created so far are not enough in themselves to realise our needs and aims. We propose to create a widespread network of relations among the local groups: also particular "twinrungs", for example, could be established between two or more places.

Meetings and exchanges between groups of a few people are naturally much more easily organised than general congresses: relations would be more intimate and could include a more detailed exchange of experiences about methods, therapies, activities etc., as well as enabling a better knowledge of social and personal problems of the stutterers.

In addition, the enterprise of local groups in this way could go some way in avoiding the problem of limited financial resources that is a critical obstacle to the work ELSA strives to accomplish for the stutterers of Europe and beyond.

The Perugia group offers itself to open a particular relationship with one or two other self-help group members of ELSA who would like to accept this invitation. Bye!

Miiena and others from Perugia, Italy.

Contact:

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# The Pendleton Fluency Project: Interim Report

## Deborah Plimmer

Specialist Speech and Language Therapist

The Pendleton Fluency Project was established in January 1992 with the aim of researching into stammering. Questionnaires were sent to all District Speech and Language Therapy Managers asking for information on the type of therapy they were able to provide for stammerers. We received 174 completed questionnaires and are currently analysing the data from these. We also sent questionnaires to all AFS members and targeted therapists in the Trent region, asking them to distribute questionnaires to their current clients. Over 1.000 were sent out and we received 78 replies. 27% of people responding had attended intensive courses. 33 people travelled outside their home district for therapy (423). Distances varied from a few miles (to a neighbouring county) up to 150 miles.

## Long term benefits

We asked people to rate the long term benefits of the courses they had attended (Figure A). 20 people felt that their therapy benefits were excellent. The types of therapy they were offered is shown in Table 1. As can be seen, the method most often referred to was social skills training. Assertiveness skills and individual counselling were also important aspects.

Seven people rated the long term benefits of therapy as "good". The most often used approaches were block modification and role play. Fourty people gave a rating of "fair". The most often used approaches for this group were block modification and slow/smooth speech (13 respondents used both of these approaches). Social skills training was only cited by five people (12,5%) whereas it was used by 50% of those who rated therapy benefits as excellent. There were three people who rated the benefits of their therapy as poor and four who said that they had not experienced any long term benefits. One of these did not specify the type of therapy he had experienced. However, of these seven people, three felt that intensive courses generally were an excellent idea if they were run well.

Twenty eight people felt that meeting other stammerers was a major advantage of attending a course. Other advantages cited were related to the type of speech control techniques that was used. Block modification, smooth speech and prolonged speech were each mentioned by ten people.

## THErapy APPROACHES CITED BY THOSE RATING BENEFITS AS EXCELLENT

Social Skills .....	12	Block Modification .....	8
Prolonged Speech .....	11	Relaxation.....	8
Slow/Smooth Speech...	11	Breathing Techniques .	7
Assertiveness Skills.....	10	Pacific Institute .....	1
Individual Counselling.	10	Psychodrama.....	1
Role Play .....	10	Syllable Timed Speech	1
Avoidance Reduction ....	9	Voluntary Stammering	1
Personal Construct Psychology .....	9		

We asked people to outline what they felt were the least useful parts of the course. 14 people did not respond to this question and 17 said that they had found all parts of their course useful. (12 of these

were from the groups who found the long term benefits to be excellent or good). Most of the answers to this part of the questionnaire relate to individual preference for types of approach. However, one of the most important factors to take into account when considering the effectiveness of therapy must be the relationship between the therapists and the course members. Three people, for example, mentioned that they felt their therapist had remained "apart" from the group, producing a "them and us" situation.

Respondents were asked why they thought maintaining change after a course was so difficult for many. 52 people replied to this question. 16 people cited the need for support after the course. Other reasons centred around the difficulty in maintaining confidence and motivation and in using techniques outside the clinic.

**Figure A**  
**LONG TERM BENEFITS OF THERAPY**



### Conclusions

It is clear that every person who stammers is different in both the way that they stammer and in the way that they tackle their stammer. This has already been well documented in literature. It follows that there is no one way to "treat" stammering although there is undoubtedly a core of proven methods beneficial to a majority of people. Most people taking part in this survey have experienced an eclectic approach from which they have been able to take away the most appropriate aspects for their personal use.

The main benefit for many has been the opportunity to meet, and share ideas with, others who stammer. Support following courses is vital to maintaining changes made. The increasing number of self-help groups across the country is a testament of how important this support is. The general feeling amongst therapists is that an intensive course should be seen as a part of ongoing therapy, not as a complete therapy package on its own. This point will be elaborated in our next report, furthermore, comments on how the courses were run point to a need for therapists to take care not to disempower their clients. Courses which are designed to enable an individual to utilise their own skills as "self-therapist" are, we feel, potentially more likely to succeed than those aimed at teaching a technique with little or no emphasis on social skills, goal setting, problem solving, coping with change, stress management and other areas of self-awareness and growth.

Both questionnaires indicate that "techniques" are seen as a set of skills to utilise when the need

arises. Like any skill, control of fluency often needs a great deal of practice and should be looked at in the light of how stammering and fluency fit into a person's view of the world and of themselves. Over-emphasis on fluency control may lead in some instances to a feeling of guilt at having failed if there is a relapse. As one person wrote, "I stopped going (to therapy) because I felt there was nothing else available for me. Most of the therapy then was based on techniques which I didn't find worked very well for me. I tended to feel it was my fault." Another wrote that when he stammers he feels that he has failed the course and is, therefore, "letting myself and the speech therapist down".

For most people tapes, cassettes and handouts were not generally available to help with follow-up work and the "self-therapy". The present project involves producing video and audio cassettes, together with a set of home assignments and information booklets to aid in the maintenance of progress following an intensive course.

It has *been* a valuable exercise to hear from people who have experienced different forms of therapy. We will continue to report on our progress during 1993.

[From Speaking Out (UK) Spring 1993]