

The Primary Healthcare Workers Project

A Summary Report

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**A four year
investigation into
changing referral
patterns to ensure the
early identification
and referral of
dysfluent preschoolers
in the UK**



The British
Stammering
Association

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The British Stammering Association

It is widely recognised that people who stammer are a heterogeneous population and although it is not known what causes stammering research suggests that a combination of factors is involved. Stammering is not simply a speech difficulty but a serious communication problem. It can undermine a person's confidence and self-esteem, affect their interaction with others and hinder their education and employment potential. The disorder affects an estimated 188,000 preschoolers, 109,000 school age children, and 459,000 adults in the UK.

The British Stammering Association (BSA), established in 1978, is a national registered charity. It is the only UK-wide charity which helps both adults and children who stammer. The BSA is the largest stammering

organisation in Europe and provides information, help and support to all whose lives are affected by stammering. The BSA is committed to developing and implementing major projects to address the varying needs of all those affected by stammering. The four year, UK-wide Primary Healthcare Workers Project, described in this report, has aimed to promote early identification and referral of pre-school stammering children among GPs and health visitors. In addition the BSA is currently working to address neglected issues concerning education and pupils who stammer, to provide a national, confidential information and telephone counselling service, and to improve the support services available to adults who stammer.

Foreword

Of all the communication problems that Speech and Language Therapists deal with, the one which is probably most obvious to the general public is a stammer. Most of us will have seen an adult with a pronounced stammer trying desperately to communicate. Although the overt signs of stammering may be quite obvious, what is less obvious to people are the associated problems which a stammerer may have, and which may have a significant effect on their lives.

Most research has been done into types and timing of treatment for stammerers and it has become obvious that early intervention may well increase a child's chance of living a life free of stammering and associated problems.

The British Stammering Association has been closely involved in instigating and supporting the Primary Healthcare Workers Project. This project has taken as its premise that the earlier you work with a child with a stammer the better the outcome for that child. The study has looked at two and a half thousand children over four years and has recognised that we need to change referral patterns to ensure this early identification and referral of

dysfluent pre-schoolers across the country. The study makes recommendations for undergraduate and postgraduate training in dysfluency and itemises some good practice guidelines, which include recommendations about training for student health visitors and communicating with GPs and also recommends the production of accessible information on early stammering which can go to parents, health visitors and other interested stakeholders.

The project notes the need for Speech and Language Therapists to continue to work proactively with parents and in partnership with health, education and social services professionals, which is entirely in keeping with the type of collaborative working practice that we all feel is necessary in the twenty-first century.

I welcome this report and I am delighted that such a comprehensive piece of work will help to form the corner stone of our thinking about early stammering and how we deal with it in the future.

Veronica Goddard, Chair,
Royal College of Speech and Language Therapists

Introduction

Why the project began

The Primary Healthcare Workers Project was initiated during the early 1990s as a result of concerns raised by parents that their GP, health visitor or speech and language therapist (SLT) had advised them not to worry about their child's stammer, to ignore it or that their child would outgrow it in time.

These first-hand accounts indicated that many health professionals across the UK remained unaware of the benefits of early referral and treatment for dysfluent children, which were being widely reported in the stuttering literature at that time. The results of research studies, both in the United States and in Australia, demonstrated that early intervention with preschoolers is particularly effective in ameliorating a stammer. Therefore a project was proposed which would aim to educate healthcare professionals about the value of identifying, referring and treating young dysfluent children early rather than telling parents to 'wait and see'.

Many health professionals across the UK have remained unaware of the benefits of early referral and treatment for dysfluent children.

The Problem

The project aimed to address existing suppositions which inhibit the prompt referral and delivery of treatment to young children who stammer, namely:

- Johnson's outdated diagnosogenic theory (1959) which suggests that if a stammer is ignored by parents and others it will not develop into a chronic disorder;
- the high recovery rates from stammering among preschoolers which give credence to the idea that many children will simply outgrow their stammer without intervention and so a referral is unnecessary;

- therapists anxiety that intervention with a dysfluent preschooler will be ineffective, will exacerbate the child's dysfluency and cause an irremediable impairment.

This was based on the prevalent notion that it is better to "watch and wait" rather than refer and intervene unnecessarily as most young children will recover from their stammer. This debate has been fuelled by Curlee and Yairi (1997) and Onslow (1999) who argue that perhaps it is less costly to "wait and see" than to intervene with a child who, given time may have recovered. However, clinicians and researchers still only have indicators of prognosis rather than reliable predictors. Thus, until therapists can consistently and reliably differentiate and screen out those children who will recover from those who are at greatest risk for persisting, it is crucial that young dysfluent children are referred to SLT for assessment as early as possible.

Health professionals and parents seemed unaware that 70% of all childhood stammering is mild in severity¹ therefore they also may mistakenly be less concerned about mild stammering and perhaps less likely to refer these children early assuming their chances of recovery to be high.

These tenets have continued to be prevalent among health visitors and GPs, affecting the age at which dysfluent children are identified and referred, and among many SLTs who believe they should adopt a "hands-off" attitude when working with young stammering children.

Such views led the project fieldworker to consider the following questions:

- I) Are dysfluent preschool age children being referred early (i.e. soon after onset), or as many as could be?
- II) What proportion of children are newly referred or re-referred under and over five years of age?
- III) What are the current referral rates and waiting times in the UK?
- IV) What effect does a specialist SLT have on referral rates and waiting times?
- V) Can dysfluency referral patterns be changed?

¹Onslow, 1999

The project's aims:

Given that the mean onset age of stammering is 32.8 months², that 75% of the risk for stammering is passed by 3;06 years³ and that the best prognosis for children who stammer appears to be related to receiving appropriate and timely therapy, it should be possible to identify most dysfluent children for therapy before they begin school.

Thus the overall objective of the Primary Healthcare Workers Project was to change dysfluency referral patterns across the UK to ensure all young dysfluent children are identified and referred to SLT as soon as possible after stammering onset. If achieved this would create greater opportunities for SLTs to deliver effective therapy at the optimum time period when it can be most cost- and time-effective and has long term benefits for the child and his/her parents.

Five goals were identified:

- 1 To educate and persuade health visitors and GPs of the importance of referring dysfluent children to a speech and language therapist earlier than has previously been the practice.
- 2 To provide health professionals with information to enable them to identify children at greatest risk of early stammering.
- 3 To help professionals feel more confident in making appropriate referrals
- 4 To increase parental awareness of stammering in pre-school age children, in order that parents will seek help and advice earlier and so reduce the time lag between the onset of stammering and referral to SLT.
- 5 To examine and evaluate any methods that effect change in the dysfluency referral patterns of health professionals.

During the course of the project two further aims emerged:

- 6 To provide practical postgraduate training courses on working with early stammering, for generalist SLTs in order to increase their confidence and knowledge in assessing and treating dysfluent pre-schoolers.
- 7 To provide information on early stammering for parents of dysfluent children, whose first language is not English.

The project report is divided into 6 sections in which the relevant literature is reviewed and the methodology summarised. The main results are described and discussed briefly and finally, the key recommendations arising from the project findings are presented.

²Yairi & Ambrose, 1992

³Yairi, 1993

Literature review

Efficacy of Early Intervention

In the past decade there has been a growth in the number of studies demonstrating that early intervention for dysfluent preschool age children can be very effective in retracting stammering behaviour and preventing long-term chronicity⁴ and that therapy can be a relatively rapid process⁵.

Early treatment is indicated to prevent the long term social and employment consequences borne by the client and society of delaying intervention.

Although there is no cure for adult stammering, therapy for early stammering is known to be effective. Starkweather (1997) recommends intervening early and close to the incipience of the dysfluency for many reasons, viz.: the young child is much easier to change than an adult; the duration of treatment is short compared to that for adults (8 weeks to a year); treatments developed for pre-school children are both efficient and effective with essentially complete remission of symptoms, no side effects and little relapse in about 95% of cases. He argues that "it is better to treat children who would recover spontaneously than not treat all, particularly as therapy does not harm the child" (1997) and asks "even if the spontaneous recovery rate should turn out to be 80%, should the remaining 20% pay the price of postponing intervention to see whether or not the stutter is going to stick around?"⁶. Hood (1999) supports this position.

Effects of Chronic Stammering

It has been observed that a higher proportion of young offenders and those in prison stammer than in the general population⁷. Other studies have demonstrated that adults who stammer can face discrimination in the workplace⁸ which in turn affects their employment potential⁹. These studies highlight the long term difficulties, principally social exclusion, which adults who stammer may encounter and reinforce the importance of identifying stammering soon after onset and providing intervention during a child's preschool years. Current academic and ethical arguments continue on whether to intervene early or withhold treatment and monitor a young child's progress for natural recovery¹⁰. On balance, however, early treatment is indicated to prevent 1) the potential long term financial and temporal costs to the NHS which prolonged therapy brings and 2) the social and employment consequences, borne by the client and society, of delaying intervention.

Epidemiological Factors

Sex Ratio Differences

It is well researched that three to four times more males than females in the school age and adult population stammer¹¹. At a preschool age, the ratio is considerably lower. Yairi and Ambrose (1992) collected on 87 pre-school children which produced a male to female ratio of 2.1 to 1 for the under fives. Comparing preschool and school age gender ratios suggests that recovery from stammering is stronger in girls than boys. However it remains unclear whether and how gender may relate to severe or long term stammering.

Age at Reported Onset

Yairi and Ambrose (1992) collected information on the reported age of stammering onset for 87 preschoolers. Results indicated that 68% of onsets had occurred between the ages of 25 and 41 months, with a mean reported onset of 32.8 months. Interestingly, they found that the mean stammering onset for girls was five months earlier than for boys, at 29.3 and 34.4 months respectively.

⁴Fosnot, 1992; 1993; Onslow, 1996; Starkweather, Gottwald & Halfond, 1990; Yairi, Ambrose & Niermann, 1993

⁵Druce, Debney & Byrt, 1997; Onslow, Andrews & Lincoln, 1994

⁶Starkweather, 1993

⁷Bryan & Forshaw, 1998; Crowe, 1991; Johnson & Hamilton, 1997

⁸Schloss, Espin, Smith & Suffolk, 1987

⁹Ayre, Wright & Grogan, 1998; Craig & Calver, 1991

¹⁰Curlee & Yairi, 1997; Onslow, 1999; Yairi & Ambrose, 1999

¹¹Bloodstein, 1995

Prevalence and Incidence Rates of Stammering in Children

Since the early 1900s researchers have been conducting studies in various countries to examine the prevalence* and incidence** of stammering in children and adults. Despite differing methodologies and sample numbers, the many studies, primarily carried out in Europe and the United States have yielded comparable results of around 1% prevalence, but more disparate incidence rates of between approximately 4-5%¹² and 14-15%¹³.

Glogowski (1976) conducted two studies in Poland using a subject pool of 875,384 school age children, and found the percentage of school age children who stammered to be 1.82 and 1.72. The most recent British study into the prevalence of stammering among children, was conducted by Andrew and Harris (1964). Research on 7358 school age children from Newcastle-upon-Tyne found a prevalence rate of 1.2 percent. Yairi and Ambrose (1992) reported a prevalence rate of around 1% for childhood stammering.

Andrews and Harris (1964) completed the only longitudinal study into the incidence of stammering. 1000 children were monitored by health visitors at various intervals, from birth to sixteen years of age. 43 of these children were identified as having ever stammered. The findings demonstrated an incidence rate of 4.9%. One percent of this sample evidenced a persistent stammer at 15 years of age and 4% of the stammering children were considered fluent by the end of the study. Data from the same study demonstrated that 76.7% of the children recovered and 23.3% continued to stammer at 16 years of age. This is commensurate with the results of more recent studies.

Rates of Recovery

In a prospective study of 32 dysfluent preschoolers, Yairi, Ambrose, Paden and Throneburg (1996) found a high rate of recovery during the early months of stuttering, and that recovery continues for at least 15 months after the time of stuttering onset. The children studied followed one of three distinct pathways, viz.: recovery within 18 months of onset (early recovery), recovery within 18 to 36 months of onset (late recovery), ongoing dysfluency for more than 36 months after onset (persistent stammering). The subjects from the two recovered groups yielded a 63% recovery rate. Yairi et al (1996) suggest that around two thirds of dysfluent preschoolers will recover from their stammer, but one third will persist.

A more recent longitudinal study of 84 children¹⁴ observed a 74% recovery rate and found that the frequency and severity of stuttering continued to diminish over time, particularly during the first 14 to 16 months post-onset, “with a 65% complete recovery rate during the first 2 years after onset and additional recovery at a later time” (p1098).

Stammering severity has often been viewed as an indicator of chronicity (i.e. a severe stammer in a young child is often perceived as a stronger indicator for persistence and a mild stammer to recovery). However, Yairi et al (1996) found that children who demonstrated moderate to severe “stuttering like dysfluencies” (SLDs) followed the early and late recovery pathways whereas the children with mild SLDs followed the persistent pathway. The SLDs were still apparent in the early and late recovery groups 12 months post onset, but within 18 months of stammering onset the “SLDs” of the recovered groups fell within the range of normal nonfluencies.

¹²Andrews & Harris, 1964; Cooper, 1972; Porfert & Rosenfield, 1978

¹³Glasner & Rosenthal, 1957; Seider, Gladstien & Kidd, 1983

¹⁴Yairi & Ambrose, 1999

* prevalence relates to the percentage of people who stammer at a given time.

** Incidence relates to the percentage of the population who have stammered at any time in their lives. (Bloodstein, 1995)

Review of Audit Studies on Dysfluent Referral Patterns

During the past six years, several therapists¹⁵ have conducted audit studies in order to understand the factors which govern the referral patterns of key referrers, including health visitors, with regard to dysfluent pre-schoolers and school age children. Although they used different methodologies, the conclusions reached are similar. Results have generally indicated that most GPs

- refer stammering children to SLT as opposed to another health professional, but beyond the stage at which therapy can be most effective (i.e. under five years of age).
- are unaware of the trend to treat stammering at an earlier age,
- have not received information on stammering during their training
- use disparate and ambiguous referral criteria, which are not based on a current knowledge of stammering.

The findings indicate that GPs need to be provided with up to date information and training on childhood stammering, risk factors and the benefits of early treatment. However, therapists have held the view that training and leafleting GPs about SLT is ineffective and does not change their referral practice.

Chapman (1995) surveyed health visitors. Responses indicated that their knowledge of causative factors and relevant parental advice did not reflect current knowledge or best practice. However, all the health visitors were interested in attending a workshop on early stammering.

The low number of stammering children GPs reported seeing may reflect the wide interpretation of the term stammering. It is possible that GPs and health visitors only included those children presenting with the severest forms of struggle behaviour. Except for Edwards (1996) survey, none of the audits provided health professionals with a definition of stammering (e.g. 70% of stammering cases are mild) when asking about their knowledge of childhood stammering. Without a definition, it is possible that those questioned based their responses on all stammering cases except the mildest and thus excluded a large number of children.

Referral Agents

Watson's (1996) results show that 31% of dysfluent children are referred up to the age of 4;11 years, but most referrals (44%) are made when children are between 5;00 and 11;11 years old. The study revealed that in the under 4;00 age group, 72% of referrals are made by health visitors, 10% by GPs and 8% by parents. In contrast health visitors contributed to 52% of the referrals in the 5;00 to 11;11 age group, parents 22% of referrals, GPs 10% and education 4%.

Watson (1996) also reviewed waiting times between referral and initial assessment. and found that across Trusts in Northern Ireland, half of all dysfluency referrals are seen for assessment 4 to 12 weeks after being referred, a third of children are seen within 2 to 4 weeks of referral and 17% wait for three or more months before being assessed.

¹⁵Chapman, 1995; Edwards, 1996; Rustin & Kelman, 1994; Watson, 1996

Postgraduate Training of SLTs

Watson (1996) investigated the relationship between postgraduate training and therapists' level of confidence in working with dysfluent children. Of SLTs who had not received postgraduate training, only 38% felt quite confident, confident or very confident in working with this client group, compared to 66% who had attended training courses. Postgraduate training clearly produced a positive change in therapists' confidence in dealing with dysfluent children. However, the length of time SLTs had been practising also had an effect. 55% and 43% practising for 0 to 3 and 4 to 10 years respectively felt not very confident in comparison with only 18% of SLTs working more than 10 years.

Watson suggested that low confidence levels may relate to the lack of opportunities and resources therapists had post-course to put newly acquired skills and knowledge into practice. She acknowledged that therapists' level of undergraduate training and their personal characteristics may also influence their confidence levels.

Until SLTs can reliably differentiate dysfluent children who will recover from those at risk for persisting, it is crucial that all young dysfluent children are referred to SLT for assessment as early as possible.

Methodology

In order to measure any change in referral patterns it was necessary to establish the current paediatric dysfluency referral rates and patterns in the UK, viz.: the main referral agents of children under/over five years of age; the mean waiting times between reported onset age and referral to SLT, referral to SLT assessment and assessment to beginning therapy; how dysfluency referral patterns and waiting times can be influenced; whether the presence of a specialist SLT affects referral rates.

Pilot Project

Hypotheses were tested out during a pilot year in two contrasting NHS Trusts (inner city and suburban/rural). The Trusts had similar preschool population sizes, although they differed demographically. Each had a therapist who was experienced in working with stammering children, but who did not hold a specialist post. A standard data collection form was used to record referral information under particular data fields which are described below. The data were logged on the computer using Microsoft Excel. As part of the pilot project, two new leaflets were developed for professionals¹⁶ and parents of dysfluent preschoolers¹⁷. Channels for mailing the leaflets and training health visitors and GPs were trialled in each pilot area and their impact on changing referral patterns was monitored. Post-project dysfluency referrals were recorded on the same data collection form. The project leaflets and activities were refined over the pilot year, before being replicated at a national level.

National Phase

A therapist from each community NHS Trust in the UK was invited to attend a regional meeting led by the fieldworker. Each therapist received a resource pack developed by the fieldworker¹³ to enable them to implement the project more easily. The purpose of the session was a) to provide a brief update on relevant literature regarding the timing and efficacy of early

intervention, b) to train SLTs to collect baseline data on their Trust's paediatric dysfluency referrals and to record the information on a standard form (phase 1), and c) to tell them how to implement the project in their Trust (phase 2).

Phase 1

Once therapists had collected and recorded information on all new dysfluency referrals (children 0-16 years of age) received by their Trust over the previous/forthcoming 12 month period, the information was sent to BSA to be analysed. Data sets received from each Trust were analysed using Microsoft Excel and given a code to ensure anonymity. Therapists' received the analysed baseline referral data on acetate in order that they could present their Trust's current dysfluency referral patterns at subsequent health visitor or GP training sessions.

Phase 2

Therapists were informed of effective channels through which they could deliver training sessions and distribute the project leaflets to their health visitors and GPs and for their health visitors and GPs on identifying early stammering and the importance of early intervention.

Phase 3

Following training and/or leafleting of their referral agents, therapists were asked to collect information on all subsequent paediatric dysfluency referrals received by the department during a 12 month period. The data were recorded on the same referral data form used in phase 1 of the project and entered on the computer using Microsoft Excel. Combined pre- and post-project results from participating Trusts were analysed by a statistician using SPSS for Windows.

Data Fields

The following data fields were used to compile information on dysfluency referrals: the male to female ratio; the date of referral; age at referral; referring agent;

¹⁶Christie, 1995

¹⁷Christie, 1996

age at assessment; previous referral; reported stammering onset age; age at start of therapy and nature of therapy given; the onset to referral interval; the referral to assessment interval; the assessment to therapy interval; additional data (i.e. the reason for the referral, how many referrals had English as their second language).

Any dysfluency referral data which contained inaccurate information (e.g. age of referral 3;02 years, age at assessment 3;00 years) were excluded, to ensure that the data included for analysis was valid. When data were incomplete (e.g. if reported onset was unknown) the individual datum was coded as such so that the remaining referral information could be utilised. Only children whose primary referral reason was dysfluency or dysfluency with concomitant speech and language difficulties were included in the data. Children who were referred to SLT for phonological or language delay but developed dysfluent speech subsequently were excluded from the sample. As the project sought to reduce the time lag between onset and referral to SLT, this interval was invalid for children with phonological difficulties who had already been referred, assessed and were in therapy prior to becoming dysfluent.

SLT courses for Generalists

During the course of the project, four regions with particular training needs were identified because of

- 1 a dearth of specialist stammering therapists in those areas and
- 2 poor access to training courses and study days because of their geographical location.

This led BSA to set up 6 pilot courses for generalist SLTs in assessing and treating dysfluent preschoolers. Three specialist therapists, two of whom currently lecture, were asked to develop a 3 day course. Trusts in each region were invited to send/nominate at least 2 therapists in order to ensure shared knowledge and peer support when SLTs returned to their departments.

Therapists attended a 2 day training course and a follow-up day approximately 3 months later. The aim of the courses was twofold: to increase SLTs' knowledge of the nature and treatment of childhood dysfluency; to increase therapists' confidence in working with parents and children who stammer and facilitate changes in practice. A pre- and post-course evaluation form was developed to measure these changes and given to SLTs to complete at the start and end of each course. A further form which evaluated the structure and content of each course was also distributed.

Bilingual Audio-tapes

During the national phase, therapists working in linguistically diverse areas identified the need for up to date information on early stammering to give to parents of dysfluent preschoolers whose first language was not English. Through collaboration with the Special Interest Group (SIG) in Bilingualism, a questionnaire was devised and mailed to SLT members (n=59) to ask them for

- 1 information on the number of dysfluent bilingual children on their caseload under and over five years of age, and their language
- 2 details of any bilingual resources known to SLTs or currently being used with dysfluent children
- 3 their experience of the best medium for sharing information with parents whose first language is not English.

This data aimed to ascertain the level of need for any resources required and the most accessible form of information for such parents.

Results

Project Participation

There were 225 NHS Community Trusts in the UK at the time the project began, excluding the two pilot project areas. 96.88% of all UK Trusts (n = 218) were contacted during the national phase and invited to send an SLT to an implementation meeting. Only 7 (3.12%) were not contacted due to time constraints. 31 regional implementation sessions were held to enable as many SLTs as possible to become involved in the project.

92.44% of Trusts (n=208) attended an implementation meeting and were trained to apply the project within their Trusts. 10 Trusts (4.44%) did not send a contact SLT to a meeting. Therapists unable to attend a regional implementation session had the opportunity to receive training by telephone. 28 therapists participated in such a session.

31.25% of Welsh Trusts participated in the project, 39.1% of Scottish Trusts, 54.5% of Trusts in Northern Ireland and 58.8% of Trusts in England.

Reasons for Non-participation

Following the meetings, 12 therapists declined to participate in the project (5.33%) because of current service pressures or because they believed their preschool dysfluency referral rate was already good.

A further 72 Trusts (32%) did not collect referral data following the implementation meeting. The reasons are equivocal but may relate to; participation raising expectation of the need for a dysfluency service; how to respond to an increase in dysfluency referrals if the Trust has no specialist.

Although these Trusts did not collect baseline information on dysfluency referrals, many therapists still chose to carry out the project activities. Thus the actual number of Trusts which dispersed information on early stammering is higher than the 123 (54.67%) which formally took part in the project. Therefore over two thirds of all UK Trusts undertook to train and/or leaflet their health visitors and GPs about early stammering.

Project Data

123 NHS Community Trusts provided baseline data on UK-wide referral trends on over 3500 stammering children (aged 0 to 16 years). Preliminary results, based on completed data sets from 12 community Trusts, were reported in an earlier paper¹⁸. In the current study, 32 Trusts completed all three phases of the project within the timescale. This provided comparative referral information based on 2648 dysfluent children. 44 and 53 children pre- and post-project respectively were excluded from the study because of data entry errors (e.g. SLTs provided incomplete information or time intervals such as onset to therapy were incompatible).

Gender

The 32 Trusts which participated provided a total sample size of 2648 children: 1747 preschool age children (468 males and 203 females pre-project and 736 and 340 post-project) and 901 school age children (324 males and 78 females pre-project and 387 and 112 post-project). This produced a male to female ratio of 2.30:1 and 2.16:1 for preschoolers and of 4.15:1 and 3.45:1 for school age children pre- and post-project respectively.

The gender distribution among under fives and over fives, pre- and post-project was analysed by ANOVA. Overall, the ratio of males to females did not drop significantly post-study ($F=0.43$, $df=1$, 31, $p=0.5187$). However, the ratio of males to females was significantly higher in the over fives than the under fives ($F=30.79$, $df=1$, 31, $p=0.000$) pre- and post-project. The ratio did not change significantly more among the under fives after the study than among the over fives ($F=0.03$, $df=1$, 31, $p=0.8674$).

Reported Onset Age

Group means and inter-quartile ranges are provided. Reported onset times for the whole sample were analysed by ANOVA. Reported onset ages were significantly earlier post-study than pre-study ($F=5.41$, $df=1$, 1923, $p=0.0200$). However, there was no difference according to gender ($F=0.47$, $df=1$, 1923, $p=0.4910$) and no correlation

¹⁸Christie & Evesham, 1998

between gender and phase of study. Onset ages had a strong positive skew with no obvious bi-modal distribution. The inter-quartile ranges demonstrate that pre-project, 25% of all stammering onsets occurred by 2;06 years of age and 75% of onsets by 4;00 years of age. However, in the post-project sample 75% of all onsets were found to occur by 3;09 months of age.

TABLE 1 Childrens' ages in months at reported time of onset, means and inter-quartile ranges for all subjects, pre- and post-project.

All children	Inter-quartile range		Age in months		
	Q1	Q3	Mean	Median	Mode
Pre-project (n=797)	30.00	48.00	43.16	36.00	36.00
Post-project (n=1154)	30.00	45.00	41.10	36.00	36.00

The reported onsets of children under five were of particular interest because of the minimal time which would have elapsed since onset. Therefore parental recall was expected to be most accurate. The mean, median and mode stammering onset ages for preschool children are reported in Table 2. The pre-project standard deviation for reported onset ages for males and under 5 pre-project was 7.586 months and 9.356 respectively and 8.180 months and 7.623 in the post-project phase.

In Table 2, the inter-quartile range of onsets based on data from preschool age children only, shows that 50% begin to stammer between 2;03 years and 3;03 years of age, and 75% of onsets occur by approximately 3;05 years.

ANOVA tests showed no significant changes in mean reported onset for preschoolers pre- and post-project ($F=0.18$, $df=1$, 1308 , $p=0.6704$). Neither was there a gender effect on mean onset age for this age group ($F=0.79$, $df=1$, 1308 , $p=0.3737$). These findings indicate that stammering onset is an independent variable and a reliable clinical measure. The median onset ages for boys and girls pre- and post-project were also consistent with the mean scores. However, a clear difference arose between the male and female mode values, which

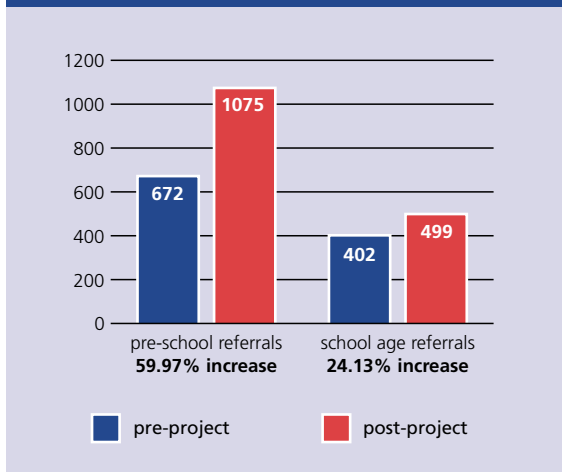
75% of all stammering onsets for preschoolers occurred by 39 months of age, with a mean onset age of 34.3 months for males and females.

highlighted that the most frequently occurring reported onset ages were 36 and 24 months pre-project and 36 and 30 months post-project for males and females respectively. This would support the research that the emergence of stammering is linked to language development, which is frequently earlier in girls. This suggests some relationship between gender and age and earlier onset of stammering in girls, possibly relating to earlier language development of girls.

TABLE 2 Childrens' ages in months at reported time of onset, means and inter-quartile ranges for male and female preschool age subjects, pre- and post-project results.

Preschool age children	Inter-quartile range		Age in months		
	Q1	Q3	Mean	Median	Mode
Boys pre-project (n=354)	28.00	38.00	33.63	34.00	36.00
Girls pre-project (n=144)	27.00	41.00	34.55	34.00	24.00
Boys post-project (n=557)	30.00	39.00	34.31	34.00	36.00
Girls post-project (n=257)	29.00	39.00	34.27	33.00	30.00

FIGURE 1 The rate of dysfluency referrals pre- and post-project.



Referral Rates for Dysfluent Children

Dysfluency referrals increased significantly across both age groups in the 32 Trusts which trained and/or leafleted their health professionals (Figure 1). Per Trust, the mean number of annual referrals increased from 33.56 to 49.25 referrals post-project ($t=3.58$, $p=0.001$). There was a significant change in the mean number of preschool age referrals from 21.00 to 33.66 post-project ($t=4.04$, $p=0.0003$). The referral rate for school age children also increased significantly from 2.56 to 15.59 post-project ($t=2.07$, $p=0.047$).

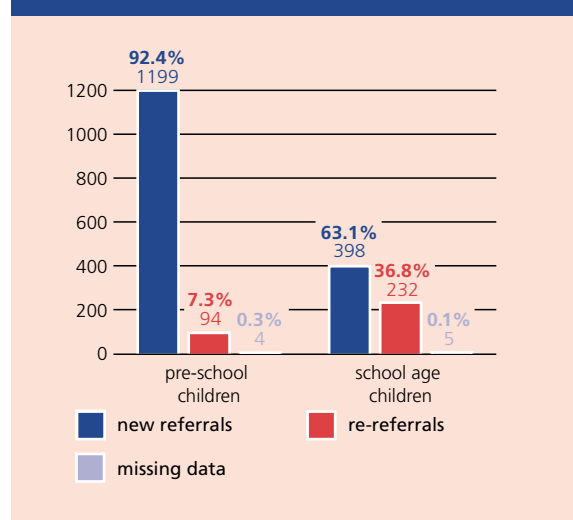
Pre-project, 65% of referrals were for children under 5 years of age whereas post-project they constituted 69% of referrals ($t=1.99$, $p=0.054$). Given that 75% of the risk of stammering is passed by 3;05 years (Yairi, 1993), a further 6% of dysfluent children need to be referred at a pre-school stage if this ratio were to be represented in this present study.

Re-referral Rate

The number of first time dysfluency referrals were compared to those previously referred for SLT. Results were gained from examining the referral status of 1,928 dysfluent children under and over the age of five years from 32 Trusts (Figure 2).

The majority of dysfluent children (62.2%) were referred to SLT for the first time when under five, but 20.6% were not

FIGURE 2 Rate and percentage of new dysfluency referrals and re-referrals by age group.



referred until they were over five. Chi square analysis showed that re-referrals were significantly more common in school age children than preschoolers ($\chi^2 = 263.333$, $df=2$, $p < 0.0000$). The high rate of re-referral (36.8%) among school age children is of particular concern.

Referral Agents

Chi square analysis on the total subject pool revealed significant increases post-project in the proportion of referrals made by health visitors, schools and SENCOs ($\chi^2 = 48.33883$, $df=11$, $p < 0.05$).

Data indicate that the project activities of leafleting and training had the greatest effect on preschool referral agents and a specific impact on health visitor referring. Post-project, the number of preschool referrals made by health visitors, schools, school nurses and SLTs increased significantly ($\chi^2 = 32.19214$, $df=9$, $p < 0.05$). The shift in the distribution of referral agents of dysfluent children over five years of age was not significant ($\chi^2=16.42321$, $df=11$, NS).

Just under 100,000 copies of the parents leaflet and 50,000 copies of the professionals leaflet were distributed from the time the project leaflets were first produced (1996). Over two thirds were requested by SLTs to give to

colleagues, health visitors, GPs and parents, around 15% were sent to health visitors directly, 6% to GPs and 8% to education and others.

GP Referrals

The proportion of GP dysfluency referrals diminished post-project, from 14.64% to 10.89% for children both in the under and over five age group. GPs were found to refer significantly later than other referral agents ($F=85.4$, $df=1$, 2646, $p=0.0000$). Pre-project, the mean age at which GPs refer dysfluent children was 77.37 months ($n=158$, SD 41.79) compared to 63.52 months ($n=916$, SD 38.10) for all other referrers, and post-project the mean GP referral age rose to 83.52 months ($n=172$, SD 46.67) but fell to 57.86 months ($n=1404$, SD 32.63) for all other referral agents.

Health Visitor Referrals

Pre- and post-project, the key referrers of dysfluent under fives were health visitors. The substantial increase in the quota of health visitor referrals from 64.28% to 74.51%, suggests that prior to the project, health visitors were failing to recognise just over 10% of dysfluent preschoolers. Thus the project activities, which aimed to update health visitors knowledge, have positively influenced their referral patterns.

Health visitors were found to refer dysfluent children at younger ages than other referral agents. Pre- and post-project, the mean referral age for health visitors was 44.04 months ($n=466$, $SD=15.91$) and 42.95 months ($n=851$, $SD=14.39$) compared to 82.05 months ($n=608$, $SD=43.13$) and 81.45 months ($n=725$, $SD=40.89$) respectively for all other referrers. However this does not represent a significant change in the timing of health visitors referrals ($F=0.45$, $df=1$, 2646, $p=0.5017$).

Factors Influencing Referral Rates

4 Trusts (12.5%) leafleted and trained their health visitors and GPs, 10 (31.3%) only leafleted their health visitors and GPs, 3 Trusts (9.34) leafleted and trained their health visitors only. 12 Trusts (37.5%) leafleted and trained their health visitors but only leafleted their GPs, 2 (6.3%)

leafleted and trained their health visitors but only trained GPs and 1 Trust (3.13%) only leafleted their GPs.

The results of ANOVA show that training health visitors did not produce a significant difference in referral rates. However, there was a significant effect of the phase of the study, pre vs. post ($F=9.87$, $df=1$, 30, $p=0.0038$). Thus the change in the referral behaviour of health visitors can be linked to leafleting health visitors with new referral information. This, rather than training was effective in increasing preschool dysfluency referrals. Health visitors who had not received training on stammering prior to the project beginning had higher referral rates post-project than those who had received training. The same pattern emerged where health visitors had not previously received general training on speech and language difficulties (not specific training on stammering) compared to Trusts in which health visitors had received general training.

The results of ANOVA of mailing GPs showed a significant effect on referral rates due to the phase of the study only ($F=11.76$, $df=1$, 30, $p=0.0018$). Although the initial mean referral rates of GPs who were leafleted were lower than in Trusts which were not mailed, (21.8 and 35.74 respectively) the referral rates for both groups were similar (49.4 and 49.22 respectively) following the mailing.

The project activities of leafleting and training key referrers were effective in increasing preschool dysfluency referrals, and had a specific impact on health visitor referring.

ANOVA showed no effect of training GPs ($F=0.34$, $df=1$, 30, $p=0.561$) although a numerical increase was observed post-project, but demonstrated a significant difference between the phases of the study ($F=6.30$, $df=1$, 30, $p=0.0177$). The mean referral rate in Trusts in which GPs were trained by SLTs increased post-project, but not as much as the mean referral rate of GPs who received no training but were

leafleted. Neither increase reached significance. The mean referral rate of GPs who had not received training on SLT difficulties prior to the project was greater post-project than in Trusts in which GPs had received prior training. Again the increases did not reach significance.

The Effect of a Specialist Therapist on Referral Rates

Dysfluency referral rates were compared pre- and post-project in Trusts with and without a specialist speech and language therapist (n=17 and n=15 respectively). The overall referral rate increased significantly in Trusts with a specialist as a result of the project activities (t=3.421, p=0.0034), whereas referrals in Trusts without a specialist did not (t=1.645, p=0.1222). The degree of increase depended on whether there was a specialist present. The results of ANOVA demonstrated that the correlation between increased referrals and the presence of a specialist therapist was statistically significant (F=6.11, df=1, 30, p=0.0193).

The referral rates of dysfluent preschoolers were higher in Trusts where a specialist was present and as a result of the project activities (Table 3). The degree of increase in referrals was statistically significant in Trusts with a specialist (ANOVA; F=9.16, df=1, 30, p=0.0050).

The mean referral rate of school age children increased in Trusts without a specialist, however, referrals in this age group increased significantly more in Trusts with a

Pre- and post-project, dysfluency referral rates were significantly higher in Trusts which had a dysfluency specialist compared to Trusts with no specialist therapist.

specialist SLT (ANOVA; F=4.95, df=1, 30 p=0.0338). Neither did the presence of a specialist impact on the referral to assessment interval nor depend on other factors such as the age of the children being referred or the phase of the study. The findings were not significant (F=0.07, df=1, 30, p=0.7889).

Waiting Times

1) Reported Onset to Referral Interval

Results of ANOVA for the reported onset age to referral interval for all dysfluent children were significant for gender and for the phase of the study (n=794 and n=1153 pre- and post-project). The time lag between stammering onset and referral to SLT reduced significantly as a result of the project activities (F=9.79, df=1, 1943, p=0.0018) by almost four months from 22.671 (SD 30.187) to 18.800 months (SD 26.322) for males and from 18.251 (SD 27.822) to 14.334 months (SD 23.239) for females. Males were referred later than females in both phases of the study, and the effect was stronger after the study.

TABLE 3 The effect of the presence and absence of a specialist SLT on the overall referral rate and on preschool dysfluency referrals received by Trusts over a 12 month period.

Phase of study	Trusts with no specialist therapist (n = 15)	SD	Trusts with a specialist therapist (n = 17)	SD
Mean no. of dysfluent referrals (pre-project)	28.066	13.285	38.411	22.743
Mean no. of dysfluent referrals (post-project)	34.200	18.758	62.529	36.898
Mean no. of dysfluent preschool referrals (pre-project)	12.200	5.453	18.411	10.362
Mean no. of dysfluent preschool referrals (post-project)	16.266	9.888	32.823	18.187

For preschool referrals (n=498 and n=814 pre- and post-project), the onset to referral interval was shorter in the post-project phase. Although a reduction in this time lag was observed for dysfluent females, the result of ANOVA is not significant ($F=1.88$, $df=1$, 1308 , $p=0.1702$). The onset to referral interval for preschool males and females respectively was 7.556 (SD 7.264) and 7.493 months (SD 7.869) pre-project and 7.064 (SD 7.075) and 5.933 months (SD 5.872) post-project.

2) Referral to Assessment Interval

ANOVA results for the mean referral to assessment period, indicated no significant difference across phases of the study ($F=0.57$, $df=1$, 1492 , $p=0.4487$), no gender difference pre- and post-project, and was not adversely affected despite a significant increase in dysfluency referrals post-project. The mean referral to assessment interval for preschool males and females was 1.804 (SD 1.545) and 1.785 months (SD 1.298) respectively pre-project and 1.742 (SD 1.428) and 1.883 months post-project (SD 1.265).

3) Assessment to Therapy Interval

The mean interval between assessment and beginning therapy did not change significantly pre- and post-project for children under and over 5 years of age ($F=0.32$, $df=1$, 1492 , $p=0.5774$). Neither was there a significant gender difference for waiting times in either age group, although the mean waiting time for therapy is clinically shorter for preschoolers than for school age children. The pre-project assessment to therapy interval in months was 0.926 (SD 1.976) and 0.578 (SD 1.370) for preschool males and females respectively and 0.922 (SD 1.776) and 1.058 (SD 4.024) post-project.

SLT Training Courses

Six training courses for generalist SLTs were piloted. Two were held within Greater Manchester as there was considerable need in the area. These were attended by 65 SLTs from 11 Trusts. Two courses for therapists working in the north of Scotland were attended by 66 SLTs from 16 Community Trusts, and two in Wales and the South West of England allowed over 72 therapists from 23 NHS Trusts to attend. Thus a total of 203 SLTs were trained.

Comparisons of the pre- and post-project questionnaires demonstrated positive improvements in therapists' skills and confidence in working with early stammering. Qualitative feedback indicated a change in SLTs practice as a result of attending the training courses.

The demand for training courses in working with young dysfluent children for generalist SLTs exceeded the boundaries of this project. Feedback from implementation meetings indicated that many other therapists wanted further training in order to feel more confident in working with this client group.

Results of Bilingualism Survey

A questionnaire sent to all SIG Bilingualism members (n=59) yielded a 47.5% response rate. Therapists most commonly encountered the following languages: Punjabi, spoken by 41.3% of parents of dysfluent children under five, Urdu (17.4%), Somali (10.8%), Gujarati (6.5%) and Bengali (4.3%). Punjabi was also the main language spoken by parents of under elevens (38.8%) and the under sixteen age group (42.3%). The remaining languages spoken by parents of children under eleven were Urdu (18.9%), Bengali and Gujarati (11.2%), and Somali (6.9%). The figures indicated that the majority of dysfluent bilingual children on SLTs caseloads form the 6-11 years category.

SLTs considered audio tapes (31.3%) to be most effective in conveying information to parents from linguistic minorities as they overcame any literacy difficulties. 17.2% of therapists favoured leaflets available in the family's own language, 12.5% preferred an interpreter, whilst 6.3% considered a video to be useful.

Slippage money was sought from the Department of Health to produce 5 language translations (Bengali, Gujarati, Punjabi, Somali and Urdu) of the BSA leaflet for parents of preschoolers¹⁹ on audio tape, providing information in parents' first language and English.

¹⁹Christie, 1996

Discussion

Gender

The current study found a pre- and post-project male to female ratio of 2.30:1 and 2.16:1 respectively for dysfluent children of preschool age (n = 1749). These ratios are not significantly different from the predicted 2.1:1 for preschoolers (n = 87), reported by Yairi and Ambrose (1992), and the ratio of 2.5:1 quoted by Johnson (1959).

The gender ratio of 4: to 5:1 in school age children and adults²⁰ is only supported by pre-project ratio of the current study (4.15:1). However post-project, a sample of 499 school age children (5:00 – 16:00 years), yielded a male to female ratio of 3.45:1 which is significantly different from previous studies.

As Yairi and Ambrose (1992, p787) note “the overall 2:1 male-to-female ratio indicates that gender preference in stuttering is beginning to surface at early stages of the disorder.” Furthermore, females tend to recover in greater proportions and recover at earlier ages than males²¹, thus the male ratio increases with age.

Reported Age of Stammering Onset

The findings of the current study on onset age are somewhat different to the research conducted by Yairi and Ambrose (1992). Comparing the onset ages of preschoolers, the current study found a mean stammering onset of 34.09 months pre-project and 34.29 months post-project and no gender difference for children of preschool age (33.97 months for boys and 34.41 months). Similarly the median onset age for preschool males remained constant in both phases of the study at 34 months and for females the median onset was 34 and 33 months in the pre- and post-project phases respectively. In contrast, Yairi and Ambrose (1992) quote a mean stammering onset of 32.8 months (34.39 months for males and 29.32 months for females, a 5 month difference in onset age) and a median of 30 months.

Inter-quartile ranges from the current project confirm that 75% of all stammering onsets for dysfluent preschoolers

occurred by the age of 38 and 39 months for boys and 39 and 41 months of age for girls. This is slightly lower than Yairi’s (1993) study which revealed that 75% of the risk of stammering onset is passed by 3;06 years of age (42 months) and significantly earlier than the findings of Andrews and Harris (1964) that 75% of the risk is over by 6;00 years of age. Yairi and Ambrose (1992) noted that 68% of all dysfluent preschoolers begin to stammer between 25 and 41 months old. They found that very few children had a stammering onset of over 4 years of age. The current study found that 50% of preschool stammering onsets (post-project) occur between 30 and 39 months for males and between 29 and 39 months for females. Thus it should be possible to identify and refer dysfluent school age children when they are at a preschool stage.

The re-referral and failure to attend rates of dysfluent children must be investigated, as well as the reasons for these courses of action.

Referral Rate

Across the 32 Trusts which participated, an additional 403 dysfluent children under five years of age were recognised and referred during the post-project phase, a referral increase of 59.97%. School age referrals increased by almost a quarter (24.13%) from 402 to 499. This suggests that project activities of leafleting and training which were directed at improving the preschool referral rate were effective in increasing the number of preschoolers referred. Given the statistical significance of the project results and the cross section of Trusts involved, if the project were replicated in all NHS Community Trusts (n = 225) there is the potential for a further 2833.59 dysfluent children to be referred and receive early intervention.

²⁰Bloodstein, 1995

²¹Yairi & Ambrose, 1999

Of equal concern is the high re-referral rate among dysfluent children of school age. The data show that 50% of males and females referred at school age had begun to stammer during their preschool years and so could have been referred much earlier. This confirms the importance of training referral agents in the early detection of stammering.

However, Yairi, Ambrose and Cox (1996) note that because recovery can take place at a very early age and within a short period after onset, it is highly probable that many cases of stuttering incidence and recovery cases go unreported. Thus in addition to the increase in dysfluency referrals observed as a result of the project, a further group of dysfluent children may never be detected.

Prior to the project, many therapists believed that their dysfluency referral rate was adequate and that training GPs would not be effective, therefore it is perhaps unsurprising that few therapists elected to run GP training sessions but preferred to train health visitors in their Trust. The project activities may have heightened awareness among referrers generally that dysfluent children should be referred to a SLT. Thus explaining why a simultaneous increase was observed in the number of referrals of children over five years of age, even although this age group were not targeted specifically.

Referral Agents

Unlike Enderby and Petherham's study (2000), which found that although referral rates of all referral agents had risen the distribution of the caseload has been relatively stable, the current study observed a change in the ratio of referrers of dysfluent children. Significantly more referrals were made by SENCOs, schools and health visitors in the post project phase, whilst GP referrals decreased. For dysfluent preschool referrals, the increase in the number of referrals by health visitors was statistically significant, whereas the proportion of GPs referrals fell in this age group. The top referrers in the current study are commensurate with those observed by Watson (1996) and other studies which have found that GP referral patterns are resistant to change²².

However, the low number of GP referrals may not wholly relate to their beliefs about early stammering, but may also reflect their role (i.e. to be more reactive), unlike health visitors, whose function is to be more proactive and preventative. Therefore, GP initiated dysfluency referrals may be less likely within the preschool population, whereas their opinion may be sought more often once a problem appears persistent.

Waiting Times

1) Time between onset and referral

For all dysfluency referrals, the time interval between reported age of stammering onset and children being referred to SLT diminished in the post-project phases of the study. A gender related difference also emerged, indicating a shorter onset to referral period for females.

For the preschool referrals a different pattern emerged. The mean onset to referral period for girls reduced whereas it remained constant for boys. However, girls still had a shorter waiting time between onset and referral than boys. The same observation was made by Yairi and Ambrose (1992), who noted a mean post onset interval of 4.89 months for preschool age females and 6.17 months for preschool age males.

2) Time between referral and assessment

In the current study, the mean waiting time from referral to assessment was similar for both dysfluent preschoolers and those of school age. Little change was noted pre- and post-project Yairi and Ambrose (1992) observed a statistically significant difference, namely that males had a later mean assessment age (40.56 months) than females (34.21 months).

3) Time between assessment and therapy

The mean interval between assessment and beginning therapy also showed little change pre- and post-project for children over five. Preschool age males waited 0.92 months to begin therapy in both phases of the project, whereas the waiting time for girls increased from 0.57 months to 1.05 months post-project.

²²Clemence, 1998

Despite the increase in the number of dysfluency referrals following project implementation in the 32 Trusts, the waiting times between referral and assessment, and assessment and therapy did not increase post-project. Although the waiting times in this study concurred with RCSLT guidelines, in some participating Trusts they were considerably longer (e.g. up to 25 weeks waiting time referral to assessment).

Training Health Visitors and GPs

The current findings suggest that the project activities of leafleting and training key referrers, particularly health visitors, were successful in altering the referral rates of dysfluent preschoolers. Written feedback from health visitors confirmed that the project leaflets and training sessions were extremely informative and updated their knowledge base of when and who to refer. This result has broader applications for health promotion activities in other clinical fields of speech and language therapy.

Because of the various factors operating in the 72 Trusts which did not participate (e.g. priorities of inner-city Trusts, geographically remote areas) it is possible that the results may have been different if the project had been implemented in those Trusts. However, the above findings suggest that the activities used in this project could be effective in improving the number and timing of childhood dysfluency referrals in Trusts which have low rates of referral relative to the population size.

Presence of a Specialist Therapist

Both pre- and post-project, dysfluency referral rates were significantly higher in Trusts which had a specialist SLT compared to Trusts with no specialist. It is likely that referral agents in Trusts with a specialist therapist are aware of such a service and so refer to it. Wilkin and Smith (1987) comment that referral patterns to different specialities tend to change over time and that influences on referral patterns are known to be related to availability of services, knowledge of referrers, political influences and public pressures.

The long term clinical and financial consequences of not having a dysfluency specialist must be explored, in relation to the length of time a child is in therapy, the type of therapy provided, and the measurable outcomes from the therapy.

Survey of Specialist Provision

A BSA study (1993) into the availability of specialist services in the UK for children who stammer indicated that only 25% of health districts offered a specialist therapy service to children who stammer. The 1992 survey found the regions most poorly served were the North West, Trent and Wales.

A 1999 survey found that of 11 UK regions, 39.3% of Trusts now provide a specialist dysfluency service. The three regions with the highest proportion of Trusts with a paediatric specialist are South Thames (48.1%), the North West (46.2%) and Northern Ireland (45.5%), and those with the lowest quota are Trent (33.3%), Scotland (26.1%) and Wales, where only 18.8% of Trusts provide specialist help.

Over the past 7 years, the number of health districts, now NHS Trusts, providing a specialist service to children who stammer has risen from 25% to 39.3%. This is an encouraging increase. However, with 60.7% of all Community Trusts not providing a specialist service, a parents probability of seeing a specialist SLT still very much depends on where in the country they live.

Data Collection Systems

One of the reasons therapists had difficulty in collecting referral information was related to their data collection system. Most SLTs found they were unable to extract the required information from the computerised database or that the database frequently failed to identify children referred for both dysfluency and language or phonological delay, thus contained inaccuracies and so information had to be collected manually instead. This issue is identified by Enderby and Petherham (2000, p138) who note that "unfortunately, the speech and language therapy service in common with many other health

services has not been well served by management information systems and there are many systems that do not allow for the retrieval of comparative data.” Collecting referral data was perceived as a laborious task because of therapists’ expectation that there would be too many referrals for which data would have to be collected and that therapists would then not received feedback on the data they provided. These concerns were unfounded as most therapists noted that there were fewer dysfluency referrals than they expected and the data collection process did not take as long as they anticipated. For most Trusts any increase in dysfluency referrals was spread over a year and equated to one extra referral per month.

In spite of the above concerns, the Primary Healthcare Workers Project has made a positive impact on SLT data collection; encouraging therapists to collect consistent data, to look specifically at their dysfluency referral patterns and aspects of these which could be improved.

Future Research Needs

The findings of the Primary Healthcare Workers Project provide signposts to future areas for research. Prospective studies are needed to examine

- the discrimination ratio (i.e. the number of correct to incorrect diagnoses of stammering amongst referrers and clinicians)
- whether diagnoses of developmental dysfluency have increased or diminished
- the incidence, prevalence and long term natural history of early stammering,
- the predictors of persistence of and recovery from early stammering²³ and the proportion of children who follow each pathway
- whether the number of children deemed as requiring intervention following initial assessment increased, decreased or remained constant pre- and post-project

Future research should focus on developing a clinically useful data collection system which can provide reliable and consistent information and which is compatible with other Trusts.

At a practical level, more time should be given to examine how dysfluent preschoolers from bilingual families can receive therapy sooner after onset and how their attendance rate can be increased in order to offer early intervention. The re-referral and failure to attend rates for dysfluent children must be investigated, particularly the reasons for these courses of action and parental expectations of therapy.

Future research should focus on developing a clinically useful data collection system which can provide reliable and consistent information and is compatible with other Trusts. Such a system would allow data to be used collectively to form a large information base and so overcome the ubiquitous problems of small subject numbers and wide age ranges. This would allow Trusts to take baseline measures, compare referral rates, recovery/persistence figures, waiting times and relate those to population size and ethnographic data and to monitor changes over time.

²³Hood, 1999

Recommendations

Policy and practical recommendations have been developed in relation to the findings of the Primary Healthcare Workers Project. Through these it is hoped that it becomes common knowledge among parents, health professionals within Primary Care Groups (PCGs) as well as educators that a preschool age child with dysfluent speech should be referred to a SLT for an evaluation rather than delaying a referral until the child is older.

The main recommendations are presented as a set of options under the following six headings: 1) prevention, 2) early intervention, 3) excellence, 4) fairness 5) multi-working partnerships, and 6) communications.

1. Prevention

1.1 Referral.

All clients with fluency disorders, particularly dysfluent preschoolers, should be referred promptly to speech and language therapy for assessment in order to a) diagnose the nature of the disorder and b) identify the appropriateness of therapy and the relevant care package – e.g. support, regular or intensive therapy²⁴. Dysfluent preschool age children should “wait less than 2 months to be seen by a speech and language therapist for an initial assessment”²⁵.

1.2 Training for Health Professionals.

The results of the current study confirm that key referral agents of dysfluent preschoolers need to be made aware of, and be able to identify, the risk factors for early stammering.

GPs ought to receive up to date input on risk factors for early stammering via child surveillance courses, as part of a general training session on speech and language development/ disorders.

Such training would ensure comprehensive surveillance and detection of dysfluency prior to school entry, so that preschool children most at risk of developing persistent stammering could begin therapy soon after onset.

1.3 Parental Awareness

Parents need to be made aware of, and be able to identify the risk factors for early stammering. Brief printed information on stammering and the risk factors should be included in the Personal Child Health Record booklet held by all parents. This would guarantee that every future parent of a dysfluent child has access to vital information on the risk factors and speech dysfluencies to look for.

2. Early Intervention

2.1 Prioritisation.

Dysfluent preschool age children ought to be prioritised for and offered treatment if they are deemed to be at risk from developing chronic stammering or to ensure that early stammering does not develop into confirmed stammering. Although there is no definitive research confirming an optimal time for intervention with dysfluent children, researchers agree that early intervention is effective and that treatment is brief with young children compared to adults.

2.2 Active Monitoring of Dysfluency

Although the longitudinal prospective studies of Yairi and Ambrose (1999), Paden, Yairi and Ambrose (1999), Watkins, Yairi and Ambrose (1999) have confirmed that around 74% of dysfluent preschoolers will recover, whilst 26% will persist, there are still no unequivocal predictors of recovery or persistence, only indicators.

Therefore dysfluent children should be actively monitored for up to 2 years through a regular review system such as Onslow's (1996) at-risk register. This could help to prevent over-servicing, reduce treatment time for those children who are likely to follow the pathway of natural recovery and ensure those at risk of persistent stammering receive early intervention.

3. Excellence

3.1 Specialist Dysfluency Therapy Provision

The results of the current project clearly demonstrate that where a specialist dysfluency service is provided, the referral rate of dysfluent preschoolers is significantly

²⁴RCSLT, 1998, p8

²⁵Communicating Quality 2, 1996

higher than in Trusts with comparable population sizes which have no specialist therapist.

All SLT departments should have a therapist who specialises in dysfluency, or identify two or more link therapists with whom to share a knowledge base and responsibility in order that an equitable Trust-wide service can be established. Dysfluency referral patterns within and between Trusts should be monitored and reviewed regularly.

3.2 Dysfluency Sessions

Therapists working with dysfluent children should have a recognised clinical session/s allocated (depending on the size of the caseload) in order to manage preschool dysfluency referrals, to share and implement best practice with other therapists and to train/update health and education colleagues on early identification. Therapists who have less experience in providing therapy for dysfluency should have access to advice from a specialist SLT to assist with training, intervention planning and second opinions²⁶.

3.3 SLT Undergraduate Training in Dysfluency

The evaluation of therapists' training course questionnaires demonstrated that many felt they required more teaching in assessing and treating stammering children at an undergraduate level in order to be better prepared for working with this client group in community clinics. There is disparity between the amount of dysfluency tuition therapists receive on undergraduate courses. A review of the time allocated to teaching dysfluency within SLT training courses should be undertaken.

3.4 SLT Postgraduate Training in Dysfluency

Greater provision of post-graduate training courses are needed in order to update both generalist and specialist therapists in the assessment and treatment of early stammering, to ensure efficacious treatment is being provided and that evidenced based practice employed. If two to three community therapists per Trust were trained on the same course, this would create opportunities to

provide an equitable Trust-wide dysfluency service and peer support. It also ensures that a specialist service is not lost if one therapist leaves.

4. Fairness

4.1 Specialist Dysfluency SLT Services

More specialist dysfluency services and centres are required given the disparities in provision for dysfluent children in the UK. Further dysfluency services throughout England and Wales should be created, starting with the regions which are most poorly served, in order that young children can be treated quickly and effectively, and receive a high standard of clinical care.

4.2 Access for Linguistic Minority Groups

Data gathered in collaboration with SIG Bilingualism, illustrated that the majority of dysfluent bilingual children are not seen by a SLT until they are of school age. A review should be undertaken to consider how families of dysfluent children from linguistic minority groups can be better informed about early intervention and accessing SLT services before their child begins school.

4.3 Access to Information on Dysfluency

There is a need for parents of dysfluent preschoolers/ service users to have access to equitable advice and information on childhood stammering (e.g. on the advantages of early intervention, the services available, expectations on parental involvement in therapy). Organisations such as BSA should collaborate with SLT departments, SIG Disorders of Fluency, RCSLT, parents and other agencies (particularly those who are from linguistic minority and disadvantaged groups within society), so that the knowledge, views and experiences of these groups can be sought and collated and useful information on early stammering produced. The format of the information should be carefully considered (i.e. not necessarily written) in order for it to be accessible to all families who use SLT services (e.g. via audio-tape for those from linguistic minorities or with literacy difficulties).

²⁶Communicating Quality 2, 1996

5. Multi-working Partnerships

5.1 Training for Education Professionals

"The SLT should ensure that advice and/or training is available and provided for any individuals, other professionals and voluntary agencies relevant to an individual client or care group"²⁷.

With the advent of primary care groups and increased multi-disciplinary working, SLTs must become proactive at training, educating and updating other professionals. To ensure children at risk for persistent stammering are identified and referred early, therapists should extend training sessions beyond health visitors and GPs, to include early years workers such as nursery teachers/nurses, preschool advisors, childminders, nannies and play group leaders.

Collaboration with voluntary organisations (e.g. Professional Association of Teachers and Nursery Nurses (PAT and PANN), Preschool Learning Alliance (PLA)), and others involved in the care of children (e.g. youth workers, foster carers) is central to the delivery of a more co-ordinated set of education and social services.

5.2 Training Student Health Visitors

All training syllabuses for student health visitors should include teaching on speech and language development, disorders and early intervention, of which early stammering should be a component. The level of input should be monitored and local SLT departments should work with health visitor tutors to ensure these topics are covered adequately.

6. Communications

6.1 Communicating with General Practitioners

"Local GPs should be informed of the services available for those with fluency disorders."²⁰. Therapists should ensure that across a Trust, GPs have equal information which reflects current knowledge of early stammering and practice regarding the advantages of early intervention.

6.2 Dissemination of Information on Early Stammering

Non-health channels should be utilised in order to disseminate parental information on recognising early stammering as widely as possible. During the project, parents of young children identified alternative routes through which they attained information/leaflets on child development/health issues (e.g. libraries, play groups, crèches, nannies, nurseries, parent magazines, parent groups, National Childbirth Trust, supermarkets, information racks, (e.g. Boots, Mothercare). These routes could be used to disseminate information on early stammering as well as national and regional media or specialist press.

Information for parents on early stammering and known risk factors should also be made available through health channels (e.g. health centres/ GP surgeries leaflet racks, ante/post natal classes, maternity ward notice boards, leaflet/s on communication development given out at an 18 month/2 year health visitor check, pharmacists, bounty packs for new parents).

²⁷Communicating Quality 2, 1996, p180

Conclusion

In conclusion, the activities of the Primary Healthcare Workers Project have challenged the common “wait and see” approach towards early stammering and demonstrated that referral patterns can be changed. As a result more dysfluent children of preschool age are being identified soon after onset and referred to speech and language therapy for assessment.

However, to sustain these changes and to adapt to future models of referral and service delivery, speech and language therapists need to remain vigilant in training health and education colleagues, in working collaboratively, in sharing knowledge about the advantages of early intervention and in monitoring departmental dysfluency referral rates and trends. With the continuing evolution of the NHS, and no doubt an increasing demand for our services, therapists need to become effective gatekeepers, be better able to gather and manipulate referral and therapy outcome data in order to demonstrate treatment efficacy and measure change.

We are living in a growing verbal economy where the currency of the 21st century will be excellent oral communication skills. A child and ultimately an adult’s ability to communicate with others on equal terms will be of maximum importance. In such a climate, the workforce may increasingly perceive a person with dysfluent speech as costly in terms of time and money.

Given that dysfluency can have a long term impact on a person’s life, impeding their education and employment potential, their ability to communicate, interact socially and form relationships, and that “effective and efficient treatment is already available for dysfluent preschoolers”²⁸ we cannot afford to take the risk of waiting to see whether a dysfluent child will recover or persist.

²⁸*Starkweather, 1997, p257*

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