

**Parental Awareness Campaign  
(Scotland)**

**Final report**

**By Jan Anderson**



The British  
**Stammering**  
Association

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## **Background**

The Parental Awareness Campaign (PAC) was a three-year project which sought to encourage parents, early years workers and health professionals to refer children under five who show early signs of stammering to speech and language therapy. This early intervention campaign was devised as the follow-on to an earlier BSA project, The Primary Healthcare Workers Project (PHWP, 1995-1999), that sought to challenge the popular misconception that it is best to 'wait and see' whether a child will grow out of early stammering. The PHWP proved successful in increasing early dysfluency referrals, particularly from health visitors, to speech and language therapy. Based on recommendations in the PHWP, the current campaign aimed to take the early referral message to a wider audience (including parents, directly) and to maintain its profile over time.

### **Onset of stammering**

Early referral to speech and language therapy is recommended as there is substantial evidence that stammering is most likely to develop in the pre-school years. In a major longitudinal study in the United Kingdom Andrews *et al* (1964) found that 50% of children who stammered had started to stammer before the age of four, while 75% started before the age of six years. More recently Yairi and Ambrose (1992) found the average age of onset, according to parental report, to be 32.8 months, ie under three years.

### **Diagnosis of early stammering**

Many children experience some dysfluency when learning to talk. This may involve repeating sounds, syllables, words or phrases, prolonging sounds and using interjections (eg 'um', 'er'). Children who stammer tend to display higher levels of these dysfluencies. Meyers (1986) and Zebrowski (1991) found that young children who stammer are 2.5-3.5 times more dysfluent than children who don't stammer. Research such as this has made it easier for speech and language therapists to differentiate between early stammering and normal non-fluency. A level of more than 10% speech dysfluency is widely regarded as one indicator for diagnosing early stammering.

In addition, the characteristics of early dysfluencies are also recognised to be important in differential diagnosis. Children most at risk of persistent stammering tend to display sound and part-word repetitions and sound prolongations. They may also display muscle tension, blocking, struggle and pitch changes.

Diagnosing early stammering involves detailed analysis of taped samples of the child's speech as well as talking to the child and his/her parents at length.

### **Spontaneous recovery**

Studies have shown that spontaneous recovery from early childhood stammering does occur. Andrews *et al* (1964) reported that 77% of his sample had stopped stammering by the age of 16 years. More recently, Yairi *et al* (1996) found that two thirds of his sample recovered within three years of onset. He identified three distinct pathways, ie a group who recovered within 18 months of onset (early recovery), a group who recovered between 18-36 months of onset and a group who were dysfluent for more than three years (persistent stammering). Unfortunately, current means of differentiating risk are not sufficiently accurate to enable speech and language therapists to determine conclusively which children will belong to which group. Yairi found that children

who demonstrated 'severe stuttering-like dysfluencies' at onset often recovered while those with mild 'stuttering-like dysfluencies' could persist in stammering long-term. In other words, initial severity of struggle is not a good indicator of prognosis.

Delaying intervention to allow for the possibility of spontaneous recovery can lead to the development of negative emotions such as fear and frustration as well as counterproductive struggle and avoidance behaviours. Ingham (1983) and Johnson (1959) reported that 17.5% of parents claimed that their child avoided speaking situations after the onset of stammering. Lees *et al* (2000) commented that 'the treatment of stammering in its pure form is less time consuming than treating the disorder after the child has developed fears about speaking and may be avoiding speaking situations. It is also more cost effective to treat the child as soon as possible after onset of the problem.' For these reasons early referral to a speech and language therapist is always recommended.

### **Early intervention**

Treatment of early stammering involves identifying and addressing environmental factors which can exacerbate dysfluency, working with parents and carers to change their interaction patterns in order to foster the child's fluency (Rustin *et al* 1996) and, in some cases, direct treatment of the stammering symptoms using approaches such as the Lidcombe programme (Onslow *et al* 1994). Treatment may involve weekly appointments or less frequent consultations. Starkweather (1997) recommends early intervention for many reasons: the young child is more amenable to change; the duration of treatment is likely to be short compared to older children and adults (eight weeks to a year); treatments developed for children are effective in achieving essentially complete remission of symptoms, with little relapse in about 95% of cases. In conclusion, early intervention reduces the likelihood of prolonged therapy later in the child's life.

### **Attitudes of potential referrers**

Early intervention for childhood stammering is dependent on the child being referred to speech and language therapy as soon as possible after onset. However, the predecessor to this project, the PHWP, found that parents tended to wait until their dysfluent child was age eight -11 years before referring them to therapy, while GPs tended to refer at 14-16 years (Christie, 1999). In a recent study in Highland Community NHS Trust, Lees *et al* (2000) sought to find out more about the knowledge and attitudes of health professionals (GPs and health visitors) that influences the decision about when to refer. Their postal survey yielded diverse responses. They found that a minority of both professional groups seldom or never refer children showing signs of dysfluency to speech and language therapy. Eight per cent of health visitors felt that children between two and five should not be enrolled in therapy and 25% felt that they could generally tell for themselves whether a speech problem would be short lived or persistent. Fourteen per cent of GPs reported that waiting lists influenced their decision about whether to refer. Both groups included a substantial number who were undecided about the effectiveness of therapy (HV - 46%, GP - 74%). All were most likely to refer where they had been exposed to postgraduate training in the treatment of dysfluency and where they were aware of local referral guidelines. This appears to vindicate the British Stammering Association's stance on the importance of targeting health professionals for training. However, delivering such training was beyond the scope of this campaign.

## **The pilot phase of the Parental Awareness Campaign**

During the first 18 months of this campaign the project co-ordinator, Doreen Faisca, consulted with speech and language therapists across the UK and compiled appropriate campaign literature before carrying out pilot campaigns in five target areas (ie Northumbria NHS Trust, Sperrin Lakeland Health and Social Care Trust (Northern Ireland), Forest Healthcare NHS Trust (London), North West Wales NHS Trust, and Renfrewshire and Inverclyde NHS Trust (Scotland)). The aims of the pilot phase were:

### **Aims**

- to identify a range of demographically diverse areas that were willing to participate
- to distribute campaign literature to parents and potential referrers via health clinics, GP practices, nurseries, community centres and libraries
- to co-operate with local speech and language therapists to deliver training sessions to health visitors, nursery staff and childminders
- to raise awareness of the campaign message in local and specialist media
- to provide limited training to participating speech and language therapists.

Ms Faisca oversaw the implementation of the project in these pilot areas in conjunction with locally based co-ordinators. She then moved on from the campaign and was replaced by two part-time project workers who separately took responsibility for England, Wales and Northern Ireland (Judith Patel) and Scotland (Jan Anderson). Results from the Scottish pilot area are included in this report.

## **The Parental Awareness Campaign in Scotland**

### **Implementation meetings**

The Scottish project co-ordinator initially contacted speech and language therapy managers in fourteen NHS regions across mainland Scotland, requesting the involvement of local speech and language therapy co-ordinators in the campaign. The active involvement of a local co-ordinator was essential as the campaign was likely to impact on local referrals and involved gathering referral data.

Implementation meetings (attended by the project co-ordinator, the local speech and language therapy manager and/or another local speech and language therapist co-ordinator) were arranged in the trust areas that responded with an identified contact (Dumfries and Galloway Primary Care NHS Trust, Fife Primary Care NHS Trust, Forth Valley Primary Care NHS Trust, Grampian Primary Care NHS Trust (Moray area only), Highland NHS Board (Highland wide campaign), Lanarkshire Primary Care NHS Trust (North only), Lothian University Hospitals NHS Trust (Edinburgh only), NHS Tayside (Perth and Kinross, Tayside University Hospitals' Trust (Dundee) and Angus)), Yorkhill NHS Trust (Greater Glasgow), West Lothian Healthcare NHS Trust).

For a full list of regions and lists of participating/non-participating areas see Appendix 1.

Implementation meetings enabled the project co-ordinator to gather background information that has increased our knowledge of services and awareness of issues in Scotland.

### **Speech and language therapy for children who stammer in Scotland**

Due to the relatively low population density across much of the country, Scotland's speech and language therapists tend to cover a wide geographical area and a broad range of client groups. Local healthcare providers, in allocating resources, have tended to overlook stammering, arguing that there are not enough referrals to justify the provision of a specialist service in their area. Indeed, it has to be acknowledged that most rural 'generalist' therapists are unlikely to see sufficient numbers of children who stammer to enable them to develop their skills and experience to specialist level or to warrant substantial specialist training.

There are a few notable exceptions to the above such as Yorkhill NHS Trust, Greater Glasgow, where there is a specialist 'Dysfluency Team' (comprising one full-time/five part-time therapists or 2.8 full-time equivalents) and North Lanarkshire, Perth & Kinross and Angus where up to four sessions (two days per week) are delivered by a clinician with specialist expertise in fluency disorders.

Elsewhere, dysfluency referrals tend to be seen by community paediatric therapists who often cover a large and diverse caseload. In some areas an adhoc system operates, whereby more complex dysfluency referrals are passed to a therapist with an expressed interest or more experience – though this is not really an option in rural areas of low population density. Until now few therapists have been allocated even a single session specifically for stammering referrals and only a tiny minority have dysfluency formally recognised as part of their post. Unfortunately, this means that when a therapist with a commitment to dysfluency leaves post she/he may be replaced by someone with no knowledge or experience of this field.

At the present time there are recruitment and retention problems in the profession across Scotland, most particularly in rural areas. Thus, speech and language therapy services are frequently over stretched and the needs of dysfluent children, as a minority client group, are often marginalised.

Against this back drop, it is not surprising that some speech and language therapy managers responded with caution to participating in the campaign. Indeed, it is good news that, in spite of limited resources, an encouraging number of speech and language therapy managers and individual clinicians expressed a commitment to developing their service in this field.

### **Aims of the Parental Awareness Campaign in Scotland**

The overall aim of the project was, building on the success of the Primary Healthcare Workers Project, to encourage parents, early years workers and health professionals to refer children under five who show early signs of stammering to speech and language therapy. More specifically, the aims in Scotland were:

- 1 To increase awareness of early stammering amongst the range of potential referrers (ie, parents, carers, early years workers and health professionals) in Scotland
- 2 To promote the early referral of young children showing signs of stammering to speech and language therapy in Scotland

- 3 To support and encourage speech and language therapists working with early dysfluency in Scotland
- 4 To monitor dysfluency referrals and evaluate the effectiveness of the campaign in Scotland

### **Methods used during the Parental Awareness Campaign in Scotland**

The methods used will be related to the aims of the project in Scotland.

- 1. To increase awareness of early stammering amongst the range of potential referrers (ie, parents, carers, early years workers and health professionals) in Scotland**
- 2. To promote the early referral of young children showing signs of stammering to speech and language therapy in Scotland.**

The first two aims of the Scottish campaign were predominantly addressed via a 'paper campaign', ie

- Campaign literature was disseminated in participating areas via health clinics, nurseries, family centres, libraries and, in some areas, community centres.
- A media campaign was conducted in local, national and specialist publications, with particular emphasis on International Stammering Awareness Day 2001.

This approach was favoured as it enabled the British Stammering Association to reach a wide audience in Scotland without making unrealistic demands of the speech and language therapists participating in the campaign. In England, where dysfluency services are more evolved, local co-ordinators were often able to allocate more time to the project and therefore incorporate awareness raising training for potential referral agents.

#### **The campaign literature**

The campaign literature comprised a poster 'Stammering – Spot it! Speech therapy is more effective before the age of five' (see Appendix 2) developed specifically for the campaign, and two leaflets 'Does your young child stammer?' and 'Early intervention prevents stammering – Referral information for professionals' (see Appendix 3/4).

#### **The media campaign**

The media campaign, co-ordinated around International Stammering Awareness Day 2001 (October 22, 2001), involved distributing a press release (Appendix 5) to all national and local dailies. Articles were also submitted to a selection of local papers as part of local initiatives. In addition, items appeared in specialist publications relevant to the target groups of the project (childminders, nursery staff etc). A sample list of publications can be found in Appendix 6. Efforts to collate a complete record of media coverage were hampered because the press cuttings agency misheard our request and searched, instead, for items on 'stamina'.

The campaign featured on television twice. On Stammering Awareness Day 2001 substantial coverage was achieved on BBC Scotland lunchtime news. In November 2001 the campaign was

highlighted on Grampian Midweek. On both occasions footage included a clip of a clinician working with a stammering child as well as interviews with the parent, clinician and project co-ordinator.

The project co-ordinator was also interviewed by several radio stations, which are listed in Appendix 6.

### **3. To support and encourage speech and language therapists working with early dysfluency in Scotland.**

It was hoped that participating in the campaign would increase commitment to childhood stammering amongst participating speech and language therapists in Scotland. It is recognised that many speech and language therapists lack confidence in treating childhood dysfluency (Christie 1999) and that the shortage of specialist expertise in Scotland means it is often difficult for clinicians to find a mentor to turn to, to discuss dysfluency referrals. Implementation meetings afforded the opportunity to reflect on existing provision and share information on practices elsewhere in the country. The project co-ordinator was also able to raise awareness of the Scottish Special Interest Group in Disorders of Fluency, a group for speech and language therapists, that holds study days on stammering in Scotland twice a year.

### **4. To monitor dysfluency referrals and evaluate the effectiveness of the campaign in Scotland.**

Local co-ordinators were asked to collate referral data on all dysfluency referrals for children aged 0-16 years for an agreed period (generally nine months) following the distribution of leaflets and posters in their area. This data was compared with referrals for an equivalent pre-campaign period. Where possible, a full set of data was to be collated from across the trust by the local campaign co-ordinator.

## **Results**

### **Project data**

The campaign materials (leaflets and posters) were distributed in 11 out of 14 mainland regions of Scotland (including the pilot). In some areas distribution was partial (eg Lanarkshire (North only), Grampian (Moray area only)).

Data was not gathered in all of the areas in which the campaign literature was distributed. This was due to a range of factors, including:

- the amount of time available/level of priority given to the campaign
- difficulties in collating referral data across the trust when no time had been allocated specifically to the task
- difficulties in accessing the required pre-campaign referral data.

Campaign literature was distributed in Forth Valley, however, this region did not manage to submit post-campaign referral data. Campaign literature was distributed in Lothian and West Lothian, however, these areas did not manage to submit referral data in the requested form.

Moray (Grampian) and Highland joined the campaign towards the end of the project, when it was too late to measure the impact on referrals, hence data was not submitted.

Hence, Table 1 represents a restricted sample of areas where data was gathered successfully for the pre- and post-campaign periods. Table 2 provides referral statistics submitted by Lothian and West Lothian.

Due to staggered start dates, it was not possible to obtain referral data for a full year pre- and post-campaign in the majority of participating areas in Scotland. Hence, referral data for comparable time periods pre- and post-campaign have been used. The duration of the periods measured is indicated for each area.

## Results tables

**Table 1**  
Pre- and post-campaign referral data in trusts where data collection was achieved (with duration of pre-/post-campaign)

Trust	Duration of pre-/post-period	Under-fives		% Change Under-fives	School-age		% Change School-age
		Pre- PAC	Post- PAC		Pre- PAC	Post- PAC	
Dumfries & Galloway	6 months	5	15	200%	3	1	-67%
Fife	9 months	16	27	69%	13	7	-46%
Greater Glasgow (Yorkhill)	6 months	15	30	100%	13	14	8%
N. Lanarkshire	12 months	18	36	100%	8	6	-25%
Renfrewshire and Inverclyde (pilot)	6 months	6	10	67%	3	1	-67%
Tayside:							
Angus	9 months	5	18	260%	0	1	100%
Dundee	9 months	11	8	-27%	3	3	0%
Perth & Kinross	12 months	9	15	67%	5	7	40%

**Table 2**

Pre- and post-campaign referral data from trusts where figures were submitted but data collection was limited and not in the standard format.

**Lothian**

(Number of dysfluency referrals to central database (age 0 to 16))

Period	Dysfluency referrals		% Change
	Pre-PAC	Post-PAC	
Nine months	31	46	48%

(Number of dysfluency referrals, age 0 to 16, to Sighthill Health Centre)

Period	Dysfluency referrals		% Change
	Pre-PAC	Post-PAC	
Nine months	15	23	53%

**West Lothian**

(% of all referrals to SLT that were for dysfluency [taken from central database])

Period	Under-fives referrals		School age referrals	
	Pre-PAC	Post-PAC	Pre-PAC	Post-PAC
Nine months	1.69%	5.2%	4.07%	2.6%

**Table 3**

Range of referral agents (pre- and post-campaign)

% change not calculated where numbers are very low.

Referring Agents	Under Fives		% Change	School Age		% Change
	Pre-PAC	Post-PAC		Pre-PAC	Post-PAC	
GPs	12	25	108%	12	15	-25%
HVs	49	67	37%	6	3	-50
Parents	8	23	188%	12	3	-75%
Schools	1	-	-	18	15	-17%
Nursery	17	30	76%	-	-	-
SLTs	-	1	-	1	-	-
CMOs	-	2	-	1	-	-
Paediatric consultant	1	-	-	-	-	-
Others	1	1	-	-	2	-

**Table 4**

Number of 'Does your young child stammer?' leaflets distributed by area

<b>Trust</b>	<b>PMs</b>	<b>GPs</b>	<b>HVs</b>	<b>EY workers</b>	<b>Libraries</b>	<b>Com. centres</b>	<b>Other</b>	<b>Total</b>
D & G	185	117	160	205	115	-	150	932
Fife	340	1,195	-	825	240	90	-	2,690
Forth V.	240	627	-	330	135	155	-	1,487
Glasgow	144	1,080	900	175	-	-	150	2,455
Gramp	80	300	50	105	80	-	-	615
Highland	330	772	405	-	200	-	-	1,667
Lanarkshire	-	597	-	490	-	-	200	1,287
Lothian	600	960	600	1,060	150	-	-	3,370
W Lothian	-	460	150	265	-	-	-	875
Tayside:								
Angus	60	340	1	410	100	-	-	911
Dundee	150	585	-	-	80	-	-	805
P & K	85	255	-	450	-	-	-	790
<b>Totals</b>	<b>2214</b>	<b>7,288</b>	<b>2,266</b>	<b>4,315</b>	<b>1,100</b>	<b>245</b>	<b>500</b>	<b>17,928</b>

**Table 5**

Number of 'Stammering – Spot It!' posters distributed by area

<b>Trust</b>	<b>PMs</b>	<b>GPs</b>	<b>HVs</b>	<b>EY Workers</b>	<b>Libraries</b>	<b>Com. Centres</b>	<b>Other</b>	<b>Total</b>
D & G	74	39	32	82	46	-	6	279
Fife	136	478	-	165	96	60	-	935
Forth V.	96	418	-	132	54	62	-	762
Glasgow	-	288	300	70	-	-	5	663
Grampian	32	120	20	42	32	-	-	246
Highlands	132	267	162	-	80	-	-	641
Lanarkshire	-	50	-	196	-	-	2	248
Lothian	240	480	-	424	60	-	-	1204
W Lothian	-	184	-	106	-	-	-	290
Tayside: Angus	24	136	-	164	40	-	-	364
Dundee	-	294	-	-	32	-	-	326
P & K	-	34	-	180	-	-	30	244
<b>Totals</b>	<b>734</b>	<b>2788</b>	<b>514</b>	<b>1,561</b>	<b>440</b>	<b>122</b>	<b>43</b>	<b>6,202</b>

**BSA website**

The number of visits to the BSA website 'under fives index page' increased significantly during the campaign. For the eight-month period from January 2001 to August 2001, before the campaign started, there were a total of 1800 visits to this page. For the same eight-month period in 2002, during the campaign, there were a total of 3716 visits, an increase of 106%.

**Comments on the accuracy and completeness of data**

The accuracy and completeness of referral data was affected by unfilled posts, lack of time for collating data from colleagues and difficulties in accessing and establishing pre-campaign referral figures. The latter was a widespread issue as often pre-campaign referrals on the central database were vague (eg 'delayed speech'). This could refer to language development or, potentially, dysfluency. It was not possible to tell without looking through past referrals manually and this

proved to be beyond the scope of many clinicians. Further, an emerging dysfluency, following an earlier referral for 'language delay' would not be recorded as a new 'dysfluency' referral.

In West Lothian pre- and post-campaign figures were accessed from the central database only. Data was provided in terms of the percentage of all referrals made that were specifically for dysfluency. Collation of post campaign figures across Lothian was not effective 'due to pressure of work and the need to prioritise clinical duties'. Here, referral data was only submitted by one speech and language therapist who has a special interest in early stammering. She collated referral data for her own clinic and accessed Lothian-wide dysfluency referral numbers from the central database. Only one day was allocated for the collation of statistics and writing of a proposal to improve the dysfluency service.

In Yorkhill (Greater Glasgow) referral rates appear lower than might be expected for this densely populated area, but please note that the period of measurement was six months pre- and post-campaign only.

In Dundee (Tayside) alone, referral rates appeared to decrease (pre-school) or remain the same (school-age) during the campaign. In this area referral data was collated efficiently across the city. It is not clear why referral rates for stammering decreased during the measured periods. It would therefore be interesting to see the results of continued monitoring in this area.

Lastly, referral rates are subject to fluctuations due to seasonal changes, holiday periods and other factors. In North Lanarkshire, for example, health visitors perform pre-school checks in bulk and write their reports several at a time, with a consequent impact on the flow of referrals.

## **Results summaries**

### **Referral rates**

**The number of referrals involved in this project in any given area was fairly small, hence, we must be cautious about drawing firm generalisations from the data. Nonetheless, it is encouraging that across the six regions (Dumfries & Galloway, Fife, Greater Glasgow, North Lanarkshire, Renfrewshire & Inverclyde and Tayside) in which pre- and post-campaign referral figures were collected in the requested format, 87% more dysfluent children under five were recognised and referred for therapy during the measured periods. This suggests that the combination of leafleting, displaying posters and raising awareness in the media was effective in increasing early referrals. School age referrals appeared to decrease by 17%, however, as numbers were small and varied across trusts this cannot be interpreted as indicative of a trend.**

The apparent decrease in school age referrals cannot be put down to the effectiveness of the campaign at this early stage. It is hoped that the campaign will impact on the ratio of pre-school:school age referrals in time – leading to a sustained increase in pre-school referrals and a sustained decrease in school age referrals as dysfluent children are recognised and referred earlier. However, monitoring would need to continue for several years beyond the current campaign to establish whether this occurs.

### **Referral agents**

**The spread of referral agents appears to have widened with an encouraging increase (325%) in pre-school referrals from parents. The percentage of all referrals coming from parents rose from 5% to 19.5% during the project.**

The PHWP led to a significant increase in referrals from health visitors during its awareness-raising phase. Many therapists commented that they had maintained close links with health visitors since the PHWP and felt that these colleagues were excellent at spotting early dysfluency and making appropriate referrals. Nonetheless, the impetus of the current campaign led to an increase in pre-school referrals of 37% amongst health visitors. GP referrals increased by an encouraging 108%.

### **Distribution of campaign materials**

**17,928 'Does Your Young Child Stammer?' leaflets and 6220 posters were distributed across Scotland during the campaign.**

Many therapists have commented that they are seeing the material on show in local clinics, nurseries and schools. However, the lifespan of publicity varies according to local practices. In some health centres, material on the walls is frequently circulated. Feedback from participating therapists suggests that they see the need for an ongoing campaign, with periodic circulation of posters and leaflets continuing for the foreseeable future. Campaign materials should be monitored and re-ordered by local clinicians who will be aware of when the profile of the campaign has diminished.

### **Additional efforts to increase awareness – the role of training**

Not all areas felt able to undertake specific local initiatives beyond contributing to the effective dissemination of the 'paper campaign' (see earlier). However, in North Lanarkshire the local co-ordinator delivered a one-day training to paediatric speech and language therapy colleagues to raise awareness of risk factors and provide an update on therapeutic approaches. In-service training to health visitors and nursery staff was also delivered in this area. In Greater Glasgow a BSA training pack was used to train Primary 1 teachers from Glasgow and East Renfrewshire. Information on stammering is included as part of the ongoing in-service training offered throughout Yorkhill NHS Trust. In Dumfries and Galloway BSA training packs were used as part of a training programme, delivered by speech and language therapists to nursery staff. In Perth and Kinross BSA talk packs were used to deliver training to GP trainees and in February 2003 a half-day training on stammering was delivered to education staff from nursery through to secondary level. In Dundee information on stammering has been included during Hanen courses for parents. In Fife all health visitors were provided with in-service training on childhood dysfluency (January 2002) and regular in service training is provided to schools across the area.

In Angus, Lothian and West Lothian no training was delivered due to limited resources.

### **Qualitative comments from local co-ordinators**

*"The project has increased our awareness of the differing advice being given by different groups of professionals on dysfluency and has allowed us to consolidate the information we would 'choose' to give."*  
Susan Bagnall, Dumfries and Galloway.

*"Participating in the campaign gave therapists a focus – it brought stammering into the limelight. Therapists with a special interest came forward to discuss the service in Fife. The speech and language therapy chiefs are supportive of service development and there will be a review in December 2002."* Lisa McInnes, Fife.

*"The referral rate has continued to fluctuate however, we are seeing an increase in younger aged referrals and referrals closer to onset."* Liz Hoey, Greater Glasgow.

*"Efforts to collate referral statistics were not effective due to pressure of work and the need to prioritise clinical duties."* Margaret Wilkinson, Lothian.

*"The project led to an increased number of appropriate referrals at an earlier age and stage of stammering, thus dysfluent children have been receiving appropriate input earlier. In-service training for speech and language therapy colleagues drew positive feedback. Speech and language therapists reported increased confidence in their competence in working directly with stammering children. Training overturned the review and monitor policy that had been adopted previously."* Caron Grieve, Lanarkshire (North).

*"Participating in the campaign has been a worthwhile exercise. The campaign gave a kick start to efforts to develop a service for dysfluent clients in Angus and the caseload seems to have snowballed. Clinical groups are being set up across Tayside to look at best practice in fluency management. BSA are wonderful in terms of the amount of support and literature given."* Dorothy Close, Tayside - Angus.

*"Having leaflets available to parents is a huge improvement as this reduces parental anxiety while waiting for assessment. Health visitors are giving out appropriate information and parents appear better informed when they reach us. The referrals we are receiving are mostly appropriate and close to onset. There has also been an increase in secondary school aged referrals. Maintaining the profile of posters and leaflets should be an ongoing project."* Carol Bissett, Tayside – Perth and Kinross.

## **Conclusions and recommendations for the future**

The number of referrals for early childhood dysfluency in Scotland increased substantially as a result of the Parental Awareness Campaign. It can be hoped, therefore, that the number of children going on to experience growing up with a stammer will decrease as a result of our efforts, even thus far.

### **Leaflets and posters**

The combination of leaflet and poster distribution used during the campaign has proved effective in increasing the number of pre-school dysfluency referrals to speech and language therapy. However, participating speech and language therapists foresee the need for an ongoing campaign. It is recommended that campaign materials should continue to be made available to trusts that have participated in the campaign so that public awareness of the importance of early referral remains heightened. It is also recommended that areas that have not participated to date should be approached again with a view to disseminating posters and leaflets in the near future.

### **Media campaign**

The press release, produced in association with a professional media consultant, proved extremely effective in attracting media attention. It is not possible to determine how far media coverage influenced referral statistics but it is likely this played a significant role in the success of the campaign.

### **Training for speech and language therapists**

The need for training in early dysfluency amongst speech and language therapists across Scotland was first acknowledged during the Primary Healthcare Workers Project. At that time, two short courses for 'generalists' were delivered to 66 therapists in the north of Scotland, by Roberta Lees, on behalf of BSA. These courses sought to update participants on current research and increase clinical confidence in working with children who stammer. BSA remains aware of the need for further training, including more specialist courses, in Scotland. Unfortunately, such training was beyond the budget of the present Parental Awareness Campaign (excepting the Lidcombe course that was delivered in Glasgow during the pilot in February 2001).

BSA recognises its responsibility to offer tangible support to the speech and language therapists who have experienced an increase in referrals as a result of the Parental Awareness Campaign. During the final year of the PAC, attempts were made to attract funds for a subsequent three-year speech and language therapist training project. Unfortunately, our fundraising did not achieve the targets necessary for the proposed project, however, all funds raised will be committed to speech and language therapist training in Scotland. A first Lidcombe training course is proposed for June 9-11, 2003. Places have been offered free of charge to trusts across Scotland.

### **Training for other professionals**

Lees (2000) findings regarding the attitudes of potential referrers (see p2) point to the need for training in early dysfluency amongst professionals such as GPs and health visitors. However, this will only become a possibility when there are sufficient numbers of speech and language therapists, confident and competent in the management of early dysfluency across the country, to deliver such training.

### **Innovative approaches to service delivery are required – the potential of telehealth**

As stated earlier, for a variety of reasons specialist services for children who stammer in Scotland are extremely limited. One potential way of addressing the issue of equitable service provision would be to utilise telehealth in the treatment of stammering, as pioneered in Canada. Telehealth has been adopted by Kully (2002) as a means of delivering stammering therapy to children who live in outlying areas where there is no specialist provision (such as the Northern Territories). Therapy (including Lidcombe) has been conducted through this medium with both children and adults who stammer. Kully has also used telehealth technology to support and train parents, nursery staff and local non-specialist speech pathologists. The benefits of this method of service delivery are reported to be: expanded access to specialist therapy; equitable service provision to clients in remote area; reduced costs in time/travel; increased family involvement; opportunities for training and supervising local clinicians and improved outcomes (due to access to specialist therapy).

Telehealth could offer an attractive solution to the challenge of service provision for children (and adults) who stammer in Scotland. Specialist services could be developed centrally and delivered locally, to the benefit of stammering children their parents and rural speech and language therapists. The technology to achieve this is already in place in Scotland – thus, this proposal warrants serious consideration.

### **A Scottish dimension to BSA**

The Parental Awareness Campaign was the first British Stammering Association project with a specifically Scottish dimension. Having a part-time project worker based in Scotland facilitated the implementation of the campaign immeasurably as it was practicable to visit all participating trusts from an Edinburgh base. In the process our knowledge and understanding of issues in Scotland has been greatly enhanced.

Having ‘dipped a toe in the water’, during the Parental Awareness Campaign, the benefits of maintaining a Scottish dimension have become evident. The British Stammering Association now intends to develop the scope of the organisation in Scotland – a move, particularly appropriate in view of the establishment of the Scottish Executive. The British Stammering Association has secured a Lloyds TSB ‘capacity building grant’ that will provide consultancy support to develop a strategic plan for the organisation in Scotland. It is hoped that a small Scottish base can be established that would serve as a focus for Scottish campaigns, support services and events. Feedback from people who stammer, speech and language therapists and other professionals in Scotland suggests all would be highly supportive of such an initiative.

### **In conclusion**

The Parental Awareness Campaign in Scotland was effective in raising awareness of early childhood stammering and in increasing early referrals to speech and language therapy. It provided a focus for clinicians with an existing interest in stammering and caused all participating areas to reflect on the service they currently provide to dysfluent children. Speech and language therapists in Scotland demonstrated a willingness to become involved, however, the need for additional training in managing childhood stammering is evident. As stated, issues of service delivery are complex in Scotland and it may be that novel solutions, such as telehealth, have a role to play in the delivery of stammering treatment in the future. In the meantime, young children who stammer in Scotland (and the clinicians who seek to help them) can hope to benefit indirectly from the lessons learned from a new BSA project that seeks to analyse existing models of excellent practice in the management of early stammering in England. The Pre-school Dysfluency Campaign will co-operate with a small number of pilot trusts in England to develop their services to under-fives who stammer (in line with best practice findings). The project will ultimately seek to produce guidelines for establishing and running a good pre-school dysfluency service that can be adopted by other trusts. In addition, the Royal College of Speech and Language Therapists, the professional body for speech and language therapists, is supporting a parallel initiative to develop a national framework for the delivery of stammering services. Dysfluent children in Scotland should face a brighter future in the wake of the Parental Awareness Campaign and in view of these projects and the ongoing efforts of BSA on their behalf.

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# Appendix 1

## **Regions contacted**

Ayrshire and Arran  
Argyll and Clyde  
Borders  
Dumfries and Galloway  
Fife  
Forth Valley  
Grampian  
Greater Glasgow  
Highland  
Lanarkshire  
Lothian  
Renfrewshire and Inverclyde (Pilot phase)  
Tayside  
West Lothian

## **Regions not contacted**

Orkney  
Shetland  
Western Isles

## **Areas that participated**

Dumfries and Galloway  
Fife  
Forth Valley  
Grampian (Moray only)  
Greater Glasgow (Yorkhill)  
Highland  
Lanarkshire (North only)  
Lothian (Edinburgh only)  
Renfrewshire and Inverclyde (Inverclyde only– Pilot phase)  
Tayside (Angus, Dundee, Perth and Kinross)  
West Lothian

## **Areas that did not participate**

Argyll and Clyde  
Ayrshire and Arran  
Borders  
Grampian (Aberdeen, Banff and Buchan, Deeside, Gordon, Kincardine)

## **Areas on which referral statistics are available in the requested format**

Dumfries and Galloway  
Fife  
Forth Valley  
Greater Glasgow (Yorkhill)  
Lanarkshire (North only)  
Tayside  
– Angus  
– Dundee  
– Perth and Kinross

## Appendix 2

# Stammering



I  
w-w-want  
to go to  
the  
p-p-park

me mummy

## Spot it

**Speech therapy is more effective before the age of five**

For information and advice call  
0845 603 2001  
(local rate call)



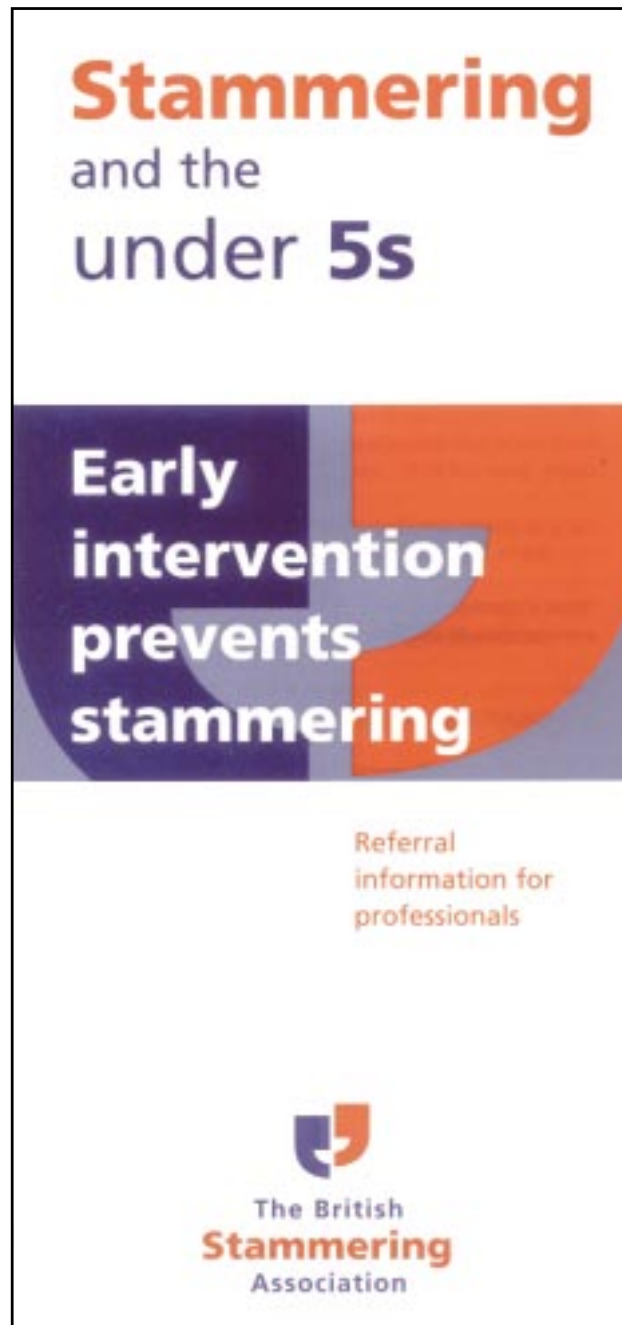
The British  
**Stammering**  
Association

Registered Charity No. 278170

## Appendix 3



## Appendix 4



## Appendix 5

### Media Release

Embargoed 00.01hours, Monday, October 22 2001

Scottish parents urged to act now on stammering

YOUNG CHILDREN who show early signs of stammering can avoid the pain of lifelong speech impairment if their difficulties are tackled early.

On International Stammering Awareness Day, on October 22, parents are being urged to act sooner rather than later if they feel their young children are showing signs of stammering – contrary to the received wisdom of many doctors and health visitors who recommend a ‘wait and see’ approach.

An awareness campaign by the British Stammering Association argues that – despite what some people may think – children don’t always ‘grow out of early stammering’; that an early consultation with a speech therapist is always the best policy.

The Association is saying to parents, doctors, health visitors, education and childcare workers in Scotland: ‘Spot it and act now, because speech therapy is more effective before the age of five.’ The Association operates a helpline: 0845 603 2001.

Jan Anderson, BSA campaign co-ordinator in Scotland, said:

*“It is worrying that parents continue to be advised to wait and see when all the evidence points to the benefits of early intervention. There are no good grounds for avoiding early referral to speech therapy.*

*“Children will be sensitively screened and monitored and recommendations can be given regarding how best to support the child. This can ease parental anxiety and give the young child the best chance of developing natural fluency.”*

Ms. Anderson added:

*“Some speech therapists I have spoken to in Scotland have commented on the low number of referrals of children for dysfluency.*

*“The later a child is referred to a speech therapist, the longer and more difficult it usually becomes to achieve natural fluency – and this means more health service resources are taken up.*

*“It is time to speak up about stammering as this difficulty has been swept under the carpet for too long.”*

(Below, contact and interview information. First, various quotes.)

John McAllion, MSP for Dundee and patron of the British Stammering Association said:

*“Having stammered very badly from my earliest years until my 20s, I can well understand the frustration, embarrassment and pain caused to those afflicted. It was only in my mid 20s, when I was persuaded to seek help from a speech and language therapist, that I began to get my stammering under control and started to lead a normal life.*

*“I very much commend the work of the British Stammering Association and their campaign to provide proper facilities to allow all youngsters afflicted by this problem to receive early treatment and early intervention to help them overcome their stammer.”*

Anne Marie Selby, mother of four-year old Jack, said:

*“Jack began repeating letters and as time went by it got worse. His eyes started to roll back and he cried when he couldn’t get a word out. At his three-year check I said I thought he had a stammer but I was told: ‘No, absolutely not – his mind is probably working quicker than his tongue’.*

*“I was told that if he still had problems at the age of four we could think about a referral to speech therapy.*

*“I’m a nurse and I was concerned. On the way out of the surgery I saw a leaflet from the British Stammering Association and found out I could self-refer. The doctor and health visitor were surprised when I did.*

*“Speech therapy was really great. Jack is like a different child. I took him for an assessment and they started a programme called Lidcombe. It needs a lot of input from the parent and you have to be 100 per cent committed to it.*

*“My husband and I took it in turns to play puzzles and word games each night – and the more Jack improved, the more delighted he became in himself. His confidence knows no bounds now.*

*“He is now on a maintenance programme but last time we visited the speech and language therapist Jack asked, ‘Why am I here? I don’t do bumps any more’.*

*“He is aware of his speech but in a positive way. I don’t have the same fears about him going to school and being bullied for being different now. His speech is in line with his peers – with only occasional whole words repeated like other children of his age.*

*“I think parents should trust their instincts and not be sidelined by professionals. You are your child’s best advocate.”*

Michelle Johnstone, mother of three-year old Anthony, said:

*“It started suddenly one day and I noticed it from then on and knew it wasn’t right. Anthony found it hard to get started. Sometimes nothing came out. He got frustrated and angry because he knew he could talk but he just couldn’t get his words out. I went to my health visitor and she said she would contact a speech therapist. I heard there was a three-month waiting list and I panicked because I knew he was getting worse. I chased it up myself and got an appointment in a week. I knew that the longer I left it, the worse it would get.*

*“It’s about a year since we started seeing our speech therapist. It’s been a long haul but it was worth it.*

*Sometimes Anthony used to stammer on every sentence. At first we went for therapy every week and did sessions at home every day, twice a day on bad days. Sometimes Anthony got bored by it – but it was worth it. He’s been fine for two months now and our next appointment is in four months.”*

Liz Hoey, team leader of the Yorkhill Dysfluency Team in Glasgow, said:

*“In my experience a lot of referrals are still coming through at school age and as a child gets older they may find it more of a struggle to speak. As a result, therapy time can be a lot longer at this stage. Treatment can be very effective in the early stages of stammering but often referrals are made well beyond the early stages.*

*“It seems to be quite a common reaction from parents and other professionals to ‘wait and see’ when actually it would be more beneficial to the parents and the child in the long-term to seek help and advice as early as possible.*

*“Not many parents know that if they are concerned about their child’s speech they can contact their local speech and language therapy department and refer them. Hopefully, this campaign will raise people’s awareness about the importance of early referral.”*

Norbert Lieckfeldt, Director of the British Stammering Association, said:

*“This campaign is the second stage of our Association’s drive to give every dysfluent child the best possible start in life. Previous experience has shown that targeted information will result in many more children being referred to speech and language therapists at the optimum time for treatment – children whose stammer would not have been spotted otherwise.*

*"This campaign has received the backing of Scottish funders, including the department responsible for health in Scotland. Scottish speech and language therapists have also been very supportive. The BSA is most grateful for the reception this campaign has received north of the border."*

Roberta Lees, University of Strathclyde, expert in the field of childhood dysfluency, said:  
*"There is no doubt that early referral to a speech and language therapist will provide early intervention for a child with a dysfluency problem, when such intervention is necessary. All the research evidence has shown that the best results are obtained with children who have had treatment early, preferably within six months of the parent/carer noticing the problem."*

For more details, contact Jan Anderson on 07740 308811 (mobile) or 0131 229 8069 or [jan.anderson@ecosse.net](mailto:jan.anderson@ecosse.net)

### **Interview opportunity**

Jan Anderson, Liz Hoey, Roberta Lees and Anne Marie Selby and her son Jack will be available for interview at Liz Hoey's speech therapy clinic on the morning of October 22.

Where? Parkhead Health Centre, 101 Salamanca Street, G31 5ES.

When? 10.00hours.

Local media organisations wishing a more local interviewee are advised to contact Jan Anderson at the above number.

### **Notes to editor**

The British Stammering Association (BSA) is a charity which was established in 1978. It is the only national organisation for people who stammer of all ages. BSA offers a free advice and information service and aims to encourage debate and research into the nature and treatment of stammering.

BSA offers a Parents' Helpline (0845 603 2001, local rate call) where parents can speak to a qualified counsellor and receive information and advice regarding speech therapy. It also operates a 'Parents Network' where parents of stammering children can share experiences and provide support to each other over the telephone. There is also a website [www.stammering.org](http://www.stammering.org)

Earlier this year, the British Stammering Association appointed Jan Anderson as its first project co-ordinator in Scotland.

### **Facts about stammering**

- Five per cent of children will experience dysfluent speech while learning to talk.
- About a third of these children will not 'grow out of it'.
- Stammering commonly begins between the ages of two and five (average onset: two years eight months).
- Onset of stammering can be sudden or gradual.
- No one cause of stammering has been identified.
- A genetic predisposition is a likely contributing factor as stammering frequently appears to run in families.
- One per cent of the adult population is affected by stammering.

ENDS

## **Appendix 6**

### **Media Campaign**

Television coverage

STV lunchtime news 22.20.01

Grampian Midweek 13.11.01

### **Radio**

Scot FM

Radio Forth

Central FM

Kingdom FM

BBC Orkney

### **Press**

Herald

Glasgow Evening Times

Telegraph

Perth Courier

Evening Telegraph and Post (Dundee)

Dundee Courier

Aberdeen Press and Journal

Other local dailies

### **Specialist magazines**

Nursery World

Therapy Weekly

Childminding (Scottish Childminding Association)

First Link (Scotland wide free magazine for parents)

First Five (Scottish Pre-school Play Association)

Cygnets (Tayside NHS Trust Magazine).