

# ‘Shout it to the top!’

## People who stammer find their voices in the Scottish Parliament

The Scottish Parliament Equal Opportunities Committee Disability Inquiry

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## **Contents**

### **About stammering**

#### **The British Stammering Association Scotland**

- *aims and background*
- *achievements 2004 – 2005*

### **The Disability Inquiry: Removing barriers creating opportunities**

### **Relevant research literature**

#### **Summary of themes**

- *being able to work*
- *using further and higher education*
- *having a social life*

### **Challenges encountered**

### **Recommendations**

### **In conclusion**

### **Acknowledgments**

### **References**

## **About stammering**

- It is not known what causes stammering but it is likely that a combination of factors is involved.
- Men are four times more likely to be affected than women and stammering can run in families.
- Stammering generally starts during the early years, when language is developing extremely rapidly. Research has shown the average age of onset to be under three years.
- 5% of pre-school children stammer when learning to talk, around a third of these will not simply 'grow out of it' and a quarter are at risk of developing a chronic stammer that may persist during adult life.
- In many cases, stammering can be completely resolved if it is treated during pre-school years. Hence, early identification and referral to speech and language therapy is recommended.
- While modern therapy can help improve fluency, confidence and communication skills in older children, teens and adults who have a persistent stammer, there is no known 'cure' for stammering.
- Stammering in the school years can affect educational performance and may lead to teasing and bullying.
- Stammering affects a surprising 1% of the adult population. Many people who stammer try to avoid revealing their difficulty and this can have a profound impact on further education, social relationships and career choices.

## **The British Stammering Association Scotland**

### *Aims and background*

The new Scottish Branch of the British Stammering Association, BSA Scotland, was founded in January 2004 as a focus for Scottish campaigns, events and support services as well as to engage with the Scottish Parliament.

Our aims are:

- to promote awareness and understanding of stammering
- to offer support to all who are affected by stammering
- to identify and promote effective therapies
- to initiate and support research into stammering.

Around 60,000 children, young people and adults in Scotland are affected by stammering, yet many have not met anyone else who shares their experience and specialist speech and language therapy services to meet their needs are extremely limited. The sense of isolation, commonly experienced by people who stammer, is compounded by the geography and population spread of our country. BSA (Scotland) seeks to address these issues by holding accessible Open Days for children/adults who stammer and parents from across Scotland; sponsoring training for speech and language therapists and providing information and support via its Scottish Helpline.

Children who stammer often face teasing and bullying in school and educational attainment can be affected at all levels by stammering. BSA (Scotland) was involved in securing funding from the Scottish Executive for a project to produce training CD Roms that demonstrate how best to support school pupils who stammer. These CDs, tailored to the Scottish primary and secondary system, will be launched in January 2006.

Stammering is no laughing matter, yet people who stammer are often the butt of jokes and subject to stereotypical assumptions and discrimination in accessing services and employment.

BSA (Scotland) believes that people who stammer should and need not face such barriers. We seek to promote positive role models of people who stammer, thus challenging public perceptions and the disabling attitudes that many people who stammer have themselves internalised. Recent legislation under the Disability Discrimination Act gives us extra muscle in tackling ignorance and discrimination. We hope BSA Scotland can also play a role in developing and providing training for employers, service providers, public authorities and others.

#### *Achievements 2004 – 2005*

- Forming the new Scottish Steering Committee, comprising people who stammer (PWS), parents, academics and speech and language therapists.
- Hosting BSA's 10th and largest ever national conference at Stirling University, 2004.
- Scottish Executive funded training CD Roms, demonstrating best practice in supporting stammering pupils in Scottish schools (for distribution in early 2006).
- Free training for speech and language therapists in Scotland.
- Winning a billboard and bus shelter campaign and 10,000 promotional leaflets in the SAPPI 'Ideas that matter' international design competition.
- Television, radio and newspaper coverage.
- Aberdeen Open Day, attended by 82 participants (PWS, speech and language therapists, parents, partners and friends).
- Establishing a Scottish branch office, Helpline and website.
- Producing 'blether', our bi-annual Scottish newsletter.
- Engaging with the Scottish Parliament...

### **The Equal Opportunities Committee Disability Inquiry: 'Removing barriers: creating opportunities'**

BSA Scotland is participating in the Inquiry through submitting:

- oral evidence (via our meeting at the Scottish Parliament on 14th June).
- written evidence, based on
  - relevant research literature
  - testimonies received via the web and selected evidence from the 14th June meeting which are summarised as themes and sample quotations.

### **Relevant research literature**

#### *Life experience – qualitative studies*

Crichton-Smith (2002) used qualitative interviews to explore the life narratives of 14 PWS from the UK and reported a common theme of 'limitation'. Participants all shared feelings of being limited in their education and employment and all felt their self-esteem had been affected by their experience of stammering.

Klompas, M. & Ross, E. (2004) interviewed 16 South African PWS, exploring employment, education and social life, amongst other areas, within their recent qualitative study. They found that most participants felt stammering had impacted on their academic performance and relationships during their education. Most felt stammering did not affect their ability to establish friendships in their social life, while still reporting experience of adverse reactions to their stammering. In terms of employment, stammering was seen to have less effect on career choice and success in obtaining work than on relationships with managers/supervisors and promotion prospects. The researchers highlighted the need for increased knowledge and understanding of stammering amongst teachers and employers.

#### *Employment*

Hayhow, Cray and Enderby (2002), in a UK questionnaire which attracted 332 PWS as respondents, found 'stammering had the greatest adverse effect on school life and occupation'. They identified evidence of PWS not choosing the career they wanted, avoiding jobs involving presentations or the phone, being told not to try for promotion and generally experiencing career dissatisfaction.

Klein and Hood (2004) surveyed 232 PWS in the US regarding their experience of employment:

- 71% believed stammering affected their chances of being employed.
- 70% felt stammering affected their chances of promotion.
- 36% felt stammering affected their performance.
- 80% believed employers would judge them less favourably than an equally qualified non-stammering counterpart.

#### *Impact of further/higher education*

Klein and Hood (2004) found that PWS with more education experienced their stammering as less handicapping. The authors suggested education made PWS more aware of their potential – but it was noted that perhaps PWS often don't pursue further education because they feel restricted, both by their speech and people's reactions to it.

#### *Attitudinal barriers and stereotyping*

There is a considerable body of research that has identified disabling attitudes towards PWS, of particular relevance here, amongst:

- teachers (Yeakle and Cooper 1986)
- employers (Hurst and Cooper 1983a) and
- careers guidance professionals (Hurst and Cooper 1983b).

Woods and Williams (1976) proposed that pervasive stereotypes concerning the personality traits and abilities of PWS exert a powerful influence on self-esteem and become internalised from an early age.

In conclusion, these findings would seem to support the themes arising in the evidence given by PWS in Scotland at the meeting in the Scottish Parliament on 14th June.

## **Summary of themes identified by PWS in Scotland in response to the Inquiry questions**

This section draws on a combination of the oral evidence provided at the meeting in the Scottish Parliament on 14th June and responses to the Inquiry questions received via our website. (Web responses were received from 6 people who stammer). The information was summarised in this form for presentation as a poster at the Oxford Dysfluency Conference, 29 June – 2nd July

### *Being able to work*

- Challenge of initial interviews, when stammering is likely to be particularly problematic, hence PWS are disadvantaged in demonstrating their potential for the post.
- Increasing emphasis on ‘good communication skills’ which are often narrowly defined.
- Assumptions are often made about the personality or capabilities of the PWS (eg, that they are nervous or less intelligent).
- Difficulties in delivering presentations, using the phone and participating in meetings.
- Difficulties accessing promotion.

“I am not able to perform at my best at interviews, hence, have for four years been working in a temporary post.” (via website)

“Colleagues make inaccurate assumptions about stammering (eg, that it is just caused by lack of confidence or that someone with a stammer is less intelligent). The majority of managers I have worked with have not realised what a huge issue stammering can be.” (via website)

### *Using further and higher education*

- Challenge of presentations, especially using microphones.
- Lecturers/tutors/peers have implied that the PWS is purely ‘nervous’ ie, does not have a specific communication impairment.
- Request for ‘reasonable adjustments’ such as more time, choice in order of presentations often not taken seriously.
- Difficulty asserting oneself in tutorials and group discussions.
- Even where students identified stammering as a ‘disability’, it did not attract any response or active measures of support.
- When contemplating further/higher education or career choice, guidance offered generally steered PWS away from roles involving communication skills.

“If a PWS asks to give their presentation first, let them go first, or if they request not to use microphone, don't force them – and so on. It is so easy for people to dismiss you, thinking you are just shy or nervous. They do not realise how much stammering can stop you from fulfilling your full potential.” (via website)

### *Having a social life*

It was generally agreed that this was less of an issue, however, people identified:

- difficulties ordering tickets or drinks at the bar
- difficulties communicating at the sport's centre or gym

- a need for customer services training
- concerns regarding the portrayal of people who stammer in films and the media.

“Acceptance of stammering by the public is the key.” (via website)

## **Challenges encountered**

Many PWS are reluctant to view stammering as a ‘disability’. Some of the issues are expressed eloquently here by Allan Tyrer ([www.stammeringlaw.org.uk](http://www.stammeringlaw.org.uk)):

“Even though my stutter had a significant impact on my life, I never used to see myself as having a ‘disability’. I was just a ‘normal’ person who had difficulty getting my words out. When I started thinking about disability more though (when I got interested in disability discrimination law), it occurred to me that people with other disabilities presumably see themselves as basically normal people too, just with a particular impairment. I would think they don't want to be considered ‘different’ either.”

Some PWS initially found it hard to relate to the way the Inquiry questions were framed. Many were not familiar with the social model of disability and equalities issues (eg, identifying barriers to access). In addition, PWS are encouraged, via therapy and self help manuals, to foster an internal locus of control which stresses their potential to change their circumstances, hence, it seemed challenging to focus on the existence of external barriers.

We recognise that this is a complex area and that extensive comment is beyond the scope of this submission.

## **Recommendations**

People who stammer in Scotland call for:

- challenging of societal attitudes through widespread and effective disability awareness training that should always include a component on communication impairment and, specifically, stammering
- campaigns featuring positive images of PWS
- greater recognition of stammering amongst teachers and speech and language therapists (from an early age to adulthood)
- increased and proactive support from lecturers/employers
- negotiation between employers/lecturers and PWS regarding helpful strategies for making the most of the person’s potential
- improvements in specialist speech and language therapy provision
- an active role for BSA Scotland!

“I think it is important to emphasise that all PWS are different and have their own strategies for dealing with stammering which should be respected.” (via website)

## **In conclusion**

BSA Scotland looks forward to continuing to participate in the Inquiry and to the publication of the final report in May 2006. We have establish links with other organisations supporting communication impaired people in Scotland such as AFASIC, Speakability and the Royal College of Speech and Language Therapists and would recommend that our submission is viewed in tandem with the written submission from latter. We are interested in gaining knowledge and understanding from other disability groups. 'Cross disability alliances are not only important for campaigning purposes. At a more basic level, information exchange will help understand the objectives of other disability organisations and foster solidarity' (ELSA, 2003).

## **Acknowledgments**

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