Longitudinal Study on Early Childhood Stuttering

Thank you to all the families who have been involved in this important research. Since 2009 over 80 families have taken part in the longitudinal study on early childhood stuttering – the first of its kind in the UK! We hope that you will enjoy reading our preliminary findings.

Background to the Study

The study is being funded by a local charity The Dominic Barker Trust. Known as Dom’s Fund the charity was set up in 1997 in memory of a witty, intelligent and much loved young man for whom the burden of stammering was so great that he took his own life.

The aims of the charity are to:
- Fund research into stammering
- Raise awareness of the issues that surround stammering
- Encourage understanding in people who meet those who are stammering
- Devise better programmes to help overcome this disability

In the past The Dominic Barker Trust has funded several research projects at Suffolk College and the UEA. This is the first study to be funded at UCS.

Meet the Research Team

Dr Penny Cavenagh, Principal Investigator
Penny is Director of Research and Enterprise at UCS. She has a PhD in medical management, an MSc in Occupational Psychology and a post-graduate diploma in Speech and Language Pathology. Prior to her career at Suffolk College and UCS, Penny worked as a Speech and Language Therapist specialising in adults with stuttering and managed the SLT service in Suffolk.

Dr Steve Davis, Research Associate
Steve has been carrying out research at UCL since 1999 on many aspects of stammering including factors linked to persistence at age 12, and research on bullying and friendships in children who stammer. Steve is taking an active role in collating and analysing the results of the project. Steve was awarded an OBE in 2009 for his services to children with communication disorders.

Sarah Costelloe, Research Associate
Sarah graduated from the University of Reading in 1997 and has been working as a Speech and Language Therapist in Norfolk and Suffolk since then, specialising in treating children who stammer. Sarah has been working on the project since 2008. Sarah visits all the families to collect the data and offer support. She also analyses the information with Steve.
Some Basic Facts about Stammering

• Stammering and stuttering mean the same thing.
• People who stammer have difficulty moving from one sound to the next in a word, or have difficulty getting a sound started after it has stopped.
• Stammering has been defined as “when the forward flow of speech is interrupted by an unwanted disrupted sound, syllable, or word, or by the speaker’s reactions thereto”.
• Stammering is NOT a problem with producing speech sounds, putting thoughts into words, or retrieving words.
• It has been known in every culture and language.
• It affects about 1 in 20 people at some time in their life.
• It usually starts in childhood between the ages of 2 and 5 years.
• More boys stammer than girls (the ratio is about 4:1).
• Stammering runs in families.
• Left handed people are more likely to stutter.
• About 80% of children who stammer will recover.

Myths About Stammering

People do not stammer because they are nervous or anxious. Research has shown that there are no differences in generalised anxiety levels between people who do and do not stammer, however as children get older they can become anxious about speaking in certain situations in case they stammer.

There is also no evidence to suggest that you can “catch” stammering by imitating or hearing another person stammer or that stammering is caused by parents drawing attention to a child’s normal dysfluencies.

There have been lot of whacky “cures” in the past such as improving posture, talking in front of the mirror, talking with various items in the mouth (e.g. stones and cicadas) or cutting the tongue! None of these have been proven to work.

Causes of Stammering

• There is still a lot we don’t really know!
• We do know that stuttering can be inherited so genetics certainly plays a part.
• From recent research on brain scans different patterns of brain activity are shown in people who stammer.
• A high number of children who stammer also have other disorders such as ADHD and learning difficulties.
• It is generally accepted that stammering is caused by the interaction of several factors (genetics, speech and language development, physical development and environment). This multifactorial model often directs treatment.
Famous People Who Stammer

Current Therapies for Children Who Stutter

There are a number of effective treatments for children who stammer. Not all therapies are suitable for all children. It depends on many factors including the child’s age, the presence of other developmental disorders, personality and family and educational environment. Treatments include Lidcombe therapy, Parent-Child Interaction Therapy, breathing techniques, speech modifying techniques and feedback devices. A specialist Speech and Language Therapist can advise on the most suitable treatments for your child at the time.

General Guidelines For All Children Who Stutter

- Be patient and give the child plenty of time to talk.
- Maintain eye contact.
- Show that you are interested in what he/she is saying and not just on how he/she says it.
- Slow down your own speech rate and pause more between turns. This is more helpful than telling the child to slow down.
- Don’t be afraid to talk about stammering.
- Encourage all members of the family to take turns talking and listening.
- Try to have a special time each day (just 5 minutes) when you play together on a one to one. Let your child take the lead and spend time just listening. Keep it relaxed and try to give specific praise for the things he/she does well, e.g. “you’re so good at puzzles” or “that was a kind thing to do”.

Useful Websites

www.dominicbarkertrust.org.uk

www.stammering.org
(This is the British Stammering Association’s website)

www.stammeringcentre.org
(This is the website of the Michael Palin Centre, a specialist centre which provides lots of useful information)

www.stutteringhelp.org
Longitudinal Study On Early Childhood Stammering

The original proposal for the research study was put forward in 2008. Ethics approval had to be sought from the NHS and this process took about 9 months. In 2009 the data collection process began. Families were sought through a variety of sources including nurseries, schools, Health Visitors and Speech and Language Therapists. This was important to try and catch children who had recently started stammering (preferably before receiving therapy).

Aims

To recruit 2 groups of children: children who stammer and children who do not stammer.

To collect data on age, gender, health, handedness, general development, speech and language development, family history of stammering, intelligence and temperament. To compare these 2 groups of children on all the above factors.

To follow up the group of children who stammer to see if they stop stammering or continue to stammer and to compare these two groups of children (PERSISTENT and RECOVERED groups).

In the long term the aim is to build a model that will predict a child's likelihood of developing and recovering from stammering. This will help Speech and Language Therapists to identify those children most at risk from persistent stammering and they can then allocate therapy resources more effectively.

Data Collection

For each child we have collected information on:

- Details of people who stutter within the family
- Birth and early development
- Health (gained in the generalised health questionnaire)
- Verbal and non-verbal IQ (from the performance on the Weschler Pre-school Primary Scale of Intelligence)
- Changes over the course of the study in the child's environment (e.g. moving house or starting school) and development (such as other difficulties emerging)
- Handedness (whether right, left or no hand preference)
- Temperament (from the Behavioural Style Questionnaire)
- Speech (By listening to speech samples measure the severity of stammering and start to make comparisons in areas such as clarity of speech and vocabulary)

And for the children who stammer we also have information on:

- The child's stammer, including the nature of onset (e.g. whether sudden or gradual), how it has progressed or resolved, symptoms noted, severity scores and details of any therapy received.
Results

Although the study is continuing and we still have much more to analyse we have some initial findings. These results are based on 41 children who stammer and 37 children who do not stammer.

1. Stammering is just as likely to start suddenly as gradually.

2. Boys are almost twice as likely to start stammering as girls.

3. Our study indicates that nearly two-thirds of children who stammer will have another family who stammers (or who used to stammer) compared to around 16% of children who do not stammer.

In other words, a child who stammers is more than four times as likely to have another family who stammers (or who used to stammer) than a child who does not stammer.
4. The children who stammer in our study started stammering between two and five years of age with most children starting between 2 years and 3 years 6 months. Boys start stammering 4 months later than girls.

5. Children who stammer score lower than children who do not stammer on the intelligence test – this may be due to children who stammer being at a disadvantage in the verbal component of intelligence testing.

6. Parents of children who stammer are more concerned about their child’s health, behaviour and attention/learning levels than parents of children who do not stammer. They also report that their child’s health and behaviour impact more on the cohesion of the family unit.

7. Parents of children who stammer rate their children as more withdrawn, more resistant to change and less regular in their daily routine when compared to children who do not stammer.

8. More than twice as many children who stammer are left-handed when compared to the amount of left-handed children in the general population.
Dissemination of Results

Our initial findings were presented by Penny, Steve and Sarah at the 9th Oxford Dysfluency Conference from the 1st - 4th September 2011.

The plan is to submit several articles to peer reviewed journals. An article is currently being considered for the Journal of Fluency Disorders.

Sarah and Penny presented the initial data and preliminary results on persistance and recovery at the 7th World Congress on Fluency Association Conference in Tours, France from 2nd - 5th July 2012.

The Future

As more children come to the end of their two years in the study, we can analyse more data on persistence and recovery. In other words, we can start to look for patterns which might explain why some children completely stop stuttering and others continue.

However, there is a strong possibility that some children who are still stuttering after two years may stop in the future, and also a smaller possibility that some children who have had a ‘recovery’ may ‘relapse’ in the future.

For this reason we would like to follow the children for a longer time. The funding for continuing the study is currently being negotiated and we hope to be in touch with families over the summer to ask for their continued involvement.

The initial data has also generated further research ideas. It is hoped that we can look at other areas including:

- Attention control in children who stammer versus children who do not stammer. Do those who stammer find it hard to focus attention and what impact does this have on recovery and success in therapy?

- The development of peer relationships in children who stammer when they enter school.

- Parental attitudes to speech therapy for their young children who stammer.

Once again we would very much like to thank you all for your help and support in making this research possible.