It’s been said that Moses had a stutter

Why do we still get to hear horrifying stories from PWS who get mistreated, mocked because people still don’t understand what stuttering is about?

Why do schools tell us they don’t have any students who stutter, why students struggle throughout their school year, without getting any help?

Why don’t politicians and other decision makers give more help and attention to a disability that enables people from communicating and taking part of a social life?

Why are organizations so successful to get their voices heard while PWS don’t want to use that term?

Why are there so many professionals still afraid to work with PWS and why are PWS still afraid to show their stutter and stand up for their rights?

BECAUSE PEOPLE HAVE NO CLUE!!!

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Is stuttering a disability?

- Wikipedia: The World Health Organization defines Disability as follows: "Disability is an umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is any problem in body function and structure. An activity limitation is a problem in executing a task or action; while a participation restriction is a problem in involvement in life situations. Disability is a complex phenomenon, affecting an interaction between features of a person’s body and features of the society in which he or she lives.

- The individual may also qualify as disabled if she had an impairment in the past or is seen as disabled based on a personal or group standard or norm. Such impairments may include physical, sensory, and cognitive or developmental disabilities. Mental disorders (also known as psychiatric or psychosocial disability) and various types of chronic disease may also be considered qualifying disabilities.

- A disability may occur during a person's lifetime or may be present from birth. A physical impairment is any disability which limits the physical function of limbs or fine or gross motor abilities.

- Mental impairment is any disability which limits the mental function or cognitions of a person. It includes disorders like depression, schizophrenia, and bipolar disorder.

- A disability may also involve features of a person's body and features of the society in which he or she lives.

ELSA, founding member of the EDF

- The European Disability Forum (EDF) is an independent European non-governmental organization (NGO) that represents the interests of 65 million disabled people in the European Union and stands for their rights.

- EDF was created in 1996 by its member organisations to defend issues of common concern to disabled people.

- EDF's mission is to promote equal opportunities for disabled people and to protect their Human Rights, making sure that no decisions concern disabled people, which is run by disabled people, and stands for their rights.

- EDF is the only European platform of disabled people, which is run by disabled people, to express themselves.

- EDF was invited in 1996 by the member organisations to defend issues of common concern to all disability groups, and to be an independent and strong voice for disabled citizens towards the EU institutions and other European authorities.

ELSA publications

- The ELSA newsletter Voice of ELSA is now incorporated in the ISA newsletter One Voice.

- Methods and Concepts of Self Help 1991

- Stuttering and Employment 1994

- ELSA Statement: “Stuttering and Employment” 1995

- ELSA Leaflet 2001

- ELSA's Stuttering And Disability Brochure 2001

- How to Engage Famous People to further the Stuttering Cause 2008

- ELSA “International and European Disability Policy Relating to Stuttering - What You Need to Know and Why” (This is the main disability publication part funded by the European Commission. Updates in 2007 & 2009 compliment the original document and have been produced part funded by the European Youth Foundation as part of their support for ELSA’s Youth Meetings.)

ELSA links on www.elsa.info

- Stuttering links (European and International links with stuttering information)

- Disability links (e.g. European Disability Forums, disability definitions etc)

- Discrimination links (with papers, surveys and the annual European Day of Disabled People)

- Other European links (European bodies)

- All publications

- Latest news about ELSA and its members

DRAFT BILL OF RIGHTS AND RESPONSIBILITIES FOR PWS

- The Right to stutter or to be fluent to the extent one is able or chooses to be

- The Right to communicate and be listened to regardless of one's degree of stuttering

- The Right to be treated with dignity and respect by individuals, groups, institutions, and the media regardless of one's degree of stuttering

- The Right to be accorded all rights mandated by laws or regulations for all citizens regardless of one's degree of stuttering

- The Right to demand the execution of guarantees for documented evidence of failure to be treated fairly under the law or to be treated with dignity and respect

- The Right to be informed fully about therapy programs, including estimates of the likelihood of success, failure, or relapse

- The Right to receive therapy appropriate for one's unique needs, concerns, and characteristics from professionals adequately trained to treat stuttering and its related problems

- The Right to choose and participate in therapy, to choose not to do so, or to change therapy or clinicians without prejudice or penalty

Stuttering and discrimination

- Wikipedia: Discrimination is a sociological term referring to the treatment taken toward or against a person of a certain group in consideration based solely on class or category. Discrimination is the act (behavior) towards another group. It involves excluding or restricting members of one group from opportunities that are available to other groups. The United Nations explains: “Discriminatory behaviors take many forms, but they all involve some form of exclusion or rejection.” Discriminatory laws such as redlining have existed in many countries. In some countries, controversial attempts such as racial quotas have been used to relieve negative effects of discrimination.

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- Discriminatory laws such as redlining have existed in many countries. In some countries, controversial attempts such as racial quotas have been used to relieve negative effects of discrimination.
DRAFT BILL OF RIGHTS AND RESPONSIBILITIES FOR PWS - cont

- The Responsibility to understand that listeners or conversation partners may be uninformed about stuttering and its ramifications or that they may have different views of stuttering than most who stutter

- The Responsibility to differentiate those reactions from listeners or conversation partners that are the result of lack of awareness or accurate knowledge of stuttering (e.g., surprise and comments thought to be helpful whether or not they are) from those reactions which result from a lack of respect or fairness (e.g., ridicule, belittling, teasing, or discrimination)

- The Responsibility to inform listeners or conversation partners if one needs additional time to communicate

- The Responsibility to enter into an open and cooperative partnership with a qualified clinical service provider with whom one has freely made a written or unwritten contract to enter into a clinical collaborative relationship.

- The Responsibility to do whatever one can to overcome life handicaps that have occurred because of stuttering, including developing a realistic appraisal of one’s strengths and weaknesses and developing a healthy sense of humor about oneself

- The Responsibility to assist whenever possible in educating the public about stuttering and its ramifications

- The Responsibility to regard and treat others who have differences, problems, disabilities, or handicaps with fairness under the law and with dignity and respect, regardless of the nature of their condition.

ISA

- International Stuttering Association (ISA) is a worldwide 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. ISA was founded in 1995 with ELSA as its model

- www.stutterisa.org

IFA

- The International Fluency Association is a not-for-profit, international, interdisciplinary organization devoted to the understanding and management of fluency disorders, and to the improvement in the quality of life for persons with fluency disorders. The IFA consist of specialists as well as people who stutter

- www.theifa.org

PWS + SLP = true?

- How can SLPs help PWS?
  - Therapy
  - Understanding stuttering
  - Demand more colleagues
  - Use legislation to help PWS to get the therapy and help they need and are entitled to
  - Assist self-help groups
  - Help children to explain stuttering to pedagogues and pupils
  - Help regain and remain self-esteem

- How can PWS help SLPs?
  - Demand more SLPs for both out volunteer
  - Help SLPs to get the status they deserve
  - Help understanding the PWS, both patients and non-patients

PWS + researchers = true?

- How can researchers help PWS?
  - Research gives the right therapy
  - Understanding stuttering, why we do what we do
  - Use legislation to help PWS to get the therapy, technical aids and help they need and are entitled to
  - Help to understand stuttering to “bury” myths

- How can PWS help researchers?
  - Demand more research on stuttering
  - Give ideas on what to do research about
  - Understanding the reason for a result

Let’s meet again

- Nordic seminar, Denmark, 3-5/9
  - tel: +45 3395 9090, www.nord-fluenz.dk
  - International Stuttering Awareness Day, 22/10
  - www.stuttering.org
  - World Congress for PWS, Argentina, 2011
  - ISA Youth Meeting (planning stage)
    - www.isa.info

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- Why do we still get to hear horrible stories from PWS who get unwanted, mocked because people still don’t understand what stuttering is about?

- Why don’t politicians and other decision makers give more help and attention to a disability that enables people to communicate and taking part of a whole life?

- Why do schools tell us they don’t have any stutterer who matters, why include struggle throughout their school year, without giving any help?

- Why are disability organizations so successful in get their voices heard while PWS don’t want to care?

- Why are there so few speech therapists who specialize in stuttering and why so little money goes to research about stuttering?

- Why are professionals so afraid to work with PWS and why are PWS so afraid to show their voice and stand up for their rights?

- How can we help each other to change that?

- THROUGHOUT RISING OUR Voices TOGETHER!!!

...YOU+ ME = true !!!!
„It’s ok that I stutter, because what I have to say is worth repeating!“

Anita S Blom
anitablom@telia.com

Chair SSF
Chair Stammeringsförbundet
Vice-Chair ELSA
Advisory Board ISA

English: www.elsa.info
Swedish: www.stamning.se

www.stutteringo.org www.anita.se
www.stutteringhomepage.com