

Parent concerns and professional responses: the case of specific language impairment

Anne Rannard, Christina Lyons and Sheila Glenn

ABSTRACT

Background

GPs and health visitors are usually the first to be approached by parents concerned about their child's speech and language development in the early years. The role health professionals play in early detection of speech and language difficulties is therefore crucial to ensure timely referral for speech and language therapy.

Aim

To examine parental accounts of health visitor and GP involvement in the assessment and diagnosis of their children's speech and language impairment.

Design of study

Qualitative retrospective interviews.

Setting

Two Local Education Authorities in Merseyside.

Method

In-depth interviews were conducted with 40 parents. Interviews were transcribed and thematically analysed. Twenty per cent of interviews were analysed by an independent researcher and consensus reached on thematic content.

Results

In many cases, parents were the first to realise that there was something wrong with the speech and language development of their child. Parents reported that health professionals tended to underestimate speech and language problems, and failed to take parental views into account. In some cases, parents found that attending a specialist unit or hospital resulted in the children reaching school age before referral to speech and language therapy was made. In other cases, health professionals appeared to rely on the possibility of spontaneous recovery, and gave inappropriate advice to parents, which resulted in delayed referral to speech and language therapists.

Conclusions

Health professionals failed to use systematic, evidence-based approaches in responding to early parental concerns. For this group of parents, such an approach resulted in long delays in referral for specialist intervention.

Keywords

health professionals; parent perceptions; speech and language.

INTRODUCTION

Many children have communication difficulties that are not picked up in the preschool period.¹ Delays in diagnosis and intervention are a cause for concern to parents, and this concern in itself is statistically significantly related to poor language development.² However, little is known about the way that GPs and health visitors react to parents' initial worries about their child's language development. This paper reports on the experiences of one group of parents whose children with persistent speech and language difficulties were later admitted to a specialist language unit.

Background

It is estimated that almost a fifth of parents in Britain are concerned about their child's speech and language development at any one time.³ Professional opinion is divided on the significance of early developmental language delay because almost 60% of speech and language problems resolve spontaneously by the age of 3 years.^{4,5} However, continuing speech and language impairment can result in later behavioural and psychiatric problems, poor academic performance, and long-term personal and social difficulties.^{6,7}

There is no universal screening for speech and language difficulties because of the doubtful value of available screening instruments, many of which

A Rannard, PhD, lecturer, School of Nursing, Midwifery and Social Work, University of Manchester. C Lyons, PhD, department of nursing, University of Central Lancashire, Preston. S Glenn, PhD, professor, Faculty of Health and Applied Social Sciences, Liverpool John Moores University, Liverpool.

Address for correspondence

Anne Rannard, School of Nursing, Midwifery and Social Work, University of Manchester, Williamson Building, Oxford Road, Manchester M13 9PL.
Email: anne.rannard@manchester.ac.uk

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lack concurrent validity, sensitivity and specificity, and do not report sample size.⁸ In the absence of formal screening, health visitors are the main referrers to speech and language therapy preschool, although there is little information in the literature on how they or GPs make their judgements to: reassure; watch and wait; or refer for specialist intervention (such as speech and language therapy).⁸ Speech and language difficulties may occur as part of a more global neurodevelopmental problem.⁹ However, many children with 'specific language impairment' have difficulties that are not explained by a primary medical condition, hearing loss, or other developmental disorder.³ These children present a major challenge to health professionals in the early preschool years, because it is often not possible to predict at the time of identification which children, particularly very young children, are likely to have persistent problems.^{4,5,8} Variations between children make prognosis difficult.⁹ Parent information can help the clinician in making referral decisions, although there is some debate as to whether parents have sufficient knowledge of normal language development to detect abnormalities in their child's speech and language system.³ To explore the issue further, this paper presents an account of the experiences of one group of parents whose children had persistent speech and language problems, to the point where all were later admitted to a language unit.

METHOD

Participants

A total of 180 children were identified from language unit records in two Local Education Authorities (LEAs) in Merseyside. All of the children in the study had identified speech and language difficulties that were sufficiently severe to warrant language unit admission. Children whose problems had resolved spontaneously were not included.

Data collection took place between 1996 and 1998 and was part of a wider, unpublished study

looking at children's experiences of moving from language units into mainstream schools. Children still in language units, and those with primary medical conditions, complex receptive problems, or structural or neurological abnormalities did not take part in the study. Parents of 180 children were identified, of whom 138 were eligible to take part. Of these, 30 parents showed initial interest but failed to respond to appointment letters or telephone calls to arrange an interview date; three had moved house with no forwarding address; six parents refused to take part and four parents were not at home for pre-arranged visits. Of the remaining 95 parents, 40 took part, giving a 29% response rate.

At the time of the study, all but four of the children were in primary school, with ages ranging from 5 years 3 months to 16 years 9 months (mean = 9.82; standard deviation = 2.39). Thirty of the children were male and 10 female. The LEA's administration sent an introductory letter and information sheet to parents, and all parents gave written consent before the study began.

A chronological or life-history approach¹⁰ was used for parent interviews, which allowed parents to describe the child's speech and language development from birth to eventual language unit admission. An interview guide exploring key pre- and post-language-unit topics was used to cover key areas; for example, age of the child at detection, timing of diagnosis, and referral for speech and language therapy. Prompt questions or probes were used as necessary,¹⁰ and all parent interviews were tape-recorded in the home. Interview transcripts were annotated with words or phrases to identify themes, using the same words that parents had used in the text. A list of main themes and sub themes was constructed, which allowed for detailed checking of each transcript and also comparison of themes to be made across cases. All transcripts were coded. In the preliminary stages of analysis, an independent researcher randomly assessed 20% of transcripts to establish consensus on themes identified. Where necessary, discussion took place until full agreement was reached, and the agreed coding frame was used to code and recode transcripts as necessary. Where there was uncertainty regarding contextual meaning, tape recordings and field notes were listened to again and transcripts re-read, to check that responder views had been accurately represented.

RESULTS

In 28 cases (70%), parents could remember when they first noticed something wrong with their child's speech and language development. Of these, 17 reported problems before the child reached the age

How this fits in

The role GPs and health visitors play in the detection of speech and language problems in young children is not well documented. However, early detection and intervention is crucial if these children are to have good long-term outcomes.

This paper reports on the experiences of one group of children and their parents, and shows that this is an important area for examination in the drive to improve children's services in primary care.

of 2 years (in two cases mothers noticed their child was making no sound from as early as 8 months). Nine parents reported problems between 2–3 years, and two between 3–4 years.

Out of 40 parents, four said that when first concerned about their child's speech and language development, they consulted their GP or health visitor, and were referred directly for speech and language therapy assessment. Of these, one child had stopped talking following meningitis; one was only making grunting noises at the age of 2 years; one child had borderline receptive problems, and one child's parents thought he was deaf.

Six children (aged 8–18 months) were referred for hearing tests by their GP or health visitor when parents consulted with concerns over the child's speech and language development. Two of these children had persistent hearing difficulties, and were referred for speech and language therapist assessment at between 2 and 2.5-years old. The other four children passed their hearing tests. Of these, one was referred by his GP for a full neurological assessment, which showed 'some delay in him in the way he responded to things'. After that he attended a child psychology unit and was later referred for speech and language therapy. His mother said:

'I've got no criticism whatsoever of the help I've had. I mean it makes me shudder to think that had I not decided off my own bat to go to the doctors and start the ball rolling I don't know what would have happened.'

Another child from this group had a family history of speech problems, and at 2 years old was making sounds but had no clear speech. The family health visitor arranged a speech and language therapy referral, and regular therapy began shortly afterwards. The other two children in this group reached the age of 3–3.5 years before being referred for speech and language therapy, one by a preschool nursery, and the other by a health visitor.

Of the remaining 30 children, three attended hospital paediatric clinics, one for coeliac follow-up, one for checks of a large head circumference at birth, and one for an enlarged spleen. Of these three children, one was referred for speech and language therapist assessment by her paediatrician at age 2 years, while despite parental concern, the remaining two children reached the age of 4 years before a similar referral was made. One of these mothers said:

'Come 18 months I was sort of getting concerned and would mention it to different

ones [at the hospital] and they would say, "oh, some are slower than others". They would just turn round and say that one day he'll come out with a mouthful and you'll wish he never had ... you know, he'll never stop talking.'

One 3-year-old child was an inpatient for several weeks on a paediatric orthopaedic ward, where one of the staff noticed that the child spoke little and that speech sounds were 'odd'. The family had previously noticed that the child was unable to form a two-word sentence, and words sounded wrong, but had decided to 'deal with one thing at a time' and let the child recover from two separate operations before requesting help with speech and language development. The local clinic subsequently referred the child for speech and language therapist assessment.

Of the remaining 26 children, six were referred by their nurseries for speech and language therapist assessment, and of these, four parents had been concerned about their child's speech and language development and had previously raised these concerns with primary healthcare professionals. Two children, who attended a child psychology unit because of temper tantrums, had finished nursery and were due to start school before the unit referred them for speech and language therapist assessment.

The remaining 18 children had difficulties in getting speech and language therapist referral in primary care settings. Parents were not satisfied with GP and health visitor responses to their concerns:

'The doctor that we saw at first was just ... it seemed as though he didn't want to listen. He was like ... "Just go away. It's all right, it'll go on its own".'

In many cases, parents said they felt those they approached did not take their concerns seriously enough:

'After he was 2, I felt concerned about his speech and I kept going to the clinic and pestering them but no way. They kept saying, "well, he's only 2". And I kept saying, "yes, but he's going to nursery".'

In 10 cases, parents specifically remembered the way health professionals responded to their concerns. Four mothers were advised not to worry because 'the older child is speaking for him/her'; two mothers were told 'he/she will speak when ready'; two mothers were told 'the speech will

come on its own'; and two mothers were told to 'wait a while longer and see what happens'.

Some mothers commented on the lack of follow up: *'He was 2 when I went to my health visitor and then she said, "leave him till he's 3," and he didn't improve. She didn't come back. I went and they actually said he should have really been looked at earlier which I was really annoyed about.'*

After repeated unsuccessful visits to surgery or clinic, many mothers said they began to think that health professionals considered them 'neurotic' or 'over anxious', or that they were worrying over nothing.

For the group as a whole, an average of 2 years passed between the first approach by the parent to health professionals and subsequent referral to speech and language therapy. Six parents were satisfied with the way their concerns were handled by primary healthcare professionals, but the majority expressed some dissatisfaction at the lack of urgency of referral from health professionals in both primary and secondary care. Only one parent said developmental screening had detected a problem with their child's speech and language.

DISCUSSION

Summary of main findings

In the majority of cases, parents were the first to be concerned about their child's speech and language development. Almost 50% of parents were concerned before the child had reached 2 years. The majority reported problems around the age of 2 years, when speech is held to be reasonably well developed.¹¹ Health professionals responded in different ways to these concerns. A small number of children were referred for speech and language therapist assessment by their GP or health visitor about the problem, and subsequently received ongoing speech and language therapy. These were the children with obvious difficulties related to a complete absence of speech, to borderline receptive problems, and to possible deafness, which may have influenced referral decisions. Children without an obvious neurological delay or primary medical condition experienced delays in referral. Their problems were related to odd speech sounds or very little speech, and were later diagnosed as specific language impairment. Delays in referral may have been due to the apparent absence of other neurodevelopmental conditions, although it is difficult to say what criteria health professionals used in responding to parental concerns because published standards for

preschool child health surveillance at general practice level are not available.¹²

There was often a considerable gap between when the problem was first noticed by parents, and eventual referral for assessment by a speech and language therapist. Many parents felt that health professionals did not take their concerns seriously enough. In a quarter of cases, parents were dismissed with comments that others in the family were speaking on behalf of the child, or that the child would speak when he or she was 'ready'. Understandably, parents became frustrated by these responses, particularly when the children were later found to have identifiable speech and language difficulties.

Health professionals appeared to rely on the possibility of spontaneous recovery of the problem rather than acknowledge that parental concerns were valid. Yet, in spite of differences in age, education level or socioeconomic status, many parents are capable of accurately reflecting their child's language development, sometimes at levels that are higher than detection rates found in medical settings.⁶ However, the use of parental concern as a basis for referral may be overshadowed by the high numbers of children whose problems resolve without treatment, to local issues of long waiting times for speech and language assessment, or to gaps in the knowledge base of health visitors and GPs. Health visitors, although the main referrers to speech and language therapy preschool,⁸ are said to base their judgements regarding speech and language problems on 'a tiny proportion' of the child development component on the basic health-visiting course.¹³ Similarly, the child development element in the medical curriculum may not fully prepare clinicians to respond effectively to parental concerns in this area. In addition, reductions in home visiting by health visitors¹⁴ could mean that there is more reliance on formalised assessment tools in clinical settings where the child's performance can be variable. Consequently, children who fail may not be referred for further investigation, but may be allocated to a 'watch and wait' process, which can result in delayed diagnosis and intervention.

Parents appeared to have more success in getting a referral for speech and language therapist assessment if nurseries support them. Possibly, health professionals take more notice of nurseries than they do of parents alone.

Limitations of the study

The study design did not include children with typically developing speech and language, and

therefore does not address the issue of children whose problems resolved after the age of 2 years. Their experiences may have been more positive than those reported here. GPs and health visitors were not included in the study, and it is therefore not known what criteria were used for referral or non-referral decisions. In addition, the low response rate could mean that those who took part in the study were the dissatisfied few and their views may not represent parents with different experiences. Children of non-participants presented with the same speech and language difficulties as those who did take part. It is possible that parents may not have wanted their children involved in a research project, or if the children were making normal progress at the time of the study, neither children nor parents wished to be reminded of past events. The findings are therefore limited, and cannot be generalised to a wider population.

Comparison with existing literature

The findings from this study may be part of a general pattern of inappropriate advice given to parents of children with special needs.¹⁵ Other instances in the literature have shown that children later found to have severe and persistent language delays were not referred for specialist opinion until months and sometimes years later.¹⁶⁻¹⁸ If this is the case, the acknowledged value of parent views in assessing their child's development should be given more importance.¹⁷

Implications for future research or clinical practice

An important future research topic is the identification of characteristics of children whose problems do not resolve spontaneously, and for this, parental reporting could be extremely valuable. In adopting a low threshold for referral to speech and language therapists, it is unavoidable that some children will be referred who need no further help. Nevertheless, health professionals and parents must work together to avoid late referral to speech and language therapy so that problems are picked up well before school entry. Although the results of this study may not be typical of the whole population of children with speech and language difficulties, there is still the view that children with special needs are not adequately served by the services they encounter. Taking parent views into account could help reverse this trend.

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Ethics committee

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Competing interests

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