Prospective cohort study of speech and language therapy services for young children who stammer in England

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan[1], the government's response to the Bercow review of services for children and young people with speech, language and communication needs[2]. This had recommended a programme of research 'to enhance the evidence base and inform delivery of better outcomes for children and young people' (p.50). The phrase 'speech, language and communication needs' (SLCN), as coined in the Bercow report, includes the full range of difficulties that children experience with speech, language and communication. This report concerns young children who stammer or stutter: the terms are synonymous. These children have disorders with the fluency and rhythm of speech, but are rarely categorised as having special educational needs or disabilities on the basis of their stammer alone. Nonetheless, children who stammer may have difficulties managing their learning in classrooms in ways that are directly related to stammering; for example, they may find it difficult to ask or respond to questions in class.

Research suggests that intervention can be successful in the early years, before the age of seven years. However, information received by BCRP from advisory partners suggested that services varied in the intervention adopted, their use of specialist practitioners and the amount of intervention offered.

Therefore, the aims of this study were to investigate the outcomes for children under the age of 7 years referred to speech and language therapy (SLT) services for help with their stammering, to identify what intervention was delivered and any factors that influenced treatment implementation and outcome.

Following a request to SLT services in England, a small cohort of 63 children was established; just under two thirds of these were boys. Data on the children's stammering were collected as they were recruited and again at follow-up approximately 8 months later as well as information about the child's background and family history of stammering. Information was also collected about the treatment received from SLT services.

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[1] https://www.education.gov.uk/publications/eOrderingDownload/Better_Communication.pdf
[2] Bercow, (2008). Research Report http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RW053.pdf

Key findings

- Parents reported that their children had started to stammer between the ages of 18 and 76 months with an average of 34.9 months.

- Children recruited to the study were varied in terms of their severity at baseline, with the mean per cent of syllables stammered being 3.4 (range 0-16.4). On a rating of the typical level of severity of stammering, the mean rating given by parents was 4.2; the mean rating for the most severe level of stammering was 5.1.

- The average time to follow-up was 37 weeks. Over that period, the severity of children's stammering had significantly reduced according to parent ratings and in terms of the per cent of syllables stammered. The number of children who were stammering on more than 3% of syllables had reduced from 18 at baseline to 6 at follow-up. Of the 55 children with parent ratings at baseline and follow-up, the majority (82%) showed positive changes; the rest of children had either not changed (9%) or were more severe (9%).

- The amount or type of therapy received was not predicted by the severity of stammering at baseline although children whose stammering was more severe at follow-up, as measured by the per cent of syllables stammered, had received significantly more contact time than those with less severe stammers. On average children had received 7.3 contacts and 3.6 hours with the maximum received over the time span of the study being 18 contacts and 15 hours contact time.

- The predominant approach to intervention was indirect whereby the therapist worked with the parent(s) to change aspects of the home environment. This kind of approach was reported by all participating therapists and used as the first level intervention. The *Lidcombe Program* and the *Parent-Child Interaction* approach were the next most commonly reported methods. Some therapists used more than one approach.

- Overall, responses to take part in the study were disappointing and there were a number of challenges in particular the recruitment of services, therapists and families to the study, negotiating local governance processes, and obtaining consistent and complete data across sites and families.

Conclusions

- There is a need for research evidence that indicates how to select the most appropriate treatment approach for an individual parent/child and to recognise indicators that the ongoing treatment approach should change.

- There is also a need for data on the longer term outcomes for children who stammer through the establishment of a long term national cohort study of children, starting in the early years and following children into adulthood.

- Research is needed to compare different methods of providing information and advice and to compare this with the efficacy of more direct interventions.

- In order to develop applied research based within clinical contexts, efficient ways to support speech and language therapists in the recruitment of children and their parents need to be established.

- The establishment of minimal data sets that can be used to compare settings and services would considerably increase the ease with which national studies could be established.

1.   BACKGROUND

1.1   Introduction

The Better Communication Research Programme (BCRP) was commissioned as part of the Better Communication Action Plan[3], the government's response to the Bercow review of services for children and young people with speech, language and communication needs[4]. This had recommended a programme of research 'to enhance the evidence base and inform delivery of better outcomes for children and young people' (p.50). The phrase 'speech, language and communication needs' (SLCN) was first coined in the Bercow report. It includes the full range of difficulties that children experience with speech, language and communication. This report concerns young children who stammer or stutter: the terms are synonymous. The World Health Organisation's[5] definition of stuttering provides some guidance for diagnosis: ' …disorders of rhythm of speech in which the individual knows precisely what he wishes to say, but at times is unable to say it because of involuntary, repetitive prolongation or cessation of sound'. Estimates for the incidence (the number of new cases within a specified time period) of stammering in the early years is around 5%; prevalence (the number of cases at a particular point in time) is around 1% indicating that for many it is a transitory problem[6],[7]. A recent cohort study[8] however, challenged these figures by reporting a cumulative incidence of 8.5% in children aged up to three years (median age of onset of 29.9 months). In that cohort, stammering onset was associated with rapid language development. A recent analysis of stammering in the Avon Longitudinal Study of Parents and Children found a prevalence of 2.34% in children aged 8 years[9] which, in accord with previous research[10], suggests recovery in the years close to onset.

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[3] https://www.education.gov.uk/publications/eOrderingDownload/Better_Communication.pdf
[4] Bercow, (2008). Research Report http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RW053.pdf
[5] World Health Organisation's (1992). *International statistical classification of diseases and related health problems, tenth revision (ICD-10).* Geneva: World Health Organisation.
[6] Yairi, E. & Grinager Ambrose, N. (2005). *Early childhood stuttering: For clinicians by clinicians,* Austin, Texas.
[7] Månsson, H. (2000). Childhood stuttering: Incidence and development. *Journal of Fluency Disorders, 25,* 47-57.
[8] Reilly et al. (2009). Predicting stuttering onset by age of 3 years: A prospective, community cohort study. *Pediatrics, 123,* 270-277.
[9] Miller et al. (2012) (2012). The Prevalence of Stuttering: Therapist Judgement vs %SLD vs Parent Report. Paper presented at the *7th World Congress on Fluency Disorders,* 2nd -5th July, Tours, France.
[10] Yiari, E. & Ambrose, N. G. (1999). Early childhood stuttering: Persistency and recovery rates. *Journal of Speech, Language and Hearing Research, 42,* 1097-1112.

Children who stammer are rarely categorised as having special educational needs or disabilities (SEND) on the basis of their stammer alone and would therefore not be represented in School Census data on SEND or SLCN. Nonetheless, children who stammer may have difficulties managing their learning in classrooms in ways that are directly related to stammering; for example, they may find it difficult to ask or respond to questions in class, they may be bullied or fear being bullied[11] or they may experience raised anxiety levels because of communication difficulties[12]. Additionally, a proportion of children who stammer may have other learning needs associated with other speech and language learning difficulties or more general learning difficulties. These latter children may be classified in School Census data on the basis of their other learning needs but their stammer will probably remain a secondary (or even an unspecified) rather than a primary learning need.

Systematic reviews and more recent randomised controlled trials of interventions for children who stammer suggest that intervention can be successful in the early years, before the age of seven years[13,14]. There is less evidence to support specific treatments with older children[15]. By adulthood many experience a reduced quality of life in comparison to non-stuttering adults[16]. Consequently recovery close to onset is desirable, whether spontaneous or facilitated by treatment. However, information coming into the BCRP from advisory partners suggested that services varied in the intervention adopted, their use of specialist practitioners and the amount of intervention offered. It was therefore agreed that it would be helpful to capture information on the management of this group of children for whom there is little data at a national level.

1.2   Aims

The overall aims of the study were to investigate the outcomes for children under the age of 7 years referred to speech and language therapy (SLT) services for help with their

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[11] Davis, Howell & Cooke, (2002) Sociodynamic relationships between children who stutter and their non-stuttering classmates. *Journal of Child Psychology and Psychiatry, 43,* 939–947.
[12] Mulcahy et al. (2008) Social anxiety and the severity and typography of stuttering in adolescents. *Journal of Fluency Disorders, 33,* 306–319.
[13] Jones et al. (2005). Jones, M., Onslow, M., Packman, A., Williams, S., Ormond, T., Schwartz, I., et al. (2005). Randomised controlled trial of the Lidcombe Programme of early stuttering intervention. *British Medical Journal*, *331*, 659-661.
[14] Jones et al. (2008). Extended follow-up of a randomised controlled trial of the Lidcombe Program of Early Stuttering Intervention. *International Journal of Language and Communication Disorders, 43*, 649-661.
[15] Bothe et al. (2006) Stuttering Treatment Research 1970–2005: I. Systematic Review Incorporating Trial Quality Assessment of Behavioral, Cognitive, and Related Approaches. *American Journal of Speech-Language Pathology. 15*, 321–341.
[16] Koedoot, et al. (2011) Quality of life in adults who stutter. *Journal of Communication Disorders*, 44, 429-443.

stammering and to identify what intervention was delivered and any factors that appeared to impact upon treatment and outcome.

1.3 Ethics

The project was reviewed by the South West 5 (formerly Frenchay REC) Research Ethics Committee, by the University of the West of England, faculty ethics committee and by NHS Research & Development governance offices for all participating sites.

2. WHAT WE DID

Given the variability in how services are delivered nationally and the fact that, compared to some other SLCN, stammering is a relatively low incidence difficulty, it was decided that an exploratory observational cohort study would be an appropriate method. The original aim was to recruit sufficient participants to allow some inferential statistics to investigate the association of explanatory factors and children's outcomes.

2.1   Research questions

The study set out to track the outcomes for individual children aged under 7 years passing through the speech and language therapy (SLT) system in different parts of England and to explore factors which might impact upon their outcomes. In particular we wanted to identify:

- What differences are there among the children seen for SLT in the severity of their stammering?
- What are the interventions received by children who stammer?
- What are the speech outcomes for young stammering children in NHS clinics 6 months after SLT assessment?
- How has the child's communication changed since assessment?
- How do differences in children and in the intervention received impact on children's outcomes?
- What are the cost implications of interventions for stammering?

2.2   Identification of participants

A request for services to participate in the study was circulated via the Royal College of Speech & Language Therapists' management network. In addition, some services that had been involved with the British Stammering Association's recent 'Every Child's Chance of Fluency' campaign[17] were approached directly. Within each service that expressed an interest, speech and language therapists who took referrals of children who stammer were invited to participate. Therapists were asked to invite the parents, of all children referred for

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[17] http://www.stammering.org/eccf.html

help with stammering under the age of 7 years, to join the study. Based on our knowledge of typical referral rates, we anticipated that we would need 10 services who could recruit three to four children per month over a period of six months to recruit 200 children and that an extra two services would compensate for recruitment difficulties. Table 1 shows the numbers of therapists and children recruited for each participating service. Not all therapists who had referrals of children who stammer within a participating service took part in the project and not all participating therapists recruited children. Of services that joined the study eight had one or more therapists with a specific role as a stammering specialist, had undertaken post-graduate training, had several years of experience of working with children who stammer and had designated time for their stammering caseload. The other services did not have such highly qualified therapists and had little (e.g. half a day a month) or no time designated for stammering referrals.

Table 1. Recruitment and service information

Service	Children Recruited	SLT roles	No of therapists who recruited children	No of therapists who did not recruit
1	3	Named lead	3	3
2	4	1 specialist	3	2
3	6	1 specialist	3	0
4	1	Named lead	1	2
5	7	1 specialist	2	2
6	2	Named lead	1	4
7	5	1 specialist	1	0
8	26	1 specialist	4	1
9	5	3 specialists	3	0
10	1	2 specialists	1	1
11	3	1 specialist	3	0
Total	63		25	15

Note. One additional service, with a specialist, withdrew from the study after all approvals had been obtained due to service restructuring/ redundancies.

2.3   Data collected at the child's first assessment (time 1)

The following data were collected at time 1:

Background information was collected on the first assessment session including the family's home language and family history of stammering. Parents were also asked the child's age when stammering was first noticed, whether it had changed in severity since then, and whether or not the child had any other speech or language difficulties. Gender, and age at assessment were also recorded.

Current stammering was rated by parents. They were asked to rate the most typical level of severity and the most severe level of stammering during the week preceding the assessment. The Lidcombe Program[18] 10 point stuttering severity scale was used where 1 is no stuttering and 10 is very severe stuttering. Parents were also asked how well their child was understood by unfamiliar adults (1 = not understood at all; 10 = always understood) and how well their child communicates (1= does not try to communicate; 10= communicates well with others).

A short sample (approximately 10 minutes) of the child's speech was collected. When appropriate, speech and language therapists used a book called 'frog, where are you?' [19] to elicit this sample. The book tells the story of a boy and a dog looking for a frog using pictures only. When therapists did not routinely see the child at the 1st assessment session a sample of parent and child talking was recorded over the telephone. This sample was coded for the per cent of syllables stammered (see section 2.6).

Parents were also asked to complete the 'FOCUS' questionnaire (Focus on the Outcomes Communication Under Six[20]) which measures change in children's everyday communicative participation[21]. Thus a child may not change in terms of the severity or amount of stammering, but their overall communicative functioning may improve (or deteriorate).

2.4   Interventions delivered to children

Therapists provided data about the number of contacts they had with children and parents, how long they spent with the child or parents and other activity (such as home visits or visits to nurseries) that took place. They were also asked to indicate their approach to intervention.

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[18] Onslow et al (2003) *Lidcombe program for early stuttering intervention: Clinician's guide*. Austin, TX: Pro-Ed.
[19] Mayer (1969) *frog, where are you?* New York: Dial Books for Young Readers.
[20] Thomas-Stonell et al. (2010). Development of the FOCUS (Focus on the Outcomes of Communication Under Six), a communication outcome measure for preschool children. *Developmental Medicine & Child Neurology*, *52,* 47-53.
[21] The FOCUS questionnaire was used prior to final publication with kind permission of the FOCUS research team.

Parents were asked to comment on whether or not the time they had spent in SLT with their child was worthwhile. Data were also collected regarding the therapists' level of expertise with stammering – whether or not they had a specialist post and whether or not they had been trained in particular approaches to therapy.

2.5   Data collected at follow-up (time 2)

The target was to make contact with the child and family six months after the original contact. However, because of difficulties recruiting children, the last children in the cohort were contacted again four months after their first assessment. Furthermore, for some children, making contact for the follow-up sample was difficult and their period of follow-up was longer. The mean number of weeks post baseline was 37.2 (SD: 7.6). All follow-up contact was made by telephone. At the first follow-up contact, parents were asked to rate their child's speech over the last week in terms of their most typical level of severity and the most severe level of stammering. They also answered questions about the time they spent as a result of their contact with speech and language therapy services and their overall view of its value to them. Arrangements were made for a second telephone call at which a sample of the child's speech was taken. On these occasions, the parent held a conversation with the child and the recording was made by the researcher using a phone attachment. This procedure has been validated previously[22]. Researchers rated the severity of the child's stammering on this second occasion and parents commented on the whether or not the sample was typical of their child's talking. Parents also completed the FOCUS questionnaire.

2.6   Coding of the speech sample

Children's speech samples were coded by a research assistant who was blind to both the parent and researcher ratings. For each speech sample the stammer like dysfluencies (SLDs) were counted as were other dysfluencies (ODs). All part-word repetitions, single-syllable word repetitions and dysrhythmic phonations were counted as SLDs in accordance with the recommendations of Yiari and Ambrose[23] who suggest that children (irrespective of age) who exhibit three or more SLDs per 100 syllables are stammering. This is calculated as follows:

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[22] O'Brian et al. (2010) A new method to sample stuttering in preschool children. *International Journal of Speech-Language Pathology*, *12,* 173–177.
[23] Yairi & Grinager Ambrose, N. (2005) *Early childhood stuttering: For clinicians by clinicians.* Austin, Texas: Pro-Ed.

$$\frac{\text{number of syllables stammered}}{\text{total number of syllables in the sample}} \quad X \quad 100$$

The per cent of other dysfluencies was also calculated. Length of sample in terms of time and number of syllables was also noted.

3.   WHAT WE FOUND

3.1   General characteristics of the participants and their families.

There were 39 boys (62%) and 24 girls (38%) recruited to the study. Just over half of the children's mothers were in full-time (22%) or part-time (30%) work. Only two families used a language other than English at home. A family history of stammering was reported in 55% of the children. Most commonly, the member of the family who stammered was the father (see Table 2) although 24% mentioned a range of other members of the family, including aunts, uncles and cousins.

Table 2. Family history of stammering

Relative	%(n)
Mother	5 (3)
Father	18 (11)
Sibling	3 (2)
Maternal mother	2 (1)
Paternal mother	2 (1)
Mother and father	2 (1)
Other	25 (15)

Parents reported a range of other speech and language difficulties in 37% of the children. These included both language delay and speech sound difficulties.

3.2   Speech characteristics at baseline

The mean age of onset of stammering as reported by parents was 34.9 months (range: 18-76 months). Parents were asked if their child's stammering had got worse, better or was about the same since onset and before they attended speech and language therapy. Of those who replied (n = 61), 48% indicated that the child was stammering more than at onset, 33% indicated that they were stammering less and 18% that it was about the same. The remaining few were unsure.

The mean percentage of syllables stammered at baseline was 3.41 (range: 0 -16.43) (median: 1.93). In this group of children, 18 (29%) were stammering on more than 3% of

their syllables. The mean number of syllables spoken by the children in the samples was 403.

The mean rating of the child's typical level of severity by parents was 4.2 and the mean rating for the most severe episode was 5.1. In this rating scale, 1 is least severe. In terms of the children's most typical level of stammering, no parent used the most severe ratings (9 and 10) to describe their child's stammering, although one parent used 9 to describe their child's most severe episodes (Figure 1).
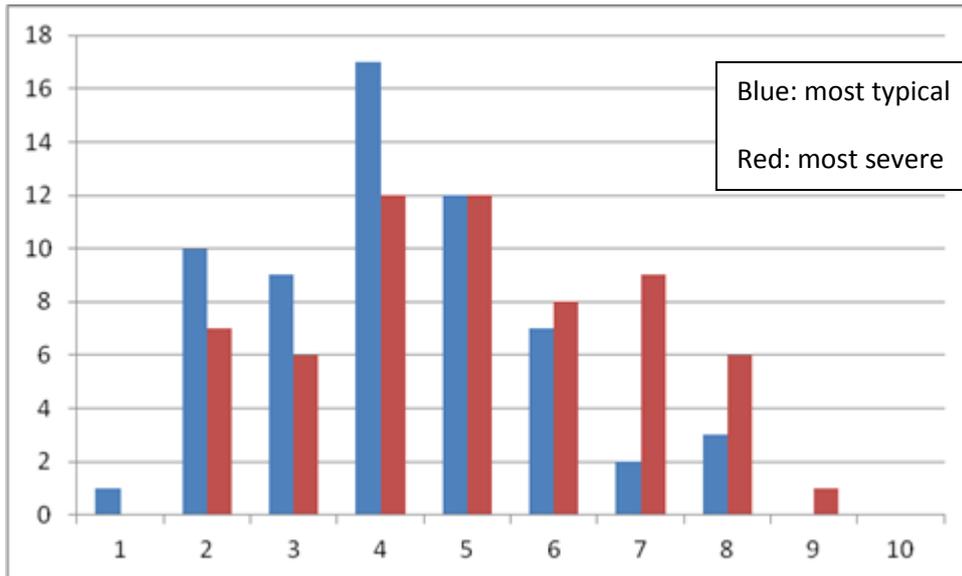
Figure 1 Parent rating of most typical and most severe levels of stammering in the preceding week.

Parents were also asked how well their child was understood by unfamiliar adults (1 = not understood at all; 10 = always understood) and how well their child communicates (1= does not try to communicate; 10 = communicates well with others). Parents indicated that generally their children were understood by others, with a mean rating of 7.6 and that their children communicated well (mean rating 8.6).

3.3   Interventions delivered

The mean number of contacts delivered was 7.3 (range 1-18), with the mean number of hours spent being 3.6 hours (range 0.5 – 15.25) suggesting that on average, individual contacts lasted 30 minutes.

Children who stammered on less than 3% of syllables at baseline received a mean of 6.5 contacts and 3.5 hours whereas those who stammered on more than 3% of syllables received a mean of 8.2 contacts ($p = .238$) and 3.8 hours ($p = .775$). As can be seen from the p values these differences were non-significant.

The predominant approach to intervention was indirect whereby the therapist worked with the parent(s) to change aspects of the home environment, including aspects of parental speaking or communication. In all cases information on stammering and advice on how to facilitate fluency was the first intervention and then followed up, when considered necessary, with a recognised/named approach such as 'Parent-Child Interaction' ($n = 6$) or 'Demands-Capacity Model' ($n = 5$). For those children receiving a direct approach, more children received syllable timed speech ($n=16$), with half as many being exposed to the Lidcombe Program ($n = 8$). However, this is related to the pattern of recruitment by therapists. Table 4 shows the approaches used by therapists: all therapists provided information and advice and the Lidcombe program and Parent-Child Interaction were the next most common. Some therapists used more than one approach, thus the numbers in Table 4 add up to more than the number of participating therapists. Box 1 provides a brief description of these approaches to intervention.

Table 4 Therapists using different intervention approaches.

Approach	Number of therapists using this approach with children
Information and advice	25[a]
Parent Child Interaction	5
Demands Capacity model	3
Syllable timed speech	3
Lidcombe program	7
Praise fluency	3
Slowed speech	1
Swindon Fluency Pack	1

[a]All participating therapists

Information and advice[24] Information on stammering and advice for parents that therapists are giving is loosely based on the demands capacities model (see below). Written information may be given e.g. the services' own information and advice sheets or the British Stammering Association (BSA) leaflet. Parents may be directed to the BSA or Michael Palin Centre (MPC) websites.

The Michael Palin Centre Parent Child Interaction Therapy[25] (MPC /PCI) combines indirect therapy methods. The indirect therapy component is aimed at helping parents, through the use of video feedback, to identify interaction strategies that support their child's fluency and enhance it in the home environment. In addition, the approach addresses other concerns, for example, in relation to confidence building, dealing with sensitive children, and establishing clear structures and boundaries to enhance family relationships.

Demands Capacity Model (DCM)[26] was developed in the USA as a way of conceptualising the relationship between children's speaking skills and the demands made upon these skills by the child themselves, their conversation partners and environments where communication occurs. Treatment aims to help parents manipulate environmental and communication factors to facilitate fluency while therapy or work with parents builds the child's capacities.

The Lidcombe Program (LP)[27] is a parent implemented behavioural treatment for early stammering. The primary treatment components are parental verbal contingencies (parents' verbal feedback) and measurement. Parents are taught how to give their child verbal feedback for stammer-free speech and less frequently for unambiguous stammering, They use a 10-point severity rating scale to record their child's daily severity of stammering. Parents' use of contingencies is carefully monitored to ensure they are given in a way that is helpful to the child and that they lead to reduced stammering in the home and their every day environments.

Syllable-timed speech (STS)[28] refers to speech where each syllable is spoken in time to a rhythmic beat. In the mid twentieth century it was used with older children and adults. It has recently been reintroduced at the Australian Stuttering Research Centre as a treatment for young children (the Westmead Program). It has been found easy to teach and use and there are theoretical reasons for thinking STS may help children stabilise their speaking during moments of speech disruption. Research is currently investigating a hybrid program using STS and verbal contingencies.[29]

Box 1 Approaches to intervention for stammering

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[24] BSA information for parents at http://www.stammering.org/under5.html
MPC information for parents at http://www.stammeringcentre.org/parent-information
[25] Kelman & Nicholas (2008). *Practical intervention for early childhood stammering.* Brackley, UK: Speechmark Publishing
[26] Stewart, T. & Turnbull, J. (2007). *Working with dysfluent children.* Revised edition. Brackley, UK: Speechmark Publishing,
[27] Packman et al. (2011). *The Lidcombe program of early stuttering intervention treatment guide.* Download available from Australian Stuttering Research Centre.
[28] Trajkovski, et al. (2009). Using syllable-timed speech to treat pre-school children who stutter: a multiple baseline experiment, *Journal of Fluency Disorders*, *34*, 1-10.
[29] Trajkovski, N. (2012). The Westmead Program (pp.195-205). In S. Jelcic Jaksic and M. Onslow (Eds). *The science and practice of stuttering treatment: A symposium.* Chichester, UK. Wiley-Blackwell,

3.4   Outcomes at Follow-up

During the first follow-up phone call, 55 of the recruited parents (85.93%) completed the speech ratings and answered our questions concerning the time spent helping their child. The syllables stammered data is based on the 45 children (70.31%) for whom we were able to elicit speech samples at follow-up. Comparison of the parent ratings at follow-up with ratings at baseline showed significant reductions in the severity over time ($p < .001$). This reduction in severity was also significant for the per cent of syllables stammered ($p < .001$). By the end of the study the number of children who stammered on more than 3% of syllables had reduced from 18 to 6. Of those who were considered to be stammering at baseline, only 3 were stammering at follow-up; of those who were not stammering at baseline, 2 were classified as stammering at follow-up. Table 5 shows the mean rating and scores at time 1 and time 2. Of the 55 children with base line and follow up data, 45 showed positive changes, 5 showed no change and 5 showed negative change over the time period of the study. Children with higher levels of stammering at follow-up, as measured by the per cent of syllables stammered, had received significantly more therapy time (but not more contacts) than those with lower levels of stammering ($p = .008$).

Table 5 Comparison of speech at baseline and follow-up

	Baseline Time 1	Follow-up time 2
Parent's rating of most typical severity	4.25	2.07
Parent rating of most severe stammering	5.09	3.0
Per cent of syllables stammered	3.38	1.22
Number of children stammering >3% syllables	18	6

In order to explore predictors of that change we have carried out exploratory analyses to investigate a number of variables (gender, family history of stammering, presence of other speech and language difficulties, age of onset of stammering, and the age of SLT assessment), as predictors of the change in parent rating from time 1 to time 2. The amount of time in therapy was positively associated with increases in parents' rating on the child's ability to communicate ($p = .029$). No other variables were significantly associated with the change in rating between time 1 and 2 ($p > .05$ in all cases). The same variables were tested against the per cent of syllables stammered at time 2; no significant associations were identified.

FOCUS questionnaire. This questionnaire provides a measure of children's functional communication outcomes. The return rate on the questionnaire was low with only 23 pairs of questionnaires returned (that is, for both baseline and follow-up). Analysis of the response pattern to FOCUS 1 showed some evidence of an association with mothers rating on Q1, the child's typical stammering severity in the preceding week, (p = .027) which might indicate some within sample bias with FOCUS engagement. Possibly parents who rate their child's stammering as more severe are more likely to complete data collection. A similar association was found between the initial severity rating and our success in collecting the final speech sample, in that children who were rated more severe by their parents at baseline were more likely to have provided a speech sample at follow-up.

For those who responded, there were no significant differences in the FOCUS scores of children above and below the 3% syllables stammered threshold at baseline. The mean change score was 19 (range: -24 to 84). According to the authors[30], a change score of more than 16 suggests that change is significant, that is, greater than one would expect to see by chance. However, the minus scores show that for some children, the change was in a negative direction. There was a significant correlation between the FOCUS change score and the change in the percentage of syllables stammered from baseline to follow-up.

3.5 Cost implications

This study did not aim to define costs of stammering services. However, we summarise here the main factors that implicated variations in costs for children who stammer.

Professional time: The main person involved with these children with respect to their stammering was the speech and language therapist. Only one child had been referred to an educational psychologist and this was due to additional problems not due to the stammering. As indicated above, the amount of time provided by the speech and language therapist was not predicted by the severity of the child's stammering at the outset. Parents had not accessed other services except in the process of seeking a referral through their health visitor or GP. Children had received some help in school because of their stammering, but this was in the form of encouragement rather than a redirection of resources.

Staff grades: Services varied in whether or not they employed specialist therapists to work with children who stammer (see Table 1 above).

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[30] FOCUS abridged manual. Downloaded from:
http://www.hollandbloorview.ca/research/FOCUS/index.php

Costs to parents: this was mainly in the form of time (5-30 minutes per day during therapy) and the cost of travelling to appointments (10-30 travelling time). Therapy appointments did not impact on parents' work and only one parent reported that they stopped therapy because they could not take time off work for the appointments.

Benefits: The effectiveness of interventions was not measured in this study. However parents were asked if they felt the therapy session(s) and the time they had spent had been worthwhile. All but one said 'yes' or 'definitely yes'. Thirty-seven parents elaborated their response and, in most cases, this was in terms of the support and help that they received as parents and the presumed rather than explicitly stated benefits to their child.

4. SETTING UP THE STUDY

This study was run in the context of SLT services within the UK NHS. There were a number of challenges that inhibited the efficient set up and implementation of study and which impacted upon recruitment and follow-up of participants.

Recruitment of SLT services and therapists: the number of services expressing an interest was, in the first instance, well within our original estimates to recruit our target 200 children. However three departments withdrew at an early stage and a fourth at a later stage because of the demands of local service restructuring. A number of changes were made to the protocol for recruitment of children in order to support the process and relieve pressures on local therapists. These changes took time to implement as they constituted major amendments and needed to be approved by the South West 5 REC and local R&D offices

R&D governance processes: The time and effort taken to gain R&D approval from participating sites varied, with some sites responding quickly with no queries and others requiring considerable additional information and alterations to the recruitment protocol. As indicated, such changes had implications for the study timing.

Examples of issues include:

- A preference for on-site principal investigator from within the service who will take responsibility for research governance. As most of the participating therapists had not had 'Good Clinical Practice'[31] training, the study would have had to train someone to undertake this role. We had rejected this study design as it required too much additional work and responsibility for some SLTs.

- The IT guidelines of some Trust made the storage and sharing of digitised speech samples, even when anonymised and with neutral and unidentifiable content, impossible. These speech samples should be part of the basic SLT assessment data but seemed to cause considerable problems for some services even though we supplied effective and unobtrusive digital voice recorders.

Service data: Rates of referrals of children who stammer were not available from all participating services; not all services routinely differentiate referrals by type of SLCN. Data that we did receive suggests that it should not have been a problem to recruit our planned

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[31] Good Clinical Practice (or GCP) training is a specific course for those practitioners who recruit patients to research and who carry out research within the NHS.

numbers within the original time-scale. For example, a service with high referral rates had 152 children, meeting our criteria, referred between Jan & Dec 2011; another had 76 within the eight months that they recruited. Our conservative estimate of a one-in-four rate of recruitment should have easily generated our target sample on the basis of these referral rates. Participating services have indicated that stresses on local services had left staff demoralised and were a factor in the low recruitment of children by therapists.

Parent perceptions of research: At time 2 follow-up, telephone calls were made to parents to collect a speech sample from the child. On these occasions, some parents were enthusiastic about the research and pleased to take part; others seemed to have forgotten that they had consented and showed little interest; eight failed to respond to our pre-arranged phone calls.

5. DISCUSSION

Generally children in the study changed for the better over time. This is seen clearly in this study where more than half of those who started out with an identified stammer (>3%) had reduced to below the threshold for the identification of stammering by the time of the follow-up. The reduction in the severity of children's stammering, as evidenced in the percentage syllables stammered, was associated with an improvement in the children's functional communication as perceived by their parent. However, natural recovery is a feature of early stammering and the rate of improvement seen in this study is not dissimilar to that reported in other studies[32], which suggests that some of the children referred to services in our study were experiencing an episode of transient stammering. In such a small sample, we were not able to identify any particular predictors of outcome.

Given the heterogeneity of the sample we would not necessarily expect an association between the amount of therapy and the children's outcome: some of the children were quite mild at both onset and outcome. Although it might initially seem surprising that the amount of therapy delivered is not related to a child's severity at baseline, it has been found in other studies that therapists' decisions about the amount and type of intervention offered are influenced by more than just the severity of a child's impairment[33]. In addition, stammering severity close to onset is not predictive of persistence and so therapists would be taking other factors into account. In fact, the amount of therapy was associated with children who had more severe stammering at follow-up, suggesting that therapists were providing more time to those with more severe problems. In addition, the amount of time given in therapy was associated with improvements in children's levels of communication at follow-up.

The most striking thing about the data in the study is in terms of which interventions children actually receive. Therapists are not offering evidence based interventions like the *Lidcombe Program* as a matter of course, but giving more general advice that could be obtained by parents from other sources. All services provided information on stammering and gave basic advice that derives from interpretations of the *Demands Capacities Model.* This advice is based upon expert opinion rather than upon research evidence. Parents in this study reported that the initial assessment and advice session was useful and some attributed

[32] *The syndrome of stuttering*. London: Heinemann

[33] Roulstone, S., Peters, T. J. Glogowska, M. & Enderby, P. (2008). Predictors and outcomes of speech and language therapists' treatment decisions. *International Journal Speech-Language Pathology*,*10(3),* 146-155.

changes in their children's speaking to the changes they had made in their environment or own rate of speech. It would therefore be useful to investigate more systematically the value and impact of information and advice on the severity and persistence of stammering. This would be particularly valuable since, increasingly people look to the internet for information and advice as well as to professional services like speech and language therapy. It would be useful to understand the potential added value provided by the contact with the speech and language therapist.

There is little guidance in the research literature regarding which interventions work most effectively for which children. In such contexts, it has been suggested that therapists work to a *'least first framework'*[34]. This process is similar to the stepped approach described by Bower and Gilbody[35] as a model for making the best use of limited resources. They described the staged increases in intervention starting with self-help without support, through guided self-help, group therapy, brief individual therapy and finally, longer term therapy. Similarly, in the *least first framework*, Hayhow suggests a series of levels of intervention moving from the provision of information and guidance through to more direct and individualised intervention. Although presented as a staged approach, there is no assumption that every child would start at the least intervention first. Instead, Hayhow suggested that assessment should aim to identify the appropriate level of intervention and that when, for example, a child is at a high risk for persistent stammering then direct therapy may be the appropriate first option. The provision of information and advice was a popular intervention in this study but it is not clear how therapists made decisions about the choice of intervention and whether they saw this as a necessary first stage, only providing more direct intervention if this first step failed.

Independently of the child's level of risk whatever is offered to parents needs to take account of resources, parent preferences and therapist skills. A low incidence population is always hard to serve, especially in rural areas, where professionals will not encounter sufficient numbers of a particular type of difficulty to gain the experience necessary for efficient implementation of an approach that requires therapist skills that are not part of their usual interventions. Participating therapists were all experienced or gaining experience at giving

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[34] Hayhow, R. (2007). The least first framework, in S. Roulstone (Ed) *Prioritising child health: Practice and principles.* London: Routledge.
[35] Bower, P., & Gilbody, S. (2005). Stepped care in psychological therapies: access, effectiveness, and efficiency. *British Journal of Psychiatry*, *186,* 11-17.

information and advice and might also use PCI with other client groups and this is possibly reflected in the interventions offered.

The process of running this study turned out to be problematic, not least because the timing coincided with a time of widespread restructuring and change within the NHS. With low incidence groups such as children who stammer, clinical cohort data has the potential to offer considerable insights into children's outcomes. However, there is clearly a need to resolve the issues of recruitment with both therapists and parent groups and to discuss with representatives of ethics committees and R&D departments ways of making research involvement more accessible and agreeable to busy parents. Agreement at a national level regarding the use of standard methods of outcome measurement, such as the use of speech samples would assist with the running of national cohorts. It is regrettable that a key method of analysis and recording of progress in children's speech is not used routinely. Furthermore, the use of digital means of collecting such speech data, which is vital for the appropriate analysis and measurement of children's speech, is further inhibited by restrictions imposed by Trust IT policies and procedures. Issues of governance and appropriate research training for therapists also need investigation.

6.   CONCLUSIONS

Although the numbers involved in this study limits the conclusions that can be drawn about outcomes for children who stammer, a number of important issues have emerged about the therapy on offer for these children and the potential for applied research in this field.

- There is a need for research evidence to help therapists select which treatment approach is best for an individual parent/child and to recognise indicators that the ongoing treatment approach should change.

- There is also a need for data on the longer term outcomes for children who stammer through the establishment of a long term national cohort study of children, starting in the early years and following children into adulthood.

- A predominant form of intervention observed in this study is the use of information and advice. The lack of evidence for the effect and acceptability of these should be addressed. Research should seek to compare different methods of providing information and advice in comparison with more direct interventions. Since some services across England have long waiting lists for treatment it might be possible to evaluate their effectiveness against non-treatment controls.

- If research into SLT is to take place within clinical contexts, efficient ways to support the recruitment of children and their parents need to be established. This may be with the support of Clinical Research Networks, the appropriate training in research practice for therapists and recognition within job descriptions that recruitment to national studies is desirable.

- The establishment of minimal data sets that can be used to compare settings and services would considerably increase the ease with which national studies could be established.

REFERENCES

Bercow, J. (2008). Research Report http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RW053.pdf

Bothe, A. K., Davidow, J. H., Bramlett, R.E. & Ingham R. J. (2006). Stuttering Treatment Research 1970–2005: I. Systematic Review Incorporating Trial Quality Assessment of Behavioral, Cognitive, and Related Approaches. *American Journal of Speech-Language Pathology. 15,* 321–341.

Bower, P., & Gilbody, S. (2005). Stepped care in psychological therapies: access, effectiveness, and efficiency. *British Journal of Psychiatry*, *186,* 11-17.

British Stammering Association information for parents at http://www.stammering.org/under5.html

British Stammering Association: Every child's chance of fluency campaign available from: http://www.stammering.org/eccf.html

Davis, S., Howell, P. and Cooke, F. (2002). Sociodynamic relationships between children who stutter and their non-stuttering classmates. *Journal of Child Psychology and Psychiatry,* 43: 939–947.

Hayhow, R. (2007). The least first framework, in S. Roulstone (Ed) *Prioritising child health: practice and principles*. London: Routledge.

Jones, M., Onslow, M., Packman, A., O'Brian, S., Hearne, A., Williams, S., Ormond, T., & Schwarz, I. (2008). Extended follow-up of a randomised controlled trial of the Lidcombe Program of Early Stuttering Intervention. *International Journal of Language and Communication Disorders, 43*, 649-661.

Jones, M., Onslow, M., Packman, A., Williams, S., Ormond, T., Schwartz, I., et al. (2005). Randomised controlled trial of the Lidcombe Programme of early stuttering intervention. *British Medical Journal*, *331*, 659-661.

Kelman, E. & Nicholas, A. (2008). *Practical intervention for early childhood stammering*. Speechmark Publishing, Brackley: UK.

Koedoot, C., Bouwmans, C., Franken, M-C. & Stolk, E. (2011). Quality of life in adults who stutter. *Journal of Communication Disorders, 44,* 429-443.

Månsson, H. (2000). Childhood stuttering: Incidence and development. *Journal of Fluency Disorders, 25*, 47-57.

Mayer, M. (1969). F*rog, where are you?* New York: Dial Books for Young Readers.

Michael Palin Centre information for parents at http://www.stammeringcentre.org/parent-information

Miller, L. L., Hayhow, R., Peters, T., Emond, A., Au-Yeung, J., & Roulstone, S. (2012). The Prevalence of Stuttering: Therapist Judgement vs %SLD vs Parent Report. Paper presented at the *7^(th) World Congress on Fluency Disorders*, 2^(nd) -5^(th) July, Tours, France.

Mulcahy, K., Hennessey N., Beilby, J., & Byrnes, M., (2008). Social anxiety and the severity and typography of stuttering in adolescents. *Journal of Fluency Disorders, 33,* 306–319.

O'Brian, S., Jones, M., Pilowsky, R., Onslow, M., Packman, A. & Menzies, R. (2010). A new method to sample stuttering in preschool children. *International Journal of Speech-Language Pathology*, *12,* 173–177.

Onslow M, Packman A, Harrison E, eds. (2003). *Lidcombe program for early stuttering intervention: Clinician's guide*. Austin, TX: Pro-Ed.

Packman, A., Onslow, M., Webber, M., Harrison, E., Lees, S., Bridgman, K. & Carey, B. (2011). *The Lidcombe program of early stuttering intervention treatment guide.* Download available from Australian Stuttering Research Centre.

Reilly, S., Onslow, M., Packman, A., Wake, M., Bavin, E. L., Prior, M., Eadie, P., Cini, E., Bolzonello, C., & Ukoumunne, O.C. (2009). Predicting stuttering onset by age of 3 Years: A prospective, community cohort study. *Pediatrics, 123,* 270-277.

Roulstone, S., Peters, T. J., Glogowska, M., & Enderby, P. (2008). Predictors and outcomes of speech and language therapists' treatment decisions. *International Journal Speech-Language Pathology*, *10(3),* 146-155.

Stewart, T. & Turnbull, J. (2007). *Working with dysfluent children revised Edition.* Brackley: UK: Speechmark Publishing.

Thomas-Stonell, N.L., Oddson, B., Robertson, B., & Rosenbaum, P. (2010). Development of the FOCUS (Focus on the Outcomes of Communication Under Six): A communication outcome measure for preschool children. *Developmental Medicine & Child Neurology*, *52*, 47-53.

Trajkovski, N. (2012). The Westmead Program (pp.195-205). In S. Jelcic Jaksic and M. Onslow (Eds). *The science and practice of stuttering treatment: A symposium.* Chichester: UK: Wiley-Blackwell.

Trajkovski, N., Andrews, C., Onslow, M., Packman, A., O'Brian, S., & Menzies, R. (2009). Using syllable-timed speech to treat pre-school children who stutter: a multiple baseline experiment. *Journal of Fluency Disorders, 34*, 1-10.

World Health Organisation (WHO,1992). *International statistical classification of diseases and related health problems, tenth revision (ICD-10).* Geneva: World Health Organisation.

Yairi, E. & Grinager Ambrose, N. (2005). *Early childhood stuttering: For clinicians by clinicians,* Austin, Texas: Pro-Ed.

Yiari, E. & Ambrose, N. G. (1999). Early childhood stuttering: Persistency and recovery rates. *Journal of Speech, Language and Hearing Research, 42*, 1097-1112.

APPENDIX 1 – BCRP REPORTS

All the BCRP reports are available from the BCRP page on the Department for Education's website: http://www.education.gov.uk/researchandstatistics/research and also from the BCRP page in the CEDAR, University of Warwick website: http://www.warwick.ac.uk/go/bettercommunication

Main report

1.   Lindsay, G., Dockrell, J., Law, J., & Roulstone, S. (2012). *Better communication research programme: Improving provision for children and young people with speech, language and communication needs.* London: DfE.

This report presents the main recommendations of the whole Better Communication Research Programme (BCRP). It draws on evidence provided in the thematic and technical reports. This report also considers the overall implications for policy, practice and research, and indeed seeks to bridge the gap between this substantial research programme and the policy and practice agenda.

Interim reports

2.   Lindsay, G., Dockrell, J.E., Law, J., Roulstone, S., & Vignoles, A. (2010) *Better communication research programme 1st interim report DfE-RR070. London: DfE.* (70pp). http://publications.education.gov.uk/eOrderingDownload/DFE-RR070.pdf

This report presents interim findings from the project that had been underway between January and July 2010; best evidence on interventions; the academic progress of pupils with SLCN; economic effectiveness; the initial phase of the prospective longitudinal study of children and young people with language impairment (LI) and autism spectrum disorder (ASD); and the preferred outcomes of children and young people with SLCN, and of their parents.

3.   Lindsay, G., Dockrell, J.E., Law, J., & Roulstone, S. (2011) *Better communication research programme 2nd interim report. DFE-RR 172.* London: DfE. (131pp). https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR172.pdf

This report presents interim findings of the project that had been underway between July 2010 – January 2011. Further work is reported from analyses of the national pupil data sets examining development and transitions of pupils with SLCN or ASD between categories of special educational needs, the prospective study, and parents' preferred outcomes (an online survey). In addition, interim reports from new projects include: the initial phase of development of a Communication Supporting Classrooms Tool; a survey of speech and language therapists' practice regarding interventions; a study of language and literacy attainment during the early years through Key Stage 2, examining whether teacher assessment provides a valid measure of children's current and future educational attainment (led by Margaret Snowling and Charles Hulme); two studies of the relationship between

SLCN and behaviour, with Victoria Joffe and Gillian Baird respectively; cost effectiveness of interventions; and the setting up of a prospective cohort study of speech and language therapy services for young children who stammer.

Thematic reports

4.   Dockrell, J., Ricketts, J. & Lindsay, G. (2012). *Understanding speech, language and communication needs: Profiles of need and provision.* London: DfE.

This thematic report examines the nature of speech language and communication needs and the evidence from BCRP studies that have explained both the nature and needs encompassed by the category and the provision made to meet those needs. This report draws upon six projects (8, 9, 10, 11, 14 and 15).

5.   Law, J., Beecham, J. & Lindsay, G. (2012). *Effectiveness, costing and cost effectiveness of interventions for children and young people with speech, language and communication needs.* London: DfE.

This thematic report first considers the nature of evidence based practice in health and education before reviewing the evidence for the effectiveness of interventions for children and young people with SLCN. The report also considers cost effectiveness and how it might be measured before examining the evidence of the cost effectiveness of SLCN interventions. The report draws on projects, 8, 10, 11 and 12.

6.   Lindsay, G. & Dockrell, J. (2012). *The relationship between speech, language and communication needs (SLCN) and behavioural, emotional and social difficulties (BESD).* London: DfE.

This thematic report explores the relationship between SLCN and behavioural, emotional and social difficulties. We argue that there are different patterns of relationship between SLCN and ASD, and different types of behavioural, emotional and social difficulties. The report draws on the 2nd interim report (report 3) and project reports 9, 11 and 15.

7.   Roulstone, S. & Lindsay, G. (2012). *The perspectives of children and young people who have speech, language and communication needs, and their parents.* London: DfE.

The BCRP ensured that the perspectives of parents and children were explored through a number of different projects. This project explores the evidence primarily from projects 9 and 12, drawing on evidence from a series of specific studies of parents' and children's perspectives and also those of the parents in our prospective study.

Technical reports

8.   Dockrell, J. E., Bakopoulou, I., Law, J., Spencer, S., & Lindsay, G. (2012). *Developing a communication supporting classroom observation tool.* London: DfE.

This study reports the development of an observational tool to support teachers, SENCOs, speech and language therapists and others to examine the degree to which classrooms support effective communication. The report comprises a review of the evidence base for developing effective communication and an account of the empirical study to develop and determine the technical qualities of the tool.

9.   Dockrell, J., Ricketts, J., Palikara, O., Charman, T., & Lindsay, G. (2012). *Profiles of need and provision for children with language impairment and autism spectrum disorders in mainstream schools: A prospective study.* London: DfE.

The prospective study was the most substantial project in the BCRP running throughout the whole period of the research. Focusing on children and young people initially 6-12 years old, we report on the nature of their abilities in language, literacy, behavioural, emotional and social development; the perspectives of the parents; the support provided as examined by classroom observations and specially created questionnaires completed by their teachers and SENCOs.

10.   Law, J., Lee, W., Roulstone, S., Wren, Y., Zeng, B., & Lindsay, G. (2012). *"What works": Interventions for children and young people with speech, language and communication needs.* London: DfE.

This report provides a review of 60 interventions for children and young people with SLCN, all evaluated against 10 criteria. The report will form the basis of a web-based resource to be developed by the Communication Trust for easy access by practitioners and parents.

11.   Meschi, E., Mickelwright, J., Vignoles, A., & Lindsay, G. (2012). *The transition between categories of special educational needs of pupils with speech, language and communication needs (SLCN) and autism spectrum disorder (ASD) as they progress through the education system.* London: DfE.

Analyses of the School Census and National Pupil Database are used to examine the transition made by pupils with SLCN or ASD over time and by age. We examine factors that are associated with transition between levels of special educational need (School Action, School Action Plus and Statement) and having no special educational need (non-SEN), including having English as an Additional Language and attainment. We also explore school characteristics associated with different transitions to other categories of SEN.

12.   Roulstone, S., Coad, J., Ayre, A., Hambley, H., & Lindsay, G. (2012). *The preferred outcomes of children with speech, language and communication needs and their parents.* London: DfE.

This report provides findings from four different studies addressing the perspectives of children and young people with SLCN, and those of their parents. Data are reported from arts-based participating workshops for children, focus groups and a survey for parents; and a systematic review of quality of life measures for children.

13.   Roulstone, S., Wren, Y., Bakopoulou, I., Goodlad, S., & Lindsay, G. (2012). *Exploring interventions for children and young people with speech, language and communication needs: A study of practice.* London: DfE.

As a complementary study to our analysis of the evidence for interventions, we also carried out an interview study of speech and language therapy managers and educational psychology service managers, on the basis of which we conducted a national survey of speech and language therapists to examine prevalence of use of the different approaches.

14.   Snowling, M. J., Hulme, C., Bailey, A. M., Stothard, S. E., & Lindsay (2011). *Better communication research project: Language and literacy attainment of pupils during early years and through KS2: Does teacher assessment at five provide a valid measure of children's current and future educational attainments? DFE-RR172a.* London: DfE. https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR172a.pdf

We report a study led by Margaret Snowling and Charles Hulme which explored whether teacher assessment and monitoring could be used to identify children with language difficulties in need of early interventions. This study was conducted to inform the Tickell Review of the Early Years Foundation Stage, in particular the proposals for a simplified framework and assessment process.

15.   Strand, S., & Lindsay, G. (2012). *Ethnic disproportionality in the identification of speech, language and communication needs (SLCN) and autism spectrum disorders (ASD).* London: DfE.

This report complements that of Meschi et al (number 11). Using School Census data from four years (2005, 2007, 2009 and 2011) the report examines the issue of ethnic disproportionality (i.e. over- and underrepresentation of pupils from different ethnic groups) with respect to SLCN and ASD.

16.   Roulstone, S., Hayhow, R., White, P. & Lindsay, G. (2012). *Prospective cohort study of speech and language therapy services for young children who stammer.*

This prospective cohort study follows children referred to speech and language therapy services because of stammering. The study tracks the children's process through the system and their outcomes.

17.   Meschi, E., Vignoles, A., & Lindsay, G. (2010). *An investigation of the attainment and achievement of speech, language and communication needs (SLCN).* http://www.warwick.ac.uk/go/bettercommunication

This technical report presents early analyses upon which the study reported in report number 11 is based.