

Draft of Future ISA 10 Recommendations

Recommendation 1: Education - Kindergarten, Primary, and Secondary Schools. The school-age years represent a time during which children are the most formidable and the influence of school personnel is greatest. Therefore schools should respond in positive ways to the affective, behavioural, and cognitive elements of the stuttering experience so that each child who stutters will realize his full potential within a safe and joyful environment.

- (a) Every kindergarten and every school, therefore, should be a "healthy kindergarten", a "healthy school", a competence centre on stuttering, an oasis where support for every child who stutters combines the best of 1) self-help procedures with 2) intervention of the highest quality, both defined on the basis of objective outcomes or other forms of accountability and sensitivity to cultural differences, local traditions and available resources. In schools each child who stutters should be able to take part in self-help groups for pupils, if they want. Krall made excellent experiences with self-help groups at schools in Germany between 1990-2008 (Krall 1990-2008, see Further Information Package page 7). Teachers should also excellent deal with: bullying, ostracism, stigmatism, misjudgement and compensation of the disadvantage. As consequence pupils who stutter will not any longer feel fear, shame, discouragement, hopelessness and will not get depression, social isolation, and attempted suicide.
- (b) Future teachers, parents and classmates should be excellent prepared dealing with pupils who stutter. Today they often report feeling unprepared and uncomfortable to handle a child who stutters.
- (c) Each child who stutters should be identified at every kindergarten, every school and intensively and respectfully observed and attended during the whole school days. Today 50% and 75% of the children who stutter are not identified as such by the teachers due to the children's reluctance to talk or elective silence (Benecken & Spindler, 2004). The point here is not to legislate for individual countries the nature or degree of intervention for children who stutter or to demonstrate other exceptionalities of communication. Rather, the point is to highlight the fact that the schools represent a golden window of opportunity for working with children who stutter so that each child can become all he or she is capable of achieving.
- (d) Development of helpful schoolbooks for pupils who stutter, adjusted to the different ages of the pupils.
- (e) Interesting and helpful ideas from ISA member associations or countries: ISA wants to integrate in this Recommendation helpful approaches from different countries, after the feedback of ISA member associations. At the moment we know from interesting approaches in many countries from outside school, from inside school we know at the moment only from USA, Burkina Faso and Germany (see chapter 2 of Further Information Package). Please tell us about interesting and helpful approaches in your country by using ISA questionnaire, because we are sure that other such models exist around the world.

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.

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 in 2008. 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 speech therapists working at every school. They are normally not experts in stuttering therapy. But it is possible to become a stuttering therapy specialist in the USA, same as in the Netherlands, too.

Another model, supported by federal legislation, exists in the USA where a speech-language pathologist is available to every child between the ages of birth and 21 who is identified to have, or to be at risk for having, an exceptionality (e.g., a communication disorder) of deleterious educational significance.

Interesting approach in Germany

Because in Germany not speech therapists are at every school, as in USA, and also it is not possible to become a stuttering therapy specialist in Germany, the German Stuttering Association initiated the following project in 2008 to change this: At least one self-help specialist (integrative teacher stuttering) will be located at every school (see Further Information Package page 3, 4).

Such a specialist will have introductory training in speech-language development and disorders and assessment and treatment methodology. This person will work with speech-language pathologists and future stuttering therapy specialists collaboratively to ensure the realization of every child's communication goals.

Recommendation 2: Stuttering and Employment. People who stutter often experience limitations in academic and career aspirations due to negative perceptions held by the general public of stuttering and people who stutter. ISA envisions a time when all people who stutter will pursue life's choices and opportunities without regard to their communication challenges, listener reactions, or any form of implicit or explicit discrimination in education or professional settings.

- (a) People who stutter, like all other people, should be evaluated on the basis of their relevant skills and internal character.
- (b) People who stutter, assuming that they have the appropriate credentials and skills, should be welcome in all areas of employment (e.g., pilot, teacher, medical doctor, speech-language pathologist, stuttering therapy specialist, priest, actor, politician).
- (c) Such openness by and to all people, including people with exceptionalities, should be a part of the educational curriculum from the earliest of school age years.
- (d) The freedom to make one's own choices, enjoyed by most people, should also be enjoyed by people who stutter. It is the cornerstone of the historic Bill of Rights and Responsibilities for People Who Stutter (Sugarman and ISA, 2000).
- (e) Similarly, the European League of Stuttering Associations made an official statement relating to Stuttering and Employment in 1995. A portion of the Bill of Rights and ELSA's position statement (see Further Information Package page 9) should be incorporated into the charter of any new or existing self-help organization.

Recommendation 3: Self-help. The self-help movement among people who stutter began in the 1960's when Shinji Ito coordinated the first meeting in Japan 1965, and the National Council of Adult Stutterers began to meet in Washington DC, USA. While the movement continues to grow to the present day, as evidenced by ISA member associations 54 self-help organizations in 42 countries. Recognizing that stuttering is a universal disorder of significant personal and cultural consequence, the vision of the ISA is to have self-helps groups for people who stutter in every town and school, and for every country on the Earth to have a self-help organization for people who stutter and that such organizations be available to every person who stutters.

- (a) Value, spirit and perspective of self-help groups for people who stutter are outstanding.
- (b) Self-help is not just a means but a goal as well. People who learn to rely on themselves, are more empowered and have better self-esteem. Serving others is same as serving yourself. Selfless service to people in need, is a spiritual goal by itself.

- (c) Socrates, gaining inspiration from the Oracle of Delphi, led his life and inspired others through a simple philosophy: "Be aware of yourself." Simply looking inside of yourself, engaging in personal introspection and reflection, is the first step toward understanding, which leads to constructive: Awareness, acceptance and change. The most important three steps in each recovering process.
- (d) Self-help organizations are currently utilizing many creative projects and procedures that might serve as examples to self-help organizations that are just beginning. These include weekly self-help group meetings in as many towns as possible, in which people who stutter share thoughts and feelings about their stuttering experiences, coping strategies, and related successes and frustrations.
- (e) Related projects and activities include: Annual meetings of the national stuttering associations, publishing books, translating existing books, making regular media releases (i.e., newspapers, radio, TV), founding new self-help organizations (i.e., at local, state, or international level; e.g., the European League of Stuttering Associations, ELSA in 1990 and the Federation of African Stuttering Associations, FASA, in 2008), holding joint conferences of self-help and professional communities, publishing a CD-R (Irwin and ISA, 2004). Every three years there is the ISA World Congress for People who Stutter.
- (f) Most national and international associations of people who stutter (including ELSA, FASA and ISA) have web sites, national associations in local languages, that provide information about local activities and about stuttering in general.
- (g) Most national associations offer very important services, by phone or email, relating best information about stuttering and therapy, especially to people who stutter and parents.
- (h) Since 1998, every year International Stuttering Awareness Day is recognized on October 22 (ISAD). This global recognition of stuttering and people who stutter is a joint project between ISA, IFA and ELSA (Sugarman and ISA, 1998). Self-help groups and the national and international associations become increasingly active as International Stuttering Awareness Day approaches.
- (i) The Stuttering Homepage (Kuster, 1998-2009) is the home of the international online conferences on stuttering every October from October 1 to 22.

Recommendation 4: Therapy. It is the wish of every individual to live a safe and prosperous life, freely accessing and to contributing to resources available within one's own community. These aspirations, however, often are blocked to people who stutter. Therefore, therapy of the highest quality, accurate information on stuttering, guidance and support should be available to every person who stutters and his or her family.

- (a) Therapy with very young children (Early Intervention): 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.
- (b) Stuttering therapy should be very individualized. Every person who stutters needs other helpful aspects from a wide range of intervention possibilities. Very welcome and helpful are also psychologists to be involved in therapy, sometimes, and/or for speech-language-pathologists undergraduates to be trained in cognitive behavioural therapy.
- (c) ISA very much appreciates the worldwide great variety of interesting and helpful therapy approaches and expressly supports the further development of these approaches. The German Stuttering Association made very interesting experience in a research project in Germany during the last years: Evaluation of different stuttering therapy approaches.
- (d) It is the belief of the ISA that the time has come to act in support of all people who stutter and a world that strives to understand; quality therapies must be available for every preschool child, every school-age child, every adolescent, every adult, and every senior adult who stutters (see Further Information Package page 8). Such services are essential to enable individuals to realize their dreams, to become functioning and contributing members of society, to alleviate the burden that is stuttering, and to improve the communicative conditions for all.
- (e) Bloodstein & Ratner 2008 excellent describe 12 helpful criteria for a high quality therapy. David Shapiro said 2009, that maybe ISA should not integrate such criteria here, because development countries are not able to reach such criteria, soon. Thomas very much supports David Shapiro's opinion and wants to discuss this important point with ISA member associations, too.
- (f) Very helpful in the therapy and evaluation process is to evaluate how behaviour, thoughts and emotions are affected by stuttering which are the hidden parts of the iceberg under the water. Based on this evaluation suggestions can be made how the person who stutters should lead his/her daily life.
- (g) There should be the freedom for every person who stutters to choose, quality therapy from different approaches in every country, or also not attending therapy.
- (h) Therapy should be free of charge.
- (i) The academic, clinical, and supervisory requirements to become a speech-language pathologist vary by country. At present, only two countries (USA and the Netherlands) have official programs of specialization in fluency disorders that recognizes speech-language pathologists who have additional training and who maintain their specialization through prescribed academic, clinical, and supervisory experiences. Other countries have unofficial programs of specialization.
- (j) Providing the resources to speech-language pathologists who wish to pursue additional training in assessment and treatment of fluency disorders.
- (k) While many developed countries have federal legislation ensuring the rights of all people (i.e., particularly those with disabling or handicapping conditions) and relatively many speech-language pathologists available to serve the needs of people who stutter and their families, a number of developing countries have neither. In the case of the latter, one way to ensure the availability of quality intervention is for ISA to secure and to allocate such resources so that at least one speech-language pathologist is available for a predetermined population density within every country. In this way, every country would have access to one or more specialists who would be committed not only to providing clinical services, but to creating clinical and educational facilities that would live, by way of training the trainers, in perpetuity.

Recommendation 5: Research and Database on Stuttering. Presently, important research is ongoing that addresses the causes, nature, development and treatment of stuttering. This must continue until the 'riddle of stuttering' is solved and until the world understands both stuttering and people who stutter. ISA, however, aspires to achieve a new wave of research that is particularly sensitive to, and reflective of, the experience that is unique to each person who stutters. To that end, ISA seeks to express positive feelings for the research that is current being done and to influence the nature of future research projects so that the uniqueness of the stuttering experience is understood across the world.

- (a) This will require identification of external funding in order to build liaisons with researchers in the disciplines of speech-language pathology, psychology, medicine, human and natural sciences, and the like.
- (b) Clearly, government, industry, and private donations are available and must be identified to support this research.
- (c) Alone, the ISA is a very strong, powerful, and essential voice of and by people who stutter. Indeed people who stutter are the experts in understanding and expressing the unique personal manifestations of the stuttering experience. In combination with other experts (speech-language pathologists, speech scientists, etc), while still maintaining the uniqueness of their own voice, the voice and potential influence of people who stutter can only become stronger.

- (d) As the ISA strives to influence the future direction of research and continue to build the database that represents the world's understanding of stuttering and people who stutter, new collaborative bridges must be built with other professional and humanitarian organizations.
- (e) The ISA seeks to conduct a needs assessment and survey, similar to the survey that was conducted (Krall, Ahlback, Ito, Pill, Randall & Schäfers 1994) so as to identify the present needs and future directions of the research to be sponsored and guided by the membership of ISA. In so doing, every country would have essential input into the future direction of ISA.
- (f) A related idea would be to co-sponsor a research conference between ISA and IFA and other organizations of speech scientists to collaborate and to build an understanding that is unique to the stuttering experience.
- (g) Another idea would be to expand the database that currently exists within separate research projects and clinical locations (e.g., schools, clinical facilities, hospitals, etc.) so that there is a national centre for data on people who stutter for each country.
- (h) ISA could be the coordinator of such data and could invite IFA and other scientific organizations to utilize the data gathered in a collaborative form to as to best build an understanding of stuttering and people who stutter.
- (i) The process of collecting and maintaining statistic and data and the use of statistics, should comply with internationally accepted norms to protect human rights, fundamental freedoms and ethical principles, to ensure confidentiality and respect for the privacy of people who stutter.

Recommendation 6: Advancing the Cause of Stuttering. The cause of stuttering should be advanced by lobbying, legislations, and fiscal allocation and planning.

- (a) Because stuttering is assumed to be a disorder of "low incidence," the public mistakenly assumes that few people are affected. In fact, approximately 70 million people across the world are affected directly by stuttering. Furthermore, what affects one person affects everyone within that person's communication system. When one considers that number of family members, friends, and associates who are affected by the stuttering of a person within that system, the number is untold.
- (b) Nevertheless, organizations such as ISA, IFA, ELSA, FASA among others are left to fund raise, as they strive to raise public awareness and positive perception.
- (c) It is the vision of ISA to identify sources for financial donations that will, ultimately, lead to the designation of a firm annual budget for construction of an international office, lobbying efforts, international communications and collaborative projects, and joint ventures between the consumer, professional, and related communities.
- (d) Initial efforts to identify external seed money might represent an ideal opportunity to forge initial collaborations that will grow into the future.
- (e) Incentives will be created (e.g., tax incentives, public information and publicity for donors) in order to encourage giving.

Recommendation 7: Change Public Attitudes about Stuttering. People who stutter and concerned others must do all they can to change the attitudes of those who continue to hold negative and stereotypical views about stuttering and people who stutter.

- (a) People who stutter are all right even if they stutter and the most important thing is how they live with it, not focusing too much on fluency shaping. Through self-help group activities, such as endeavors for developing communication skills and self-expression they are excellent able to achieve personal growth as persons who stutter.
- (b) People who stutter should do all they can to manage both realistic and positive attitudes about stuttering and people who stutter. Venues for such influence were discussed previously: Kindergarten, primary and secondary schools, working place, parents, public information campaigns, media spots, conferences and workshops, and more.
- (c) Although public attitudes are slow to change, positive change is being observed (Cooper & Cooper, 1995).
- (d) Once each person who stutter commits to doing all he or she can to eliminate negative stereotypes and misperceptions, each person then must commit to maintaining one's own positive perception of himself or herself, one's own integrity, and one's own confidence that there is no limit on one's ability and should be no limit on one's ambition.
- (e) Stutter is not who one is, but is a reflection of what one does, thinks, and feels. Only one can define himself or herself.
- (f) People who stutter, like all people, should be defined on the basis of their character and abilities, aware of one's own humanness that evidences limitations and challenges.

Recommendation 8: Screening and Diagnostic Evaluation of Stuttering. All children should be properly monitored across the lifespan by a qualified speech-language pathologist for development and maintenance of speech fluency. Should deviations of fluency be identified, that specialist will coordinate a proper program of intervention with the individual and his or her family.

- a) There are many models for identifying children who demonstrate, or are at risk for demonstrating, a disorder of communication including stuttering. One such model in the USA, supported by federal legislation, provides for communication screening of all children by a qualified speech-language pathologist at specified points across the school years.
- b) From the screening process, children are identified for whom additional assessment is advised. This subsequent evaluation is conducted as a diagnostic evaluation.
- c) If a disorder of communication is found to exist as a result of the diagnostic evaluation, the child is referred to a speech language pathologist (i.e., and occasionally allied professionals; e.g., learning specialists, psychologists, special educators) for a program of intervention.
- d) A model such as this could be adapted to each country, taking into account available resources, specialists, and cultural, educational, and medical factors.

Recommendation 9: The Importance of Parents and the general public to Understanding the Stuttering Experience. The ISA dreams of a future where children who stutter are born into a world that understands stuttering. This world will be characterized not only by tolerance of people with differences (i.e., such as stuttering), but will nurture those differences in order to enable people who stutter to realize their dreams and to be limitless in how they seek and contribute to the future.

- (a) The ISA, in combination with other international associations (i.e., ELSA, FASA, etc.) will communicate the essence of this document and the Bill of Rights to humanitarian organizations as mentioned in the distribution list, below.

Recommendation 10: Stuttering and Film, Literature and the Media. In films, literature, and media, people who stutter are portrayed to often from a negative and demeaning perspective. This characterization only perpetuates the stereotypes, bias, and misinformation that plague people who stutter world wide. ISA seeks to achieve a more realistic and positive perspective toward stuttering and people who stutter in all venues.

- (a) A representative from ISA, national associations of people who stutter or qualified speech-language pathologist should serve as a consultant whenever a speech or language disorder is a topic of interest in a film or theatrical production. A medical doctor typically serves as a consultant whenever television or movies portray a character with a medical illness so as to convey art as realistic reflection of life. This model can be followed in such venues, particularly when stuttering or a person who stutters is incorporated into the theme of interest.