



WHAT IS DOM'S FUND?

Dom's Fund

The Dominic Barker Trust, a charity called Dom's Fund, was set up in memory of Dominic Barker (pictured left) for whom the burden of stammering was so great that he took his own life.

Most of us take for granted the ability to speak on the 'phone, to ask for what we need when shopping, and to answer questions in a job interview. But stammerers frequently struggle to make themselves understood by those who do not recognise the difficulties and frustration a stammerer experiences.

The Dominic Barker Trust funds research into stammering.

The research has been based in Ipswich at Suffolk College, an accredited college of the University of East Anglia. In future the base will be in Norwich, at the University of East Anglia (UEA), in the newly formed School of Speech and Language.

Research projects will continue in Suffolk.

Working with:

BRITISH STAMMERING ASSOCIATION (BSA)

15 Old Ford Road, London E2 9PJ

T 020 8983 1003 F 020 8983 3591

helpline 0845 603 2001 www.stammering.org

The British Stammering Association works on behalf of stammerers of all ages and their families, providing a free information service on all aspects of stammering and stammering therapy as well as a programme of events.

COMMUNICATIONS FORUM

which brings together organisations concerned with communication problems and promotes initiatives to increase awareness of communication issues among the general public and statutory and voluntary organisations.

ICVS: the Ipswich Council for Voluntary Service

SAVO: Suffolk Association of Voluntary Organisations

The Dominic Barker Trust Hon DCL (East Anglia)

Registered Charity No 1063491

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A rare accolade.... Honorary Doctorate of Civil Law



The Dominic Barker Trust received an honorary degree conferred by UEA, the University of East Anglia, on 28th October 2004 at the Suffolk College, Ipswich.

Honorary Degrees are awarded to those individuals with a national or international reputation; individuals who have made a significant contribution to Ipswich or the County of Suffolk.

It is extremely rare for a Trust to be awarded an Honorary Degree and the Trustees are delighted that the research and work already done and being done by the Trust has been acknowledged in this way.

Eleanor Barker received the degree and made the speech of acceptance on behalf of the Trust. The picture shows the Trustees and Professor Dave Muller the Principal of Suffolk College.

From left to right: Toby Kramers, Dr Christopher Brown, Eleanor Barker, Guy Barker, Professor Dave Muller, Simon Wallis, Sir Malcolm Pill (Chairman of the Trust).

Research and Suffolk

The aim of the Trust is to fund research which would not otherwise be done.

The research at UEA will build on the work already completed by Isobel Crichton-Smith and the small team at Suffolk College over the past six years. The Trustees are grateful for the support of Jayne Taylor and Claire Webb, former and current Deans of the School of Health.

The Trustees consider it important that links with Suffolk are maintained and that research projects continue in Suffolk.



STUDENT NOMINATED CHARITY 2003

The Dominic Barker Trust was one of three charities nominated by the students' union at Suffolk College.

In the photo: Anthony Wills (from left to right), student representative, with Rachel Pennick and son George, Helen Barker, Isobel Crichton-Smith, and Alan Barker (right) receiving a cheque.

Dominic Barker Research Centre

is located within the School of Health at Suffolk College and is the base with resources for research. It provides a "home" for research into stammering with facilities and resources for clients and families taking part in projects.



The Mayor of Ipswich, Councillor and Mrs Richard Risebrow, at the opening.

The Research Centre was officially opened on 6th February 2003 by David Sheepshanks, Ipswich Town Football Club chairman, and Robert Rous, High Sheriff of Suffolk.

Guests were welcomed by Christine Dobson, Assistant Principal, Higher Education: 'We are very pleased that a good foundation in health-related research will be further developed through the research centre. We have had significant community support, and we value our links with trusts, voluntary agencies, charities and local government'



Alan Barker, Robin Sheepshanks and Robert Rous.



Christine Dobson from Suffolk College, David Sheepshanks, chairman of Ipswich Town Football Club (centre) and Isobel Crichton-Smith cut the tape to open the Dominic Barker Research Centre.



Study Days

Building on the success of the first study day in 2000, the Dominic Barker Trust hosted two more study days in the Dominic Barker Research Centre at Suffolk College.

On 17th May 2002 Dr Trudy Stewart (in red in above photo), from St James's Hospital in Leeds, presented lectures and a workshop on the Diagnosis of Normal Non Fluency and Early Stammering. Thirty-four speech and language therapists attended from East Anglia, London, Surrey and Kent.

Dr Stewart's initial lecture discussed the research into features of normal non-fluency and early stammering, from the last decade. She went on to explore new procedures for the transcription of dysfluent speech. All participants took part in a workshop where they had the opportunity to practise their newly-acquired transcription skills in readiness to use with their own clients. This event was extremely well-received and participants found it both informative and interesting.

On 20th September 2002 Gail Smith, from East Leeds Primary Care Trust, presented an interactive study day and workshop on Psychodrama. This is a psychotherapeutic technique suitable for use with clients over the age of ten who stammer or have voice difficulties, and enables them to make changes to their feelings, thoughts and behaviour. The delegates found it an extremely educational and entertaining day.



Who's Who



At UEA

At Suffolk College



Dr Jan McAllister MA, PhD, is the Joint Director, Speech and Language Therapy programme, School of Allied Health Professions, UEA. This School, which opened in 1990, has working links with clinicians, professional bodies as well as other UEA academic departments which have shared interests.



Isobel Crichton-Smith MSc, MRCSLT was appointed Research Fellow for the Trust in 1998. Previously Isobel had worked as a Speech and Language Therapist with adults and children in Colchester and then for four years as a therapist in Ipswich. Her work was in various settings including a language unit attached to a primary school, a multidisciplinary assessment centre and two community clinic, where she had the opportunity to work with children with complex special needs and communication disorders including specialist working with both children and adolescents who stammered.

She recalls "With my practical background I have been able to offer a hands-on approach, extensive local knowledge and experience in working with adults and children who stammer."

As well as setting up the research projects, Isobel completed her MSc in Human Communication at UCL in 2001, and gained a distinction. In 2002 Isobel became the membership secretary and web administrator of the National Special Interest Group in Dysfluency - a group run for SLTs who specialise in working with people who stammer.



Rachel Pennick provided administrative support for the work being done by Isobel and Fiona, which involved contacting parents, arranging appointments and maintaining the equipment. She says "I thoroughly enjoyed being part of the small team". She can also add 'toy repairer' to her list of skills.



Fiona Stewart MRCSLT was appointed as a part-time researcher. Her experience as a paediatric Speech & Language Therapist for Central Suffolk PCT, specialising in work with children who stammer meant that she was able to assess candidates to take part in the research and complete video sessions with families. In addition, Fiona has been able to provide advice and support to parents on helping their child's fluency.



Tammy Davidson BSc, BA, has been appointed to the Dominic Barker Research Studentship for research into stammering at the School of Allied Health Professions, UEA.

Tammy grew up in

South Africa. Her first degree was in Physiology and her second in Speech and Hearing Therapy. She had several years clinical experience in different parts of South Africa before coming to the UK in 2000. She worked in Glasgow before moving to Norwich in 2001 where she is currently working as a speech therapist in the community. She has a particular interest in patients with motor neurone disease.



Dr Claire Teevan-Hanman BSc, PhD, was the Research Assistant for 3 years (including maternity leave). Her role included involvement with the analysis of data for the Parent Child Interaction project.

Research

The Research supported by The Dominic Barker Trust at Suffolk College was undertaken by a small team led by Isobel Crichton-Smith, the full time Research Fellow. Isobel and the team worked closely with National Health Trusts in the East Anglia Region and focused its research in its local area.

Three studies have been completed already:

Communicating in the real world: accounts from adults who stammer

Stammering: an investigation into speech and language therapists' attitudes and beliefs.

Parent child interaction therapy with young children who stammer: 5 case studies.

A fourth study the "Play and Fluency project", referred to in the newsletter, is in the process of being written up.

The following is an account by Isobel Crichton-Smith, The Dominic Barker Trust Research Fellow, Suffolk College, Ipswich, abridged, with permission, from an article Isobel wrote for SIGNAL

The Trust chose to base the project in its local area and has been supported from the outset by Suffolk College in Ipswich, whose Principal, Professor Dave Muller, will be known to many speech and language therapists for his work in aphasiology. The project aims to:

- undertake research into the treatment of stammering
- disseminate research findings to a local and global audience
- provide a local resource for speech and language therapists and people who stammer.

The Trust recognises that, although research into stammering is being carried out all over the world, there are only a few dedicated research projects in this country. The Trust is committed to providing support for independent research that will enhance the knowledge and understanding of stammering in this country and at an international level.

Adult study

In 1998, when the Trust was launched, the media coverage inspired many people to make contact with the project. The majority had a story to tell about their experience of living with a stammer. About this time, Corcoran and Stewart (1998) published research based on the qualitative analysis of interview narratives from adults undertaking therapy that identified a common theme of 'suffering'. No published research existed on the lived experience of people who stammer in the UK, hence, a project was undertaken to formally gather these stories and look for any common elements.

The resultant piece of research was entitled 'Communicating in the real world accounts from people who stammer'. It involved undertaking qualitative interviews with fourteen adults from varied backgrounds who had all grown up with a stammer. Some participants had received help for their speech, others had not. The accounts appeared to differ greatly. However, when compared more closely, a common theme of 'limitation' emerged. Participants all shared feelings of being limited in their education

and employment and all felt self-esteem had been affected by their experience of stammering.

Management of stammering

During the interviews participants were asked how they managed their speech on a day-to-day basis. The responses could be categorised into four strategies.

Some participants did nothing and this was labelled as 'no change'. Others used techniques they had been taught by a professional (these 'taught changes' were not mentioned as often as I was expecting!) Some participants chose to 'highlight' their stammering with humour, labelling or sweating. However, most frequently mentioned were 'intuitive changes' such as rehearsing, planning and using run-ups, word and situational avoidance.

Situational dependence

One similarity across participants was that the way they managed their speech was situation dependent. However, situations varied between participants. For example, some participants said that they would only use a taught fluency technique at home whereas others would apply it only in a work situation such as a meeting.

Similarities and differences

All in all, the accounts of living with a stammer were like life itself – very varied. That is not to say that there weren't common experiences shared by all respondents. The differences arose out of the different ways that the individuals responded to and handled these experiences.

Personal reflections

The interview process led me, as a researcher, to wonder what type of comments I would have elicited if I had been operating in my other professional role as an SLT. I certainly felt that in my researcher role I was privy to very candid accounts of the management of stammering. As with all interviews, I accepted what I was told was truthful though without additional methods (or triangulation) it was difficult to corroborate the information. Since completing this particular piece of research I have thought a lot about the concept of disclosure and how important this may be when working with adults who stammer. Sometimes I was offered unexpurgated 'warts and all' accounts of life in great detail, while other accounts were more guarded and lacked cohesion, as if bits had been edited out. I reflected on the amount of information I would be prepared to tell a researcher and how that might differ from what I would tell a therapist. One lesson (or perhaps bias?) I have learned is that a discussion between therapist and client may be strongly influenced by what the client feels the therapist wants them to say. This, in itself, can produce one of those roadblocks that get in the way of the therapeutic process.

Therapists' attitudes and confidence study

In 2000, following completion of the adult study, I undertook a research project as part of an MSc in Human Communication.

For this, I focused on SLT attitudes towards and confidence levels in working with stammering. My personal interest in this area began in my previous job as an SLT with an interest in stammering — but with no recognised specialist post in paediatric dysfluency available in my NHS Trust. I was one of the few therapists interested this client group and, as such, my caseload expanded accordingly. I was occasionally (and still am, unfortunately) confronted with other therapists' negative

perceptions of stammering. I wanted to discover whether these attitudes were symptomatic of my local area or whether they represented more wide spread attitudes. From a review of the literature I discovered that attitudes towards stammering had been investigated in a variety of ways. Mainly, research stemmed from the USA. One particular paper by St Louis and Durrenberger (1993), reported on therapists' preferences for working with different client groups. They found that working with children and adults who stammer (and cluttering) were rated towards the bottom of the majority of respondents' preferences. More popular areas included language delay, phonological disorders and aphasia.

The only published study regarding therapists in the UK was a joint study by Lena Rustin and Eugene Cooper in 1985. They compared US and UK attitudes and reported universally held attitudes towards stammering, eg, that stammering was multi-factorial in nature. Unfortunately, they also found that therapists held negative/stereotypical attitudes regarding people who stammer as well as the parents of children who stammer.

Using the same inventory of questions, I surveyed 261 therapists in the UK to discover whether attitudes had changed. I specifically targeted a mixture of therapists with varying levels of interest in dysfluency, from those with no clients to those with a specialist caseload. I included therapists who were and were not trained in Lidcombe therapy. The results showed that some attitudes had remained constant whereas others had changed. Of particular interest was a significant move toward early intervention, which had not been so clearly indicated in the previous study. The good news was that therapists' attitudes towards clients who stammer and their parents showed much less evidence of negative stereotyping.

Intra-group differences

The sample characteristics made it possible to compare results from different therapists within the group. As a whole, generalist therapists were less clear in their responses to the questionnaire than specialists. The study indicated that specialists held some firm ideas about intervention and about other therapists' ability to work with people who stammer. Unfortunately, they felt that therapists were not adept at treating stammering which, as previously indicated in other studies, appears to be a continuing area of concern.

Interestingly, therapists trained in the Lidcombe Programme held more positive attitudes towards people who stammer and working with stammering than therapists not trained in this approach. There are a multitude of possible explanations for this finding, including that these therapists tended to work with a paediatric caseload. It is possible that they had a different experience from therapists working predominantly with adults. Alternatively, of course, there may be something about the Lidcombe Programme which makes therapists positive about working with stammering. In the absence of any additional research we shall just have to guess!

Confidence levels

I also asked therapists about their confidence levels regarding managing a paediatric and adult caseload. Therapists were asked to write down factors influencing their confidence levels. The findings indicated that the majority of therapists felt confident working with a familiar caseload (i.e, a paediatric therapist would indicate that they felt confident working with a paediatric caseload). An intra-group analysis of the results did however, indicate that the majority of recently qualified therapists did not feel confident working with adults and over a third did not feel

confident working with children. Telephone Interviews were undertaken with ten therapists to investigate the area of confidence. These interviews, in combination with the findings of the survey, highlighted the importance of training, experience and professional support as key factors for maintaining confidence.

Parent-child interaction study

The research project is now focusing entirely on pre-school children. The arrival of the evidence-based Lidcombe Programme in the UK highlighted the need to critically evaluate similar therapies such as parent-child interaction therapy (PCI, Rustin et al, 1996) and investigate their place in the therapist's repertoire of interventions for children. To begin our investigation, five detailed case studies were conducted in 2000, using PCI with children under five years of age. The study lasted twelve months and consisted of three phases: baseline, therapy and maintenance. During the therapy phase the children received six sessions of weekly therapy at home. The results indicated that, from the baseline to the therapy phase, levels of dysfluency reduced in all five children. Three children were described by their parents as fluent at a six month follow up after the end of the project. One child was greatly improved at three months post maintenance but has since left the area and the final child, with a concomitant language disorder, was still experiencing levels of dysfluency similar to the start of the project. Therefore, initial, albeit limited findings suggested that PCI was effective for the children in the study. Interviews with the parents revealed that they enjoyed the study, they liked the play based approach and particularly appreciated the therapy being carried out in their homes. A single case study, looking at changes in parent and child interactions over the course of the study, was presented at the 6th Oxford Dysfluency conference and will be available in the forthcoming proceedings. Additional results from the case studies are still undergoing analysis and will be available in 2004.

The fourth project to be funded by the Trust, to investigate the relationship between play and fluency in both fluent and dysfluent children, is currently underway. The results from this study will inform the ongoing evaluation of current therapies and hopefully provide a foundation for the development of an innovative approach to intervention for pre-schoolers who stammer.

References

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- Rustin, L, Botterill, W. & Kelman, E., (1996) 'Assessment and Therapy for Young Dysfluent Children'. Whurr.

For further details :

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SIXTH OXFORD DYSFLUENCY CONFERENCE 2002

Isobel presented a paper on “Changing Conversational Dynamics: a case study in parent child interaction” which was published in the conference proceedings.

Cash from the Blues



“Cash from the Blues” was the headline in the East Anglian Daily Times in September 2002, when the Trust was one of the charities chosen by Ipswich Town Football Club to benefit from money received for winning the Fair Play League.

D-D-Don't Mention the Disability

Jaik Campbell is a stand up comedian from Suffolk who has a stammer. He has taken part in many shows, including the Edinburgh Festival and we are grateful to him for promoting the Trust at various events.

www.jaikcampbell.com

Please visit the website:

www.dominicbarkertrust.org.uk

Sincere thanks to Plum Lomax for setting up the website.

Date for your Diary

There will be an OPEN EVENING on Wednesday 9th November 2005 at Suffolk College at 7.30 pm.

A buffet supper will be provided by the students

The Trustees are grateful to Cathy Shelbourne for her initial work on this newsletter, to Technographic Design & Print of Halesworth for its design content and production, and to Ashton Graham, Solicitors, of Ipswich and Bury St Edmunds for funding its distribution.

Play and Fluency Project

Finn Bentley is a confident, outgoing little boy with a stammer. 'His stammer began two weeks before the birth of his sister Rose,' recalls his mother Sally. "Now we are seeing a pattern taking shape. When he is ill, or it's the school holidays, the stammering increases. During the playgroup term-time, we have a routine, and he is more relaxed."

Finn and his mother took part in the Play and Fluency Project run by the Domininc Barker Trust. Co-ordinators Isobel Crichton-Smith and Fiona Stewart are investigating the relationship between play and fluency in both fluent and dysfluent children. Thirty children in total, half of whom stammer, have been referred to the project by health visitors. There are four sessions, including two in which a video camera records the child participating in structured and unstructured games.

"Our previous research project indicated that children stammered more during pretend play rather than in structured, turn-taking play," says Isobel. "We are currently collecting data which shows that

language used in imaginative, make-believe situations is more complicated. If a child talks about what they see and do, the language is short and factual - and they do not stammer as much. We encourage children to take part in activities a year below the level they're at so that they build up their confidence."

"By working with fluent children as well, we can make comparisons, and build up a data base."

Sally Bentley has found the project very beneficial - and not just for Finn. "He has made fantastic progress demonstrated by a period of two weeks with fluent speech. Not only did he look forward to his sessions, we parents did too! The advice we received has made us much more aware of how to play in a way that encourages fluent speech. For example, not asking direct questions, but instead giving him options for answers relieves the pressure on him."

For parents of fluent children, the project was also valuable. Michelle Semple-Morris, mother of four-year-old Tajah, found that " the



Three-year-old Finn Bentley gets his trucks lined up in a row for Isobel Crichton-Smith (right) from the Domininc Barker Trust, and his mother Sally (centre).

whole experience helped me to get a better understanding of how my daughter thinks and expresses herself". Amanda Groom, mother of Toby, youngest of three children, realised that "it made me sit down and play with him. So often I'm dashing around after the others, and it was good to have time with him. Taking turns in the games helped his attention, and the whole experience has calmed him down a bit"

OPEN EVENING 2002

Moya Willson, ProVice Chancellor of UEA and Erik Lamens, a Belgian film producer, were guest speakers at the open evening in October 2002 at Suffolk College.

Erik spoke movingly to a packed audience about his childhood stammering, and dramatically illustrated his experiences with his own film clips.

www.ErikLamens.org



*Picture from the film 'To Speak', 1998
Erik Lamens*



Moya Willson, ProVice Chancellor of UEA