

**Joint Symposium**  
**Sept 2<sup>nd</sup> and 3<sup>rd</sup> 2013-12-03**  
**at**  
**Stammering Support Centre**  
**Leeds**  
**held in association with ECSF**

**A Report**  
**by**  
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### **Executive Summary**

On Sept 2<sup>nd</sup> and 3<sup>rd</sup> 2013 the Stammering Support Centre, in association with ECSF hosted a meeting of researchers, speech and language therapists, and people who stammer for a “joint symposium” to discuss important issues in the field of stammering. The meeting aimed to facilitate a coming together and a dialogue among those with key interests in the study of fluency disorders.

Participants opted to work in one of three groups; risk factors and early intervention, treatment/management, and public awareness. Each working group was given a set of previously agreed questions which covered such topics as key research questions, roadblocks to achieving goals.

The meeting was successful in identifying a number of areas of development and research; such as the identification of a minimum data set when assessing young children, a proposal to measure outcomes for adult therapy using client evaluations and looking at other public awareness campaigns to inform a similar venture for stammering.

If developed further, these proposals could enhance the understanding and treatment of those who stammer. The symposium also enabled people who stammer (PWS)<sup>1</sup>, clinicians, and researchers to increase their understanding of each other and develop useful partnerships in the field of stammering.

## **Background:**

### *Introduction*

Stammering is a severe communication disability which impairs social, emotional and educational development. It frequently becomes a focus for teasing and bullying and can cause social isolation, anxiety and depression. Stammering conceals intellectual ability and affects educational choices and attainment. In chronic cases, it may affect a person's ability to achieve their potential and to make their full contribution to society.

### *The Stammering Support Centre*

Situated in the North of England, in the city of Leeds, the Stammering Support Centre (SSC) opened in April 2011 with support from Yorkshire and Humber Primary Care Trusts, the Action for Stammering Children, the British Stammering Association (2 charitable trusts) and the Department for Education. The Centre offers highly specialist speech and language therapy assessment and therapy for children, young people and adults who stammer. It also acts as a resource for speech and language therapists (SLTs) across the Yorkshire and Humber region, offering a variety of training courses for professionals working with individuals who stammer. In addition the Centre has a small research capability and is currently working on a number of projects including mobile technology for PWS.

The Centre is particularly proud of its client focus and routinely works alongside clients of all ages, families and other organisations such as the British Stammering Association, to create a truly client centred service for those who stammer.



## Summary of the literature

Stammering (or stuttering) is a type of dysfluent speech where the flow and timing of speech is disrupted by repetitions, prolongations and/or “blocks”. There may also be associated behaviours or movements, such as facial grimacing, which develop as a result of tension and attempts to force sounds out (Enderby 1996). There may be significant variability in an individual’s experience of their stammering over time. Stammering can become more complex as a child gets older and continues to stammer (Packman & Kuhn 2009).

### *Incidence:*

Stammering has a relatively low incidence and crosses all socio-economic, cultural and ethnic groups. However, in childhood 20% of children experience a period of non fluency. Of these 5% will have a stammer that lasts in excess of 6 months. In 1% of children this will persist into adulthood (Mansson 2006). Recent studies suggest this may be higher.

### *Causation:*

Although the cause of stammering is not known, a number of factors have been identified as significant in its development in children; genetics (Buck et al 2002; Costa & Kroll 2000), associated language and linguistic difficulties (Anderson et al 2006; Howell et al 1995), neurological abnormalities (Watkins et al 2005, 2008; Alm 2004), gender (Craig et al 2002; Yairi & Ambrose 2005) and environmental factors (Starkweather 1990). Stammering can be acquired later in adults where the causation factors are: neurophysiological, physiological, pharmacological, psychogenic, reoccurrence of developmental stammer or idiopathic.

### *Covert features*

An individual can have a stammer that is obvious to others and/or may use a range of strategies to conceal it from other people. A person who stammers may therefore have both open stammering and more covert hidden aspects. In addition, communication situations perceived by the individual to exacerbate the stammer are frequently avoided because of anxiety and fear of negative evaluation by listeners.

### *Impact of Stammering*

Stammering frequently has an emotional and psychological impact caused by a breakdown in communication (RCSLT 2009) and it can mask several features of a person such as personality and intellectual ability. Research has shown that stammering is often a focus for teasing and bullying in young children (Langevin et al 2009; Crichton-Smith 2002; Davis et al 2002; Hugh-Jones & Smith 1999) and ridicule in adults which in turn can lead to social anxiety (Craig & Tran 2006). Around 50% of adults who stammer meet the criteria for social phobia.

In children, stammering can impair social, emotional and educational development and risk the attainment of the Every Child Matters (ECM) goals. It may cause the child or young person to become withdrawn, anxious and suffer lack of confidence.

In adults, stammering can compromise self esteem, relationships, and career choices/pathways (Enderby & Emerson 1995; Hayhow 1999). It can result in discrimination, education/employment difficulties and a compromised life style (Crichton-Smith 2002; Kathard 2004; Klompas & Ross 2004; Yaruss & Quesal 2006). As a consequence adults who stammer may not achieve their full occupational potential.

### *Public perception*

Although there have been improvements in the understanding of stammering, there is still a considerable degree of misinformation among the lay public about the nature of stammering. Yaruss et al (2002) reported that a number of surveys reveal that many people believe stammering to be a learned behaviour, the result of nervousness or anxiety, or possibly the result of unidentified brain damage. While these hypotheses are not supported by current research, these and other myths persist in society. It is likely that inaccurate and stereotypical opinions about stammering contribute to negative societal attitudes toward stammering and individuals who are dysfluent. There is a correlation between the stammering severity and lack of positive regard in others. In addition, there are a number of erroneous beliefs about appropriate treatments for stammering, with a large percentage of the population believing that it may be advisable not to mention stammering in young children and leave it for maturity to resolve.

### *Employment*

Stammering is a significant vocational handicap. Negative attitudes towards those who stammer have many consequences including limiting occupational, educational and social opportunities. Some employers hold negative attitudes towards adults who stammer and this impacts on successful recruitment or promotion for those individuals.

*“The ability to communicate is an essential life skill for everyone, however there is an insufficient understanding of speech, language and communication impairments nationally and locally. The risks associated with speech and language communication impairments are multiple – low educational attainment, challenges to mental health, poorer employment prospects and in some cases, a descent into criminality.”*

*(DCSF 2008)*

### *The management of stammering*

Children: SLT services for children can include indirect work on environmental factors and family interaction, speech and language development, and direct work such as teaching fluency strategies.

The evidence shows that early intervention is beneficial and cost effective (Manning 2001; Hunter 2007). It has been shown to prevent the development of persistent stammering and ensure the child does not develop maladaptive ways of coping with stammering leading to poor educational attainment and social isolation (Stewart & Turnbull, 1995). Many early intervention

programmes show favourable results with young children (Millard et al 2009; Jones et al 2008).

For some children stammering becomes more severe the longer they have been stammering and intervention with children with severe stammering can be lengthy (Kingston et al 2009; Jones et al 2000). Early intervention is crucial for the identification of children who will not recover without help and are at risk of persistent stammering (Bloodstein 1987).

It is recommended that in all management programmes designed for children SLTs should work closely with education staff to develop appropriate and relevant approaches to support the child in the school environment and in their social life (Stewart & Turnbull 2008).

It is likely that some children with more complex needs and whose stammer may be in addition to other disorders are not being identified at key stages in their development and may not be accessing stammering services appropriately.

Older children & adolescents: SLT services for older children and adolescents usually involve mixed approaches including the promotion of positive psychological change and teaching behavioural management of speech (Crichton-Smith 2002; McNeill et al 2003). Intervention for older children with persistent stammering can significantly improve an individual's mental health, social well being, academic progress, career pathway and therefore their contribution to society in adulthood. These outcomes mirror the UK Government's agenda set out in *Every Child Matters*<sup>1</sup>, the recommendations in the *Bercow Report*<sup>2</sup> and *Better Communication*<sup>3</sup>.

Adults: Management of stammering in adults can be complex and lengthy and may include aspects of psychological change and reconstruction, for example, personal construct therapy, solution focused therapy, cognitive behavioural therapy. However, SLT interventions, including group therapy, have been found to be effective and have good longer terms outcomes relating to the social benefits of improved mental health and better career/employment prospects. Surveys show that SLT benefits the majority of clients (NSA survey, RCSLT 2009), especially where the intervention focuses on attitudes towards speaking rather than solely on the mechanics of speech. Evidence indicates that treatment for adults is significantly different when provided by specialist SLTs rather than generalist therapists (Davidson Thompson 2008). Specialists working with adults who stammer require good quality and regularly updated training in order to respond to client's values and circumstances.

Group therapy has a strong evidence base. According to Fawcus (1995): "*the group situation is a powerful force for change*". Manning (2001) also indicates that:

*"the experience provided by group interaction is a valuable part of a comprehensive treatment programme"*.

He goes on to explain:

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<sup>1</sup> Every Child Matters, HM Government (2003)

<sup>2</sup> The Bercow Report: DCSF-000632-2008

<sup>3</sup> Better Communication: an action plan DCSF-01062-2008

*“if the goal of treatment is to help the speaker change both the fluency in his speech as well as understanding of himself and his interaction with others, group treatment is essential”.*

In conclusion, it is clear that there are a number of significant challenges in the field of stammering. These issues range from confusion over the place of early intervention, the validity of many current treatment techniques for stammering, especially with regard to young people and adults and the on going lack of understanding and awareness in the general public about stammering.

## **The Joint Symposium**

Each year there are opportunities for researchers and clinicians working in the area of fluency disorders to meet at various regional, national, and international conferences. At these events individuals formally present current research and informally discuss and debate important issues. Similarly, though much less frequently, PWS also gather to discuss stammering and related issues at meetings and at the conference organised by the British Stammering Association. In addition there are ongoing discussions on social media sites to which all may engage.

While there is some overlap in the attendance at these meetings and discussions, there is no one forum at which all 3 interested parties are encouraged to attend.

In an attempt to address these concerns, in 2002 the NSA hosted a new type of research conference that was specifically designed to facilitate collaboration between and among individuals interested in fluency disorders. The specific goals for this conference were (a) to identify research needs in various areas of the study of stammering, (b) to develop approaches for addressing those needs, (c) to facilitate collaboration between researchers and consumers, and (d) to facilitate collaboration among researchers.

This event was significant in terms of generating collaboration and specific research projects but has not been repeated for over 10 years. A second joint symposium would seem long over due to address the current challenges in the field.

### *Symposium Attendance*

The symposium was designed to include scientists conducting research on stammering, clinicians with a significant interest and experience in working with PWS, and PWS who had previously expressed an interest in participating in a dialogue about key areas of stammering. In total, approximately 30 people attended this symposium with a relatively even split across the 3 groups. A complete list of participants is included in Appendix A.

### *Symposium Structure and Agenda*

Based on the experience of the NSF symposium, it was decided to use a similar open format. Thus, 3 groups were established in which participants could discuss topic areas. Also, unlike other conferences, participants were able to move between groups as they wished. This enabled individuals to maximise the opportunity to meet with like minded people, and promote and develop their interests, be it in research, management of stammering or awareness raising.

The meeting also included plenary sessions following each discussion session so participants could receive updates about other working groups and comment on them. This updating also facilitated cross fertilisation of the

discussion groups and enabled items of interest to be discussed further in alternative groups.

The complete agenda for the symposium is included in Appendix B.

## **Initial Working Group Discussion Topics**

### *Topic areas*

Prior to the symposium, Dr T Stewart from the Stammering Support Centre met with Dr Kurt Eggers from the ECSF to agree the topic areas. The following three areas were decided upon:

- Early intervention and risk factors. Designed to explore research on risk factors that may contribute to the development of stammering and the influence of these risk factors on treatment recommendations for preschool children who stammer. Suggested topics included: genetic and environmental factors influencing the development of stammering and ways of assessing the value of early intervention.
- Treatment. Designed to explore different approaches to stammering therapy. Suggested topics included: ideal outcomes of treatment, strategies for measuring outcomes and future needs in therapy.
- Public awareness of stammering. Designed to explore public attitudes toward stammering, including the attitudes of clinicians and others who have an impact on people who stammer. Suggested topics included: methods for measuring and assessing attitudes, strategies for increasing public awareness, and ways of changing attitudes within key populations.

### *Discussion questions*

In order to focus the discussion groups on key issues currently facing researchers, clinicians and users, an initial group of discussion questions based on the previous symposium were circulated to participants. They were asked to comment on the appropriateness and relevance of the questions and to add any additional questions and comments as required. Several responses were received and the initial questions were modified in responses to these comments. Some additional questions and issues were also given to specific discussion groups for inclusion in their deliberations. The following are the questions agreed by the participants:

#### Session 1

- What are the key research questions in this area?
- What is currently being done to address these questions?
- What are the needs for additional research to address these questions?

#### Session 2

- How can the identified current and future needs for research in this area be met?
- What are the roadblocks to meeting these needs?
- What collaborative and other strategies can be developed to overcome these roadblocks?

### *Session 3*

- What action plans based on new and existing collaboration can be developed to generate needed research in this area?
- How can we work to apply research findings to key areas?
- What roles can consumer organisations play in these efforts?

### *Additional group specific questions:*

Early intervention and risk factors. This group were asked to address the following additional questions:

- What fundamental research questions need answering?
- Do we need more research into self management?
- What is brain research and chemical imbalance telling us?
- Who experiences the “problem” of stammering in childhood?

Treatment group. This group were asked to address the following additional questions:

- What fundamental research questions need answering
- What research would address stakeholder needs?
- How can we best address the need for outcome measures?

Public awareness group were asked to address the following additional questions:

- Do we need more research into self management?
- What is the relationship between promotion, education public awareness and better understanding and better outcomes for people who stammer?
- What role should consumer groups play?
- Who experiences the “problem” of stammering?

### *Group leader and “scribe” roles*

Once these topic areas had been agreed, group leaders and “scribes/secretaries” were recruited to facilitate the working group discussions. Group leaders were recruited from each participant area i.e. researcher, clinician and from a user group. Leaders were briefed to allow the free flow of discussion, to facilitate the engagement of all group members, encouraged to facilitate the inclusion of many different areas and points of view throughout the group discussions and not to bring “prepared” materials to direct the discussion. They were asked to make brief notes at the end of the each session.

Scribes were recruited from a pool of clinicians available from the SSC and from specialist clinicians working in the Yorkshire and Humber geographical area. The “scribes” were asked to make detailed notes during the discussion

sessions; including a record of who was present at each session. Digital recorders were used by the scribes to improve the accuracy of their recordings.

#### *Verification of the records of each symposium session*

At the end of each session the scribes met with the group leaders to verify the summary which was to be fed back during the plenary. In many cases the group leaders used the scribes' notes to ensure the accuracy of the feedback.

A final record of each group session was produced by the scribes within 3 weeks of the symposium and was verified by the group leader and one other participant. This final summary provided the basis of the summary in this document.

### **Working Group Outcomes**

Because working groups were encouraged to “follow their own lead” in discussions about current research issues, a wide variety of topics were addressed. As a result, it is difficult to provide a concise summary of the outcomes of the symposium. Nevertheless, the following are brief overviews of the outcomes of each working group's discussions.

#### **Risk Factors, Early Intervention**

*What are the key research questions in this area?* The group began by considering the role of risk in relation to early stammering and specifically the risk that a neural deficit is more long term than transitory. If a child has a short-term risk s/he can fail to recover because of environment factors. The group posed a number of questions in relation to this:

- At what point does the behaviour become hard-wired?
- By reducing the length of time they are stammering, are we protecting them from a learned behaviour?
- Can environmental change be harmful?
- Can intervention be counter productive; i.e. SLTs are intervening when it is noted that the child is responding to stammering when in fact it would be preferable not to intervene at this point.

The group noted there was good evidence about brain function in children who stammer. Three possible groups were put forward:

1. Neural deficit may be short-lived.
2. Stammering resolves but it takes time.
3. Vulnerability persists. In this case a child may recover but then may regress at times of stress. At this time, the child cannot respond to therapy except as tool to support.

In these scenarios the group thought that therapy can be effective but would not eliminate the possibility of stammering ever happening again. Being able to facilitate periods of stammer-free speaking during childhood must be better than stammering all the time. Children often respond well to further therapy when it takes account of their development and targets whatever is particularly relevant at the time that stammering reappears

The group went on to agree the need for long-term studies, while acknowledging the difficulties associated with research studies i.e. expensive, time-consuming, ethics. The discussion then focused on what are the key elements of data that would be required to answer the questions. In relation to the question “*which risk factors or protective factors are linked to spontaneous recovery or chronicity?*” The following were agreed:

- internal (resilience, temperament, language and motor skills)
- external (environment, communicative and family / other children reactions)

A number of other key research questions were identified by the group:

1. *What factors would lead us to choose a particular treatment?*
2. *What treatment is appropriate for which children?*
3. *How do we tailor treatment to the individual child?*
4. *Can early intervention be harmful?*
5. *How to map patterns of stammering over time (through parents, clinicians)?*
6. *What is happening during recovery (what is actually changing in the brain, behaviourally, temperamentally etc.)?*
7. *How do we link the different kinds of studies, e.g. brain imaging vs. behaviour - synthesis of results?*

It was felt that Q1 was the priority question and that Q2 & Q3 and some of the other questions were linked to this, with Q7 also a main issue.

They then identified a number of studies in the literature which went some way to address some but not all of these questions (i.e. Månsson H. 2000; Zebrowski , Reilly S, Onslow M, Packman A, et al.. 2009; Sheena Reilly, Mark Onslow, Ann Packman, Eileen Cini, Laura Conway, Obioha C. Ukoumunne, Edith L. Bavin, Margot Prior, Patricia Eadie, Susan Block and Melissa Wake 2013)

The group then moved on to consider what were the needs for additional

research to address these questions. They identified the need for

- Increased joint working, with universities and clinicians collaborating in a research platform to draw research and clinical practice together
- Mechanisms to enable research i.e. funding, support, ethics etc
- Clinicians to be routinely collecting data in individual treatment sessions.

Group agreed that a more uniform, coherent and systematic form of data collection was needed with clinicians supporting parents to play a crucial role. It was then agreed to structure the group's discussion along the lines of:

**What** – data will be collected?

**Who** – will collect the data?

**How** – that data will be collected / managed? (e.g. where it would be held, ethics involved, problems / barriers to be managed)

This would form an action plan for the group.

### **1. What?**

The group identified the need for a minimum data that everyone would already, incidentally gather; information that does not interfere with individual SLTs 'own agenda' and based on assessments / information gathering already carried out.

The minimal data set to be collected from all early years (up to 8 years) children referred, worldwide and to start with the intakes of new children.

The purpose for data collection would be:

- To comparison of clinical data to research data.
- To compare (over time) sudden onset with gradual onset
- To accumulate better documentation of risk factors
- For the purpose of gathering a pool of clinical data for research (not as yet specified)
- For longitudinal studies i.e. to gather information on persistence and recovery. Over time, with follow ups, more information will be gathered on persistent stammering

Data to include a speech sample, gathered at the moment a client entered clinic. The possibility of samples being taken via telephone was also discussed.

Major roadblock to research was thought to be the storage of speech samples. Different countries have different data control policies. (Sharing of data is tightly controlled in England and particularly within NHS). The group recognised the need to investigate national agreed criteria for recording and storage.

### The Data

The group agreed to use data at initial interview/appointment and also data collected at follow up sessions up to 8 years of age. This minimal data set would result in breadth of data rather than richness of data. It was decided that speech samples may / may not be included.

The minimal data set to include:

- Speech sample (see previous discussion)

The following information from the interview with parents:

- Time since onset
- Type of onset (sudden/gradual)
- Male/female
- Family history of stammering and where in the family (relationship to child)
- A question to elicit description/comment about the child's personality or disposition re temperament

In terms of the stammering components the following would be required:

- Co-morbid conditions
- Episodic nature?
- Developmental milestones
- Speech development, in particular, 'Was talking clear at the time stammering started?'
- Speech intelligibility

Environmental aspects:

- Child's reaction to stammer
- Parent's reaction to stammer
- How does the child respond to the parent's response to the stammer?
- Any awareness? How was this displayed?
- Parents rating scales

## **2. Who?**

The group reiterated their desire not to overburden local clinics. They thought that it might be easier to gather from specialist centres initially but recognised that data exclusively from specialist centres did not provide breadth of data and may be biased towards features of complex/persistent stammering.

With regard to the follow up data; this was to be collected by whoever had the duty of care at the time. 6 month periodical reviews were recommended with the reviews to be continuous until the child was 8yrs regardless of whether they were still on an active caseload.

At follow up the basic data would be omitted (gender / family history etc) and then a series of simple questions would be asked:

- Is your child still stammering?
- Nature of stammer?
- When did you last hear your child stammering?
- Has there been any treatment?
- A question to establish the level of concern

The group went on to consider how the data might be used. They agreed that it could be used to apply research findings to key areas e.g. temperament, risk factors.

Finally the group considered how consumer associations could be involved. It was thought that there needed to be some awareness of action being taken to

gather data and asking consumers to act as supporters of the project to enable sharing of data.

### Action

- To promote the collection of this data set through local and national group meetings for clinicians, and through publications
- Specific work on the policy and consent issues for using the data to be investigated by group members.

### Treatment

Initially the group opened their discussion with queries regarding the title of the group 'Treatment'. Alternative terms were suggested and it was agreed that the concept to be discussed needed to incorporate; therapy, interaction, intervention, education and learning, wider society, the immediate environment of the client and the person themselves, including self management as well as being managed by others. As a result the group decided to address issues of MANAGEMENT rather than treatment. They then went on to discuss the need to define what is being managed (i.e. in order to design treatment and match it to the clients, it is important to establish what a stammer is and what it is to each individual and/or each family of a child who stammers). Comments were made about seeing stammering in a context; the identification of stammering does not necessarily mean that it is or has to be a problem for the person, or that it has to be managed in a problem solving way.

The discussion then moved to consider outcomes. The group addressed the need to make qualitative and quantitative research about treatment outcomes relevant and accessible to:

- clinicians
- clients
- commissioners

The group identified the need to quantify quality through nesting or embedding qualitative data in a numerical format and discussed the importance of having longitudinal studies as a means of being objective and having a method of capturing what doesn't work or go well, in order to present an accurate success rate.

The group considered the value of using client stories, in bringing behaviour and attitude outcomes together in a format which will meet investors' needs.

It was agreed that the following factors were missing:

- A proper specific measure of quality of life
- A way of measuring therapy outcomes
- Money and time to invest in research

The group agreed the need to work towards:

1. Defined criteria for effectiveness
2. Defined criteria for quality of life
3. Panel of researchers to lead on quantifying quality
4. Multidisciplinary team working i.e. collaboration between clients and researchers and clients which could be virtual.

5. Providing information about what therapy is about. The group agreed the need to show what was on offer through:
  - Written information
  - Marketing and branding therapy
  - Podcasts with clients talking about therapy
6. Comparing the process of using outcome measures to identify the best outcome measures.
7. Clinicians all using the same robust outcome measures so that best practice could be shared. This should be by specialist centres to create a domino effect.

The group agreed that outcomes should not be defined by therapist or researcher but by the person who experiences the therapy. This would enable a better understanding of the client's experience of therapy, allow the evaluation of management in a systematic way, all of which will enable us to educate and inform commissioners about what people who stammer want out of the service. This will be a national project which would be new and innovative.

**Action:**

A pilot study on client experience of therapy

- To inform research
- Focus on experience (thoughts, feelings and behaviours)
- Working nationally and collaboratively
- How to quantify quality

Survey monkey to be sent to all individuals (children, young people and their parents and adults who stammer) who have completed therapy in the last 6months.

4 Solution Focus Brief Therapy (SFBT) based questions to be used and participants to answer using scales to quantify experience of therapy and space to elaborate experience.

Q1. What was your experience of therapy?

1 \_\_\_\_\_ 7

As +ve as it could be

Not at all +ve

Q2. What aspects of therapy enabled it to be a +ve experience?

Q3. What aspects of therapy meant that it was not a +ve experience?

Q4. What else would have improved the experience?

Please feel free to add any other comments about your experience.....

**Starting points:**

- Sharon Millard to look into ethics around the project.

- National/local SIG presentation
- To identify project roles within the members of the action group

## **PUBLIC AWARENESS**

### *The Key Research Questions In This Area*

This group discussed the purpose and benefits of raising awareness in: PWS, general public who don't stammer and commissioners who pay for SLT services. They also discussed how to change awareness and identified the key research questions in relation to these points. In addition they explored work currently being done to address these questions and identified the areas in which additional research was needed.

The need for public awareness was identified as follows:

1. For people who stammer - to counteract self-limiting beliefs and to raise awareness of the benefits of therapy.
2. For the general public - to allow the addressing of misconceptions, overt prejudice, negative attitude, and discrimination including sub conscious biases in order to remove the barriers imposed on PWS.
3. For commissioners - to ensure funding of therapy services for PWS, and mitigate against cuts to services. To raise awareness that therapy is not based on medical model of cure but on reducing negative impact so they don't assume the outcome is poor if fluency isn't achieved. There's a need to collate more evidence for Speech and Language Therapy.

### *How to change awareness*

The group assumed research regarding attitude change in other areas already exists and that knowledge could be learned from approaches in other fields. Stammering needs to consider what techniques have been successful elsewhere.

Public opinion changes as a result of people having information. There is a need for people to talk about stammering and to stammer more openly.

People who stammer need to be more visible for attitudes to change.

The group discussed the difference between clinical based evidence and evidence base practice and the need for commissioners to have evidence from PWS. Therefore with regard to public awareness related to service delivery the group thought it was important for people who stammer to get involved. In that regard it would be useful to have stories from people who used to hide stammering and now accept it more openly.

### *What Is Currently Being Done To Address These Questions*

Most research that has been done has focussed on people's attitudes to stammering and their misconceptions, and shown there to be prejudices. This includes culturally different attitudes. Ken St. Louis developed the Public Opinion Survey of Human Attributes (POSHA) to assess public attitude. In addition the group referred to evidence regarding the stress response in listening to stammering which may underlie negative reactions.

However, it was acknowledged that there is little research on the effects of raising awareness. There is some research locally being carried out in awareness raising for example in reception staff. It was thought that reception staff wanted to know the best way to help and that raising awareness leads to increased comfort for other people and specifically a more positive interaction with the reception staff for PWS.

There was a discussion regarding components of training which allow for attitude change. It was thought that it was useful to allow people to express their discomfort in listening to PWS and that they benefitted from having the opportunity to interact with people who stammer.

Use of the word fluency was discussed and a dislike of dichotomy between the words stammering and fluency was expressed. There was thought to be a need to get the message across that there is no total fluency. Important for people who stammer to understand that benefits of therapy include increase in confidence and communication ability and that use of word fluency may mislead them into expecting a cure.

### **What Is The Need For Additional Research**

The group identified a number of needs:

- A foundation of underlying research to address the following:
- A unified all encompassing definition that captures the complexity of the condition. The group considered the use of the 'stammering syndrome' in this context but felt that PWS may not like to hear that they had a 'syndrome' which also pathologises and medicalises stammering. However, the group agreed there was a need for stammering to be seen as a complex condition.
- To consider how attitudes affect people who stammer
- To address the issue of how therapy can make a difference; such as improving social communication, confidence, self-esteem, and reducing negative impact. There is a need to demonstrate what works in therapy and the cost benefit of early intervention and quality of life for adults.

The group considered the relationship between research and action in this field and wondered if public awareness should be research led? It was agreed that research can inform regarding the effectiveness of awareness campaigns and the mechanisms by which these are made effective. Some specific examples of research pertinent to this were outlined by group members.

The concept of openness was explored with reference to literature from the disability movement about internalised oppression. The group noted the representation of dysfluency in the media and commented on the management of normal non fluency which is frequently subjected to editing. The group talked more generally about openness in the context of social change for example gay and lesbian movements. There was some discussion about generational differences in willingness to be open and that this might reflect social change (with younger generations more willing to stammer openly). However, members noted that because many PWS are reluctant to be open and/ or speak about stammering more widely than the

responsibility falls to just a few people. Thus, the group felt there was a need for good stammering role models i.e. “happy stammerers” and portraying stammering as not as painful as it sometimes depicted.

The group then moved on to consider what aspects of awareness they felt were desirable to raise. Members of the group commented on the fact that the UK was well informed about stammering but there are certain subgroups that are not well educated e.g. specific ethnic groups. The group agreed that there was a need to include PWS from all groups in awareness raising. Other members talked about the need for awareness to address the level of isolation and in supporting people who feel isolated as a result of stammering.

In summary the group considered a number of action plans:

- learning from existing research about awareness including the work of other charities
- the possibility of survey carried out through social media sites regarding effective awareness campaigns.
- looking at other countries work in this area i.e. Ken St Louis
- carrying out a Delphi study with adults who stammer and learning particularly from ‘happy stammerers’ about what works and how this can inform therapy. Producing a summary document on evidence for interventions illustrated with case studies.

### **Summary and future directions**

This symposium provided an excellent forum for researchers, clinicians and users to meet, discuss and exchange ideas. The groups engaged in wide ranging discussions around the key questions which were posed. Individuals were able to interact both formally in the groups and informally with other like minded participants.

New projects and collaborations were discussed and participants looked to develop their ideas in partnership with others.

The meeting demonstrated clearly the importance and commitment of researchers and clinicians in collaborating with users and user groups in future research into the area of stammering.

There is a need for more regular meeting such as the symposium to further develop the collaboration between researchers, clinicians and users. Perhaps future meetings may also include participation from other scientific and clinical areas, such as psychology.

The symposium was successful in initiating ideas. However, the true evaluation of the meetings success will be in moving the ideas forward and all of us look forward to that process.

## Appendix 1

### Group membership

#### **Risk factors**

Chair: Kurt Eggers

Scribes: Stephanie Burgess, Claire Bull and Susan Clark

Jacqueline Carmona, Rosemarie Hayhow, Elaine Kelman, Veerle Waelkens, Jo Kitchen, Sarah James, Trudy Stewart

#### **Treatment/management**

Chair: Alison McLaughlin

Scribes: Susan Clark, Theresa Howarth and Stephanie Burgess

Isabel O'Leary, Ruth Edwards, Claire Bull, Margaret Leahy, Katy Bailey, Sharon Millard, Paul Brockelhurst, Jonathon Linklater, Michael Turner, Penny Palin, Kate Williams, St John Harris, Trudy Stewart

#### **Public awareness**

Chair: Norbert Lickfeldt

Scribes: Theresa Howarth and Jo Kitchen

Bob Adams, Michael Turner, Penny Palin, St John Harris, Jonathon Linklater, Sharon Millard, Trudy Stewart, Paul Brocklehurst, Katy Bailey.