

Further Information Package

Background information probably only during the development phase

The following will help to understand ISA 10 Recommendations Development better.

1. Our Dreams for Self-help and Therapy

(From ISA keynote speech, 2000, Krall)

Our most fundamental dream has become our vision: A world that understands stuttering. But how do we translate this dream into concrete steps for the foreseeable future until e.g. 2010 or 2030? The attainment of our vision means, that the following dreams must come true.

We dream ...

... **of a world that understands stuttering**, where people who stutter will not feel the need to hide their stuttering any longer, will not be misjudged as fools, psychopaths and figures of ridicule, and that stuttering will not affect their lives negatively.

... **of children** who stutter, who will be born into a world of greater tolerance and support.

... **of parents and the general public** in our world, who better know how to deal with stuttering.

... **of schools** in our world, to which stuttering pupils really like to go. We dream of them having a better opportunity to access effective therapy, to have well-informed teachers, and accepting peer group and to be able to take part in self-help groups for pupils, if they want.

... **of therapy** in our world, of having more and more stuttering specialists in all countries – especially in developing countries. We call for the most highly qualified and competent stuttering specialists, we don't want the 10% amateur any longer. We dream, that charlatans no longer work in this area, that therapists don't make false promises relating to recovery, that no person who stutters is denied entry into the field of speech language pathology because he/she stutters. We dream that people who stutter don't need ten but only one type of effective therapy.

... **of stuttering and employment** in our world, which is not a problem any longer. We dream that people who stutter work in jobs they really can and want to do – without discrimination – and have expert, competent career guidance.

... **of future films, literature and the media** in our world, where people who stutter are not portrayed as fools any longer, but as being positive, friendly, lovely – although they stutter.

... **of research** in our world, which solves the stuttering problem before 2030. By genetic technique, or other interesting approaches.

... **of self-help groups** in every town of our world, national associations in every country, and a strong and helpful international network of ELSA and ISA, in cooperation with IFA, WHO, UNICEF and other international organizations, e.g. the World Federation for Mental Health.

... finally **of ourselves**, of people who stutter in our world that we are strong and calm enough to handle our stuttering as best as possible. That we talk if we want to talk. And if we really want to involve ourselves in therapy, the patience and staying power to practice our new skills and lifestyle every day, possibly for our whole life. We dream of being loved, of stress reduction, of increasing our self-acceptance, self-esteem and self-confidence. We dream of positive thinking, and possibly changing our attitude and assessment of stuttering, saying and living, one day: "Stuttering is not a problem – it is a challenge." We dream that our soul will find the peace of mind. We dream of complete mental health.

And to reach all of them, we also dream a Big Financial Dream:

We dream ...

... **of a financial situation** which is much better than today! Of a budget of 10 Million US\$ a year, to finance the needs and our dreams.

... **of having a fully paid Executive Director**, some staff and a nice office in our world, so that our projects can be managed more professionally.

... **to have our own house**, somewhere in our world, our own property for ISA, ELSA, FASA or the national associations in their countries, possibly even together with the IFA. Until 2005, no stuttering association owns

any property. Since July 2006 this changed. The German Stuttering Association bought a wonderful office with many rooms in Cologne.

"We are searching for sponsors,
for further building our strong house
of stuttering self-help
in our world."

We dream of a home that represents cooperation between all the agencies that best work for the good of those who stutter. This house could be a wonderful collaborative project with many departments. There could be many such houses in the world. A name like "International Agency for the Prevention and Management of Stuttering" could possibly be a good idea if we would make the house a joint project.

Our dream house: "International Agency for the Prevention and Management of Stuttering"

Departments:

• UN	• Self-help	• Public Relations	• Executive Director
• WHO	• Therapy	• Cooperation	• Conference Room
• UNICEF	• ISAD	• Museum / Exhibition	• Coordination
• Research	• IYCWS 2004	• Fundraising	• Publishing House
• Kids	• School	• Working Groups	• World Congresses

Dreaming of progress, cooperation, sponsorship and our own house, I want to share another little anecdote.

The Parthenon of the Acropolis is over 2400 years old and even today is the visible reminder of the political, economic, cultural and philosophical heyday of Athens. How could Socrates, Plato, Aristotle and their philosophies have developed without this Acropolis – without the dream and decision of Pericles and the citizens of Athens, to build this impressive building? Do you see the quality, beauty, area, age and the excellent condition of this old building at the following picture? And yet this Parthenon of the Acropolis was built in only 9 years.

It was most fascinating to learn that besides public treasury and many private sponsors one main sponsor supported this building. That cooperation and sponsorship made this dream of a building come true. The main sponsor was absolutely fascinated by the idea of building the Acropolis (Parthenon). He very often visited the building site, and every time tremendously enjoyed the progress of the building. I want to ask you. Isn't the Acropolis an interesting example of private sponsorship in ancient times, and how quickly people can realize such a dream project?

Can you understand my feelings, when I learned all that about the Acropolis?

2. School and Kindergarten

Future competence centres on stuttering? They should excellent deal with bullying, compensation of the disadvantage, organizing professional help and/or therapy at school and trying to integrate all that what is mentioned in ISA 10 Recommendations.

2.1. Interesting and helpful ideas from ISA member associations or countries relating to school and kindergarten

ISA wants to integrate good and helpful ideas or projects from ISA member associations or countries in future 10 Recommendations, in this chapter or other chapters. Please tell us about such projects in your association or country. Please see and use the ISA questionnaire. Thank you so much.

Here should be in future much space for future interesting and helpful ideas from around the World:

1. ...from country a
2. ...from country b
3. ...from country c
4. ...from country d
5. ...from country e
- ...etc.

For example we want to highlight the following interesting approaches outside and inside of schools, today:

2.1.1. Outside School

Interesting approaches in many countries:

Since over 20 years national stuttering associations made excellent seminars, workshops or similar events for pupils who stutter. The Japan Stuttering Project (JSP) makes a summer camp with 80 to 100 pupils and parents every year.

2.1.2. Inside School

Interesting approach in Burkina Faso

In Burkina Faso there was an excellent project at some schools of the capital city Ouagadougou, over some months, together with speech therapists and students of speech therapy from France. A wonderful presentation about this helpful project was held at the 2. African Congress for People Who Stutter in Ouagadougou, in October 2008.

Interesting approach in USA

In USA there are "school speech therapists" working at every school. They are normally not experts in stuttering therapy. But it is possible to become a stuttering specialist in the USA, same as in the Netherlands, too.

Interesting approach in Germany

Because in Germany normally not "school speech therapists" are at every school and also it is not possible to become a stuttering specialist in Germany, the German Stuttering Association initiated an interesting project in 2008 to change this. See next chapter 2.2.

2.2. For better understanding we want to tell very intensively from a current project in Germany: The letter to all leading politicians

The following **four pages** relating to school and kindergarten are from the 24 pages letter of the German Stuttering Association (5 pages letter, 4 pages further information, 14 pages ISA keynote speech 2000, 1 page distribution list) to all leading politicians in Germany, from April 11, 2008. We suggest **not** to integrate these **four pages** in ISA 10 Recommendations **in that long form**, but maybe in a future shorter form. But today we prefer the long form for better understanding, so that the 54 ISA member associations know exactly all about the German approach from 2008.

The headline, reference of the German letter was:

School Days Often are the Worst Times in the Life of a Person Who Stutters

After the headline and an introduction of half page there were:

The Following Recommendations From the German Stuttering Association

The Main Objective of Our Campaign 2008:

We Will Have Better Schools and Kindergartens in Germany Very Soon,

- a) in which also children who stutter want to go with pleasure,
- b) in which parents can bring their stuttering kids without thinking,
- c) which are at the current state of the science relating to stuttering.

Our Demands, to Reach this Objective

- 1) Integrative teaching and supporting to all stuttering pupils in all **normal schools** by:

a) At least one teacher (working title: "Integrative Teacher Stuttering") at every school, (class 5th to 13th) who intensively takes care to every single pupil who stutters and makes also regularly group meetings with all pupils who stutter of the school, if the pupils like this (see enclosure "Further Information", p. 1).

- b) A concept of support for pupils who stutter at our primary schools.

c) Implementation of social, psychological and speech therapy concepts which considers the current state of the science, in the integrative teaching and supporting (class 1st to 13th).

d) Regularly dutiful further education conferences for teachers of all schools, held e.g. by the special trained future "Integrative Teacher(s) Stuttering" of the school and integration of the theme Stuttering in the obligatory part of the university education of future teachers.

2) Consideration and development of helpful concepts for the social intercourse with stuttering children, also in **all kindergartens**, especially under the aspect of **Early Intervention**.

Further Objectives, Demands of Our Campaign 2008

- 1) It should be trained, in Germany, to the profession of „ Stuttering Therapy Specialist “ – for children and adults – who is able to make therapy by using the current state of the science, who, especially under the aspect of Early Intervention, is able to treat also very young children, exactly then, when potential stuttering is recognized by parents, educators of kindergarten or doctors for children, e.g. at the age of two or three. The question arises, whether, for future treatment of stuttering, maybe two or more „Stuttering Therapy Specialists“ should be trained, having different priorities, according to the age of the child who stutters. For example:
 - a) The „Stuttering Therapy Specialist“ for Early Intervention from possibly two years.
 - b) The „Stuttering Therapy Specialist“ for elder children and adults?
- 2) A better education of the doctors for children. That they can better inform parents about current therapy methods.
- 3) People who stutter should work in jobs they really can and want to do – without discrimination.
- 4) Having expert, competent career guidance. People who stutter have very much possibilities. They work in nearly all jobs. Also e.g. as pilot, teacher, doctor, priest, actor, politician (!). Making courage and clearing up, this could be part of future supporting of children and young persons who stutter not only in our schools.
- 5) Film, literature and media: People who stutter should not be portrayed as fools any longer, but as being positive, friendly, lovely – although they stutter.
- 6) More money for research. There is hardly no research relating to stuttering therapy.

In the German letter to the leading politicians the following two chapters were integrated in the 5 pages letter.

The "Healthy School", the "Healthy Kindergarten" Also for Children Who Stutter

Because our children are our greatest good and worldwide people dream about better, really healthy schools/kindergartens also for children who stutter, that is the reason for us, to make this to our present main objective.

Children who stutter are normally at all kindergartens and schools. Teachers and educators at kindergartens often don't handle with care with them – and this up to the 13th grade. A „Continue as Before“ would be gross careless towards children who stutter at schools and kindergartens. We want, that children who stutter in future go to school/kindergarten with pleasure, future stuttering school leavers possibly say: „My school days mostly made me happy, and I already learned very much in school about that, how to handle my stuttering better and better. My teachers and class fellows very good handled with my stuttering.“

The World Health Organization (WHO), UNICEF, many parents of children who stutter, experts and people who stutter are glad, when we make something for the physical and mental health of our children in Germany.

To Frequency of Children Who Stutter at Schools

Children who stutter are often not recognized at schools. They have learnt to hide themselves and their stuttering also by avoidance. Because of that, teachers and headmaster often guess, that there are no children who stutter at school. By carefully trying to find all children who stutter, people reach that numbers, which are known in science. At a school for the 5th to 10th grade, having for example 650 children, it could be easily happen, that a future „Integrative Teacher Stuttering“ has to care with six, twelve or maybe more children.

In the German letter to the leading politicians the following headline and the chapters a) to f) were the 4 pages part "Further Information":

2.2.1. The „Integrative Teacher Stuttering“ (working title)

a) Who could do this? Teachers, Speech Healing Teachers, future Specialists in Stuttering Therapy?

One or more teachers teaching at the school. Obviously experts. Possibly Speech Healing Teachers, who are teachers at the school or special trained teachers for the support of pupils who stutter.

b) How much lessons a week should/could a teacher be employed for pupils who stutter?

According to the need of support (e.g. number of pupils who stutter, number of the pupils of the school, etc.) the "Integrative Teacher(s) Stuttering" could be employed by more or less lessons a week, at the respective school, by the headmaster of the school.

c) What means "Taking Care"? What possibly could belong to the scope of duties of the "Integrative Teaching Stuttering", obviously in consistent coordination with organizations of therapists and teachers?

Nearly everything, what proved to be good in self-help groups and therapy, worldwide, is also helpful for pupils, e.g. in group- or single sessions. Here a little selection:

1. Making courage, being the person to turn to, being lawyer, during the whole school days, also in the upper classes of a secondary school. Searching for all children who stutter of the school, finding. Informing the pupils concerned about causes of stuttering, chances for healing, different methods of therapy clearly explained, stuttering and occupation, partnership, humour, jokes, fear about stuttering, techniques of relaxation, etc.
2. Electing speakers of the group, making theatre plays, making music, painting pictures about stuttering. Carefully preparing and supporting: appearing on stage or making speeches at school events. Making recommendations. Making courage for a soon therapy, or making courage for no therapy at the moment.
3. Cooperation with therapists, parents and teachers of the school. Training of all teachers of the school relating to stuttering. Sometimes according to the need: Visit of that lessons, where pupils who stutter are and discuss the matter of stuttering together with classmates and the teaching teacher.
4. Making interesting projects together with the group, which not necessarily have to deal with the theme of stuttering. Maybe making a common trip, e.g. in the swimming pool or common walking tours, possibly a trip with overnight stay/s. Maybe to a "youth seminar stuttering" or to the annual national congress for people who stutter.
5. Slowly, carefully and step by step taking away the fear and shame for stuttering of the pupils who stutter. Possibly also by practices for desensitization, as for example „Intentionally Stuttering“, ordering a meal in a restaurant or buying rolls. If fear and shame become more minor or possibly disappear completely some time, also stuttering has the good chance to become more minor.
6. Don't care much about stuttering or finally nothing – here the „Integration Teacher Stuttering“ could make an essential contribution already during school days.
7. Finally „Taking Care“ could mean – obviously after having intensive discussion and potential development of helpful concepts, together with therapists, organizations of therapists, etc.: A more or less intensive therapeutically intervention in the school by the „Integrative Teacher Stuttering“ or, if necessary and wished by the child and the parents, possibly also, an intensive stuttering therapy using recent knowledges by "Specialists in Stuttering Therapy" at school?

Obviously we don't want to take away their clients from speech therapists and other groups of professions. We are interested in finding a solution, which is all right for all sides and we are sure, that this solution exists. We are open and glad about every further and possibly helpful idea, especially from the organizations of teachers and therapists, too, improving the situation at our schools.

We are searching for the best concept in Germany.

d) Some Essential Statements from the Book of Carl Dell, USA: Treating the School Age Stutterer

Dell, C. (1979), the American original version is published under the title: Treating the School Age Stutterer – A Guide for Clinicians, Stuttering Foundation of America, USA – Translated from American and revised by Andreas Starke, 3rd revised edition, October 2001, published by Demosthenes, German Stuttering Association. (Annotation from June 2nd, 2008: The translator of this text for reference for ELSA and ISA, Thomas Krall, unfortunately was not able to use the American original version for this text, but made a retranslation from German into English)

Carl Dell, one of the leading stuttering therapy specialists worldwide, a person who stutters, writes in his book „Treating the School Age Stutterer“: „We can give much to the child, what it will get otherwise nowhere! These children need all help, which we can give“. (Dell, p.16) Take loving and intensive care of is nearly the most important thing for the child who stutters. „Taking care“ in such a way, should certainly have clear positive therapeutic effects on social, emotional, psychological and speech therapeutic fields. The whole, from many experts highly appreciated book from Carl Dell is regularly a call to the theme „Taking Care“.

„We have to prevent the growing of stuttering and we are not allowed to ignore it.“ (Dell, p. 39) „Let us break through and turn round the vicious circle as early as possible.“ (Dell, p. 44)

„Although my stuttering was not cured during my school days, the therapists reached some very important things. They were an address for me to turn to, where I could come every time, to speak with somebody, without laughing or making disparaging comments about me. There I could take the liberty of communication, in spite of my stuttering. What for a great feeling it was! My dog was the only other living being, where I felt the same. There was a place, where I could hear something about stuttering, this mystic thing, about that nobody else was talking about with me. I needed a secure place, where I could touch it and take up it. Being a little boy this was absolutely positive for me.“ (Dell, p. 17)

„In fact my school therapist did not heal me, but he was requiring very urgently. I think, that these experiences were the foundation stone for my final success. I am sure, that my therapy as an adult would be much more difficult, without having the experiences of early therapy. The most valuable present was certainly the fact, that they took care about me. They took care about me! They gave me the feeling, that I was valuable as a human being, although I stuttered. Because of this experience stuttering could never so deeply destroy my picture of myself, as this happen by many young people who stutter. The care and warmth, which I got from my therapists, helped me, not being crushed as a human being.“ (Dell, p. 17).

„We know how we can give feelings of self-esteem and dignity to these children. Being together with us they find acceptance, warmth and understanding. In us they find somebody, who listen to them, although they stutter, somebody, who don't frighten and refuse them, but also will help.“ (Dell, p. 16)

In case of not feeling enough competence, having fear to get injuries or an increasing of stuttering, for pupils who stutter, possibly the following quotation is helpful to a future „Integrative Teacher Stuttering“: Dell „never had noticed this in reality, not a single time! If the therapist has a negative attitude towards the child or if he shows signs of refusal, during appearance of stuttering, stuttering can increase, but I had the experience, that most of the therapists are sweet, calm persons, who accept and understand the stuttering of their young patients. Such attitudes will not increase stuttering.“ (Dell, p. 20)

You not should stop quoting Dell, at this point. He is sure, that his school therapist could reach still more, from the point of view of today. He writes: „Although I am still thankful for the school therapists, who helped me, I believe, that it is possible to do more than that, what they could achieve. The most important thing would be in the past, that they tried to turn back the progressive development of stuttering. Unfortunately too many light and beginning people who stutter become severe, chronic people who stutter, and I believe, that a school therapist can prevent this development. At least there are two reasons, why speaking get worse, during school days for most people who stutter. The first is, that most of them do not get professional help, during first phase of their stuttering and the second is, that therapists are not able to use that necessary methods, which could prevent the abnormal increasing of speaking. In my opinion the solution of the problem of stuttering is early intervention, which is able to turn back the progressive growing of this disorder. I made the experience, that stuttering can be cured, when this intervention takes place early enough.“ (Dell, p. 17, 18)

Andreas Starke, one of the leading “Stuttering Therapy Specialists” of Germany, also a person who stutters, translator and revisor of the book of Carl Dell, writes in the preface of the German edition, page 9: „The idea, of training and employing “Stuttering Therapy Specialists” for children who stutter, has not yet succeeded in USA, although some engaged therapists demonstrate the advantages over and over again. We surely cannot hope for the overall employment of “Stuttering Therapy Specialists” for Germany, e.g. at public health offices, as long as stuttering is not realized as a problem of public health precaution.“

e) The „Study Group Stuttering“ Project in NRW and RLP Germany

Similar positive and very encouraging experiences were made in the integration project „Study Group Stuttering“ at three German schools, since 1990 till today: In Northrhine-Westfalen: In Duesseldorf (1990 till 2001), at the comprehensive school Kikweg, 5th grade till 13th grade. In Rhineland-Pfalz: In Gerolstein (2002 till 2004) and Kaisersesch (2005 till 2007), at the Regional Schools, 5th till 10th grade. At a fourth school, called Primary- and Regional School in Treis-Karden, 1st till 10th grade, Rhineland-Pfalz, too, the „Study Group Stuttering“ is in its initial stages, since September 2007, because the leader of the „Study Group Stuttering“ teaches at this school, first since August 2007. The „Study Group Stuttering“ could be also designated as a „self-help group for pupils who stutter“, under technical direction by a teacher. (Krall, 1990-2008 in coordination with the district government Duesseldorf and the supervision- and service direction Trier) - That goals will pursued in the „Study Group Stuttering“, which, a future „Integrative Teacher Stuttering“, could clearly following more intensively, because the teacher in Germany, Thomas Krall, was not a speech therapist but a person who stutters.

f) The „Study Group Stuttering“ from Germany in Literature

Andreas, 12 years (1999), was member of the „Study Group Stuttering“ at the Comprehensive School Kikweg, in Duesseldorf. He positively expressed himself, at over more than one page, in: Interview with Andreas: My hobby is writing letters. In: Hildebrand, Maike and Kowalczyk, Charly: If I could speak fluently – Life stories from people who stutter, p. 27-28, Idstein 1999

Schiekeb, 12 years (1999), was member of the „Study Group Stuttering“ at the Comprehensive School Kikweg, in Duesseldorf. He positively expressed himself, at one and a half page, in: Interview with Schiekeb: Before I speak, I should breathe in. In: Hildebrand, Maike and Kowalczyk, Charly: If I could speak fluently – Life stories from people who stutter, p. 93-95, Idstein 1999

Schindler (1992) takes the following opinion: „Having this kind of imparting of knowledge, the young persons could understand themselves as acting persons, because people do not relieve a decision about a therapy from them, but only the possibilities becomes open for that. They approach to stuttering by a method, which they can understand and accept as young persons. During the discussion of topical problems, common alternatives of action are developed and tested.“ (Schindler, Angelika: Young people who stutter – Therapy: I'm not a bit keen on that? In: Demosthenes-Institut: Therapy advisor stuttering, p. 125 f, Cologne 1992)

Starke (1999) speech therapist, stuttering therapy specialist, a person who stutters, writes: The „Study Group Stuttering“, the 12 years old Schiekeb is reporting about, seems to be one of more very useful measures to me, pupil who stutter can be protected and supported. Thomas Krall made an important and exemplary example by this. In any case stuttering has to become subject between pupils, parents, teachers and the class.“ (Starke, Andreas: In epilog, in Hildebrand, Maike and Kowalczyk, Charly: If I could speak fluently – Life stories from people who stutter, p. 155 f, Idstein 1999)

Krall, Thomas with Martin: A letter to you, in Demosthenes-Institute, project manager Kerstin Weikert: When speaking is squeezing – An advisor for young people who stutter. Stuttering – What can I do? Who can help me? „Study Group Stuttering“, for pupils who stutter, at the Comprehensive School Kikweg, in Duesseldorf. Demosthenes-Institute, German Stuttering Association p. 46 – 50, Cologne 1996

Krall, Thomas: I did not want to become unmasked as a person who stutters. In: Hildebrand, Maike and Kowalczyk, Charly: If I could speak fluently – Life stories from people who stutter, p. 146 – 153, Idstein 1999. Statements to „Study Group Stuttering“: p. 151. Hildebrand and Kowalczyk write in the introduction: „We made 18 interviews for this book. They were edited by us relating size and language. At the same time we tried to keep the individual every day language. Because of that, we hope, the persons who talk become more visible for the readers.“ p. 12

Schindler, Angelika: Stuttering and school. Problems and forms of mastering, in relations with pupils who stutter. In Teacher – Pupil, Classes. Berlin 1996

Schindler, Angelika: Stuttering and school – An advisor for teachers. Pedagogical possibilities of support in normal schools: „Study Group Stuttering“, for pupils who stutter, at the Comprehensive School Kikweg, in Duesseldorf – Interview with Thomas Krall, teacher – by Demosthenes, German Stuttering Association, p. 94 - 100, Cologne 1997

2. Inter discipline experts conference relating stuttering and school, October 25th, 2000 Cologne <School – (no) a reason to have fear> An action of the German Stuttering Association. Pamphlet: Proceedings of all speeches. p. 8, 29-32, 53-56. At the stage sat: Simon Eichinger, Knud Mackenroth, Dr. Vera Mackenroth, Sandra Firmenich, Melanie Lütkeimer, Prof. Dr. Jürgen Benecken, Dr. Kerstin Weikert, Heinrich Wild-Mateyka, Thomas Krall.

In Film/Video/ at a Video Conference

Kofort, Michael and Dutzmann, Volker – Concept Axel Ganter and Michael Kofort, in collaboration with: Thomas Krall and Udo Stier: „My pupil stutters – An advisor for teachers“. A film of the German Stuttering Association. With permission of the school ministry of NRW, Cologne 1993/94

1st International Stuttering Awareness Day – October 22nd, 1998 – there was an announcement, three minutes long, of the „Study Group Stuttering“ in all classrooms of the Comprehensive School Kikweg, in Duesseldorf, and participation at a video conference together with a school from Finland.

In Television

1.) The „Study Group Stuttering“ is shown in the youth programme of Second German Television (ZDF). 1994

2.) One pupil from the „Study Group Stuttering“ takes part at the RTL-Talkshow: Schreinemakers Live. 1996

3.) The „Study Group Stuttering“ is shown four times in Second German Television (ZDF) and in Children Kanal. 1999

At National Congresses

The „Study Group Stuttering“ drives to congresses of the German Stuttering Association and takes part at the programme. 1997 to Reutlingen, 1998 to Berlin, 1999 to Munich and 2000 to Frankfurt.

At International Congresses

1.) Presentation of the concept of the „Study Group Stuttering“ at the congress of the European Association of People who Stutter, European League of Stuttering Associations (ELSA), in Dublin, Irland, 1998

2.) Presentation of the concept of the „Study Group Stuttering“ at the congress of the World Association of People who Stutter, International Stuttering Association (ISA), in Johannesburg, South Africa, 1998

End of the 4 pages information about the German approach from 2008

3. Therapy

3.1. The problem of therapy (From ISA keynote speech, Krall, 2000)

Our experience with both self-help and therapy is that stuttering can be effectively managed and treated. However, stuttering management is a long term challenge and requires hard work, time and commitment, also because the hidden aspects of stuttering compile often more than 90% of the problems of a person who stutters (iceberg analogy).

There are so many badly qualified therapists, and many charlatans pepper the therapy scene. We need more competent, well-qualified stuttering specialists and more public education about current therapy approaches, especially relating to early childhood.

The following thesis is under discussion in many self-help groups:

To control stuttering and to maintain fluency is often a similar life experience as to learn a musical instrument, sports or a second language, and involves an entire lifetime of maintaining these techniques.

A friend from self-help, Germany, 45, underlines the above thesis:

I have learned three foreign languages in my life: English, French and "Fluency".

The best method of stuttering therapy remains a controversial issue. Prof. Fiedler, Germany, said in 1993:

"Every method helps".

This is a provocative but very interesting statement. "Every method helps" is just as true as: Every school teacher can teach, every tennis trainer and every piano teacher can give lessons. This thesis provokes many questions, for example:

- What is the best method for me?
- Who is a very good teacher for me?
- When I should take lessons? At the age of 3, 15, or 55?
- How can I identify a serious method and a serious trainer?
- What is my goal related to recovery from stuttering? Am I content with a little progress on the scale from 1 to 10 or do I want perfect fluency?
- How strong is my will, my staying power to practice the selected method possibly for years, or indeed my whole life?
- Who can best help me deal with my negative thoughts and feelings and help me become a more confident speaker?
- Who can help me in finding my personal way as best as possible?

It is good to know that we have relatively good answers for most of those questions, today. One thing is certain: From the perspective of people who stutter, it is important to have access to information which allows for good decisions. It is very helpful to contact the local self-help groups and the national associations for people who stutter, or to look at the homepages of those groups, or at the Stuttering Homepage.

3.2. Therapy with Very Young Children (Early Intervention)

American experts report on it, that "Stuttering Therapy Specialists" would have very good chances for complete healing a beginning stuttering in this early stage. The sooner, the better. Hopefully at once, at the beginning of stuttering, the therapeutic treatment should follow. Very often this **early** recognition and treatment (Early Intervention) has too little succeeded.

Many children lose their stuttering also without therapy. This is typically for stuttering. Unfortunately it is not yet possible to foresee, which children will probably lose their stuttering and which not, although some experts write that they can (Howel).

4. ELSA Amersham Draft Statement of Employments Rights, from 1995

This statement reads as follows:

- 1. People who stutter wish to compete on equal terms with other people based on their relevant skills to do a job.**
- 2. Perceived ability or inability in reference to fluency in communication skills should be a judgment made by the individual stuttrer and not by the employer.**
- 3. People who stutter are responsible as individuals for their own employment development and needs in partnership with employers and with support from national stuttering organizations.**
- 4. ELSA advocates National Stuttering Organizations to educate employers and the wider public as to the nature and effect of stuttering and to promote good employment practices.**

The statement continues:

We urge further active change and development in the employment rights for people who stutter. This may involve representation with organizations of disabled people who are demanding equal opportunity legislation in the field of employment and disability.

5. About the World Organization of People Who Stutter, International Stuttering Association (ISA)

a) What is the ISA Today?

The International Stuttering Association (ISA) was inspired by the self-help movement by people who stutter for people who stutter. The ISA a world-wide network of people who stutter, a non-profit umbrella association dedicated to close cooperation among independent national and international self-help organizations of people who stutter. Founded in 1995, we currently consist of 54 member associations from all over the world.

b) The 54 Member Associations of the International Stuttering Association

Argentina Asociacion Argentina Tartamudez	Israel AMBI - Israeli Stuttering Association
Australia Australian Speak Easy Association (ASEA)	Japan 1. All Japan Genyukai Association 2. Japan Stuttering Project (JSP)
Austria Österreichische Selbsthilfe-Initiative Stottern (OeSIS)	Luxembourg Schwätzen ouni Angscht
Belgium Belgium Stuttering Association	Mali Association Vaincre Bégaiement (AVB)
Benin Association Espoir Pour Les Begues	Mauritanie Association Mauritanienne Des Personnes Begues
Brazil Associacao Brasileira de Gaguera – ABRA GAGUEIRA	Nepal Nepal Stutters Assocoation (NSA)
Bulgaria SIZ - Bulgarian Stuttering Association	Netherlands Nederlandse Stottervereniging Demosthenes
Burkina Faso Association Action contre le begaiement (ACB)	New Zealand New Zealand Speak Easy Association, Inc.
Cameroon Speak Clear Association of Cameroon (SCAC)	Nigeria 1. Nigeria Stuttering Association (NSA) 2. Stuttering Association of Nigeria
Canada 1. Association des bégues du Canada Inc. 2. Canadian Stuttering Association 3. Speak Easy, Inc.	Norway Norsk Interesseforening for Stamme (NIFS)
Croatia Hrvatska udruga za pomoc osobama koje mucaju "Hinko Freund"	Poland PZJ - Polish Association of People Who Stutter
Congo Centre Parole Bégaiement	South Africa Speakeasy Stuttering Association
Denmark Forenigen for Stammere i Danmark (FSD)	Spain 1. Balearic Association of Stutterers 2. TTM/Fundacion Espanola de la Tartamudez
Estonia Estonian Association of People Who Stutter	Sweden Swedish Stuttering Association (SSR)
Finland Association of the Finnish Stutterers	Switzerland VERSTA
France 1. Association Parole-Bégaiement (A.P.B.) 2. Association Vaincre le Bégaiement	Uganda Easy Speak Association
Germany Bundesvereinigung Stotterer-Selbsthilfe e.V.	United Kingdom The British Stammering Association (BSA)
Hungary Démoszthenész	USA 1. Friends: The Association of Young People Who Stutter 2. National Stuttering Association (NSA) 3. The Speak Easy International Foundation, Inc.
Iceland Málbjörg	
India Fluency Club	
Iran Iranian Association Self-Help for Stutterers	
Ireland Irish Stammering Association (ISA)	
Kyrgyzstan Kyrgyzstan Land of Trust	
Lithuania Lithuanian Stuttering Problem Club	
	International member associations 1. European League of Stuttering Associations (ELSA) 2. Federation of African Stuttering Associations (FASA) 3. Passing Twice Gay, lesbian, bi and trans people who stutter 4. TTM-L Group "Nosotros Los Tartamudos"

c) History of ISA

The history of the ISA is the history of stuttering self-help, the World Congresses for People Who Stutter, the European League of Stuttering Associations (ELSA) and the Federation of African Stuttering Associations (FASA).

- 1965 Japan**, Shinji Ito made first self-help group meetings of people who stutter.
- 1970** Some time around 1970: Several self-help groups and national associations were founded.
- 1986 Kyoto, Japan.....1st World Congress for People Who Stutter**
The beginning of global cooperation. Shinji Ito, chair of the Japanese organization suggested founding an international organization.
- 1987 St. Andreasberg, Germany** First international meeting on the European level.
- 1989 Köln, Germany.....2nd World Congress for People Who Stutter**
Delegates of European associations prepared the founding of the European League of Stuttering Associations (ELSA) for 1990.
- 1990 Darmstadt, Germany** The European League of Stuttering Association was founded.
- 1992 San Francisco, USA.....3rd World Congress for People Who Stutter**
• The most important question: Do we need an international organization?
• A meeting of delegates of national organizations decided to answer this question over the next 3 years.
- 1995 Linköping, Sweden.....4th World Congress for People Who Stutter**
• The International Stuttering Association was founded on July 25.
• Three years of intensive preparation and discussion led to this historical step.
• Twenty-five national associations voted YES.
- 1996 Cooperation** with the World Health Organization (WHO) until 1999
- 1998 Johannesburg, South Africa.....5th World Congress for People Who Stutter**
• First World Congress on stuttering in a developing country.
• A Delegate from the World Health Organization took part for two days.
• ISA decided vision: A world that understands stuttering.
• ISA decided: Every year at October 22 is International Stuttering Awareness Day
- 1998 Online Conferences** in cooperation with the Stuttering Homepage (Judy Kuster) were held every year from 1.10. - 22.10., until 2008, to highlight and prepare International Stuttering Awareness Day, October 22.
- 2001 Ghent, Belgium.....6th World Congress for People Who Stutter**
ISA decided:
• The 1st International Year of the Child Who Stutter will be in 2004.
• To publish the Bill of Rights and Responsibilities of People who Stutter in 2001.
• To develop a CD-R relating the worldwide problem of stuttering at schools.
- 2004 Was the 1st International Year of the Child Who Stutter**
- 2004 Perth, Australia.....7th World Congress for People Who Stutter**
• ISA presented the CD-R relating the worldwide problem of stuttering at schools. Title: Stuttering a resource for children, teachers and parents.
- 2005 Douala, Cameroon** 1st ISA African Congress for People Who Stutter
• First time: International Speech Project (ISP).
- 2007 Dubrovnik, Croatia.....8th World Congress for People Who Stutter**
• School was highlighted as very important point for future change.
• First ISA writing contest was celebrated .
• ISA decided to develop 10 ISA Recommendations for all national associations of people who stutter (ISA Member Associations), the European League of Stuttering Associations, ELSA, for governments of that countries which have probably no national association of people who stutter, the World Health Organization (WHO), the UNICEF, the UN and international organizations of experts, researchers, medical doctors, teachers, Kindergarten educators, psychologists, speech therapists, and all others who are committed to understanding stuttering and the welfare of people who stutter.
- 2008 Ouagadougou, Burkina Faso** 2nd ISA African Congress for People Who Stutter
• School was again highlighted as very important point for future change.
• More than 350 Delegates attended at the opening ceremony.
- 2008 Ouagadougou, Burkina Faso** The Federation of African Stuttering Associations (FASA) was founded.
- 2011 Buenos Aires, Argentina 9th World Congress for People Who Stutter**

d) Five Reasons for Founding the ISA in 1995

1. The strong need for an international association for countries both in and outside of Europe. ELSA, founded in 1990, is a good model.
2. The chance for people who stutter to speak with ONE voice internationally.
3. Therapies, therapists and much more were often criticized in many national associations.
4. A precedent was set by the International Blind Union (established in 1929) and the International League of the Deaf for people with disabilities to be represented by international organizations. Why should people who stutter not speak with one voice?
5. Think globally, act locally. The World Congresses every 3 years are a good forum to create policies and international projects on stuttering.

e) Objectives of the ISA

Our mission is: To improve the conditions for children, adolescents and adults who stutter and parents of children who stutter in all countries, by:

1. Sharing concepts and information about self-help and therapy methods.
2. Outreach to make the movement bigger.
3. Facilitating communication and cooperation.
4. Educating the general public.
5. Stimulating research.
6. Being an advocate.
7. Assisting in founding of international working groups.
8. Initiating public relations projects.

6. Recommendations from ISA member associations

There are a huge number of very helpful brochures, guidelines, books, dissertations from many ISA member associations or other organizations like the Stuttering Foundation of America - in America, Australia, Asia, Africa and Europe.

For example:

- Guidelines for talking to a person who stutters. (USA, NSA)
- Guidelines for employment. (USA, NSA)
- Notes to listeners – what to know and what to do when speaking to a person who stutters? (USA, NSA)
- If you think your child is stuttering: How to Decide and 7 tips for talking with your child. A new risk factor chart. (Homepage: Stuttering Foundation of America)
- How to find a good therapist? (Germany)
- When children stutter – How to find a good therapist? (Germany)
- Active self help group sessions. Ideas and suggestions: What can be done? (Germany)
- FAQ - What you always wanted to know about stuttering. (Germany)
- Guidelines for teachers. (Germany)
- Stuttering and school – one good prepared lesson about stuttering. (Germany)

Please add interesting documents of your association in ISA questionnaire, if you want. Thanks so much.

7. Epilog

Or suggestions of words, for letters to organizations of the following distribution list.

In summary we want to emphasize at this point again, that we would be very pleased, if the countries are able to further develop, step by step, towards a positive, helpful, normal, relaxed, updated intercourse with the speech- and communication handicap stuttering.

If you wish consolidate information, we suggest the enclosures to this letter or to contact us. Our next ISA World Congress for People Who Stutter will be in Argentina 2011. Your visit is very welcome.

We hope, that you now better understand our 10 Recommendations, and you, possibly together with us, will initiate step by step the necessary changes in your country, Europe, all countries. You are the motor for political changes in your country, Europe, all countries. We are very pleased about cooperation with you. Please support our ISA 10 Recommendations and help us on the way, towards fulfilling our dream – our dream of „A World, that Understands Stuttering“ already during school days.

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