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Whose job is it? Parents' concerns about the needs of their children with language
problems

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Abstract

This study examined the perspectives of parents of children with specific speech and language difficulties (SSLD) in the UK and described the issues they raised when considering provision to meet their children's needs. The study utilised a mixed methods approach. Data from interviews were analyzed using a computer-based qualitative interview analysis method (ATLAS/ti), with reference to evidence from a parent-completed rating scale and assessments of the children's language and educational development. The issues generated by the analyses were considered in relation to whether the child attended mainstream or special school. Results are discussed in the context of current educational policies for inclusive education and parental participation in meeting children's educational and social needs.

Whose job is it? Parents' concerns about the needs of their children with language problems.

Language is a cornerstone of early development. When a child's early language skills are compromised because of developmental difficulties parenting patterns and educational provision are challenged. How parents and professionals work together to support the development of children with language difficulties is of significant concern. The current study addressed these issues by considering the perspectives of the parents of children with specific speech and language difficulties (SSLD). These are children with a primary language problem, one that is not a result of other intellectual, sensory or physical difficulties; these children are often referred to as experiencing specific language impairment (Bishop, 1997; Leonard, 1998).

The involvement of parents in the education of children with disabilities in the United Kingdom is considered not only a right, but also a necessary component of the delivery of effective and efficient provision (Department for Education and Employment 1997, 1998, 2000). It is also a legal requirement under the Education Act 1996, legislation that is comparable to that in the United States, the most recent being the 1997 Amendments to the Individuals with Disabilities Education Act (IDEA '97). Guidance is provided by a Code of Practice (Department for Education and Skills, 2001).

Parental involvement covers many aspects including the assessment process, where parents' knowledge of their child is an important source of information; decision-making, where parents have a right to receive full information, call their own experts, and express a preference for provision; and educational intervention to which parents may contribute. Parents also provide an important source of information on the working of the systems designed to meet their child's needs. Although such

information concerns an individual child's pattern of experiences, patterns across individuals can be analyzed and the results generalized to wider groups. As such parents have an important role in closing the audit loop on the system's effectiveness.

As provision for children with disabilities is being made increasingly in inclusive settings in both the US and the UK, it is important to understand parents' perspectives on the benefits and drawbacks of this approach. Parents of children with disabilities and parents of typically developing children have mainly positive attitudes to the inclusion of children with disabilities in mainstream provision (Bennett, DeLuca & Bruns, 1997; Duhaney & Salend, 2000; Galant & Hanline, 1993; Guralnick, 1994; Guralnick, Connor & Hammond, 1995; Miller et al., 1992). Parents who are supportive of inclusive policies consider that this means acceptance, belonging, "fitting-in", not being different, making friends locally, and participating in local community activities (Erwin & Soodak, 1995; Hewson & Sisson, 1996; Petley 1994; Schwartz, Staub, Galluci, & Peck, 1995). Parents who support inclusion consider that children with disabilities develop better social skills, academic abilities and motivation from being alongside their typically developing peers who act as role models (Guralnick et al., 1995; Palmer, Fuller, Arora & Nelson, 2001; Ryndak, Downing, Lilly, & Morrison, 1995). Many parents give greater importance to their child being accepted socially and as part of the community than to academic achievement (Bennett, Niswander, & DeLuca, 1996; Palmer et al., 2001; Sheldon, 1991).

Studies in both the US and UK that have explored aspects of inclusion, including parental views of supports needed and barriers encountered, have revealed variations in parental perspectives. Parents may lack knowledge of the services available (Wesley, Buysse, & Tyndall, 1998), although intervention programs at community level may redress these deficiencies (Buysse, Wesley, & Skinner, 1999).

Parents of typically developing children in inclusive schools have been found to hold more positive views about inclusion than parents of children in non-inclusive schools, and to believe that it was valuable to their child's development (Diamond & LeFurgy, 1994; Guralnick et al., 1995; Miller et al., 1992).

Parents may have concerns about the quality of the special support available and the possibility of rejection of the child by peers (Galant and Hanline, 1993; Guralnick, 1994; Guralnick et al., 1995). They may have to fight for the provision necessary, a task for which not all parents have the necessary resources (Petley, 1994). Riddell, Brown, and Duffield (1994) found that middle class parents, either alone or in liaison with voluntary agencies, were more successful at gaining extra resources for their children than working class parents.

Concerns about inclusion also involve its suitability relative to the severity of the child's disability, age, and whether the education of typically developing children will be affected (Palmer, et al., 2001; York & Tundidor, 1995). Children with behavior problems seem to be rejected more often and their parents are aware of the drawbacks of inclusion for them (Guralnick, 1994). Since children with SSLD frequently experience additional problems with behavior, there may be similar drawbacks for this population (Botting & Conti-Ramsden, 2000; Lindsay & Dockrell, 2000).

The age factor is relevant to both the language and educational needs of children with SSLD. Speech and language therapists (SLTs) in the U.K. typically concentrate on the pre-school and primary (elementary) age range (Lindsay, Dockrell, Mackie & Letchford, 2002). The nature of the primary curriculum and classroom practice facilitates the delivery of in-class support either by the SLT or by the teacher under their guidance. Speech and language therapists in the U.K. are developing in-school practice that facilitates program delivery within inclusive settings. As

curriculum demands change in later primary school, it is more difficult to integrate therapy with teaching (Law et al., 2002).

Parents recognize that the philosophy of the school and the attitudes of individual teachers involved are important for successful inclusion (Bennett et al., 1997; Bennett, et al., 1996; Erwin & Soodak, 1995; York & Tundidor, 1995). However, parents and teachers do not necessarily agree on the benefits of inclusion (Bailey & Winton, 1987; Wesley et al., 1998). Seery, Davis, and Johnson, (2000) reported that despite much apparent similarity of views between parents and professionals, a finer grained analysis revealed important divergences. For example, twice as many professionals as parents provided only a conditional affirmative response to inclusion continuing. In addition not all parents want inclusion for their child (Grider, 1995). In England, there were more parental appeals to the Special Educational Needs Tribunal against local education authorities which refused to grant a “special” rather than “mainstream” school place (Special Educational Needs Tribunal, 2000).

Many parents of children with special educational needs recognize that not all parents want the same type of education for their child. They would like to be presented with facts by supportive professionals and to be able to make a choice of education based on that information (Erwin and Soodak, 1995; Hewson and Sisson, 1996; Stokes, 1993). The complexity of the perspectives of parents of children with and without disabilities is evident from a review of 17 studies by Duhaney and Salend (2000). Where parents place a higher priority on socialization they tend to favour an inclusive education setting, while parents who are more concerned with academic goals tend to favour the availability of a continuum of services (Palmer, Borthwick-Duffy & Widaman, 1998).

Parents exert influence on their children's development both directly through their own parenting behavior and indirectly through the decisions they make about their child, including schooling. Consequently, enhancing effective parental involvement, in both modes, is one means of optimising the development of children with disabilities.

Bronfenbrenner's ecological systems theory (1979, 1992), provides a useful model for conceptualizing the factors relevant to helping children with developmental difficulties, including parents and schools (Granlund & Roll-Pettersson, 2001; Sontag, 1996). It stresses the inter-connectedness, and hierarchical arrangement of four systems: micro-, meso, exo- and macro-systems. There is no single focus on child deficiencies or the environment as explanations of poor development. The model is transactional and complex in that child and systems affect each other. The dimension of time in the changing pattern of interactions and nature of children's development has also been recognized (Lindsay, 1995). A concept of particular relevance here is that of "environmental niches" which are "particular regions in the environment that are especially favourable or unfavourable to the development of individuals with particular personal characteristics" (Bronfenbrenner 1992, p. 194). This has relevance both to consideration of inclusion and to the particular aspect of parental involvement. Parents' perspectives, support and understanding can enhance the match between the child's characteristics and the environmental niche. Their perspectives may include the perceived benefits and disadvantages of different types of education and therapy provision, while parents may also act as practical interfaces between other professionals and the child with respect to identification, assessment and intervention (Roffey, 1999; Wolfendale & Bastiani, 2000). Parents also have perspectives, as consumers, of the operation of education and healthcare systems, and of their

interaction. Finally the values, laws, customs, and resources of a particular culture provide the context for parental perspectives on issues such as the philosophy and nature of inclusive education, and on the laws and support mechanisms, including financial priorities, which support it.

Public schools in the U.K. operate within local education authorities (LEAs) which have statutory duties for the assessment of children with special educational needs (SEN) and making provision to meet those needs. Similarly, health care including speech and language therapy is provided by health trusts. Children considered to have special educational needs will be entered on the school's SEN register and have an individual educational plan (IEP) devised by the teacher. Where a child has more substantial and persistent SEN professionals from outside the school, including SLTs and educational psychologists will contribute to the IEP. Where a child is considered to have severe and complex SEN, a statutory multi-professional assessment is conducted, to which the parents must be invited to contribute, and the child may be made the subject of a statement of special educational needs. The statement specifies the provision that must by law be made to meet the child's special educational needs, and lays the foundation for the development of further IEPs (Huefner, 2000). This status is applied to about 3% of school pupils, over half of whom attend mainstream schools. There are now very few residential schools for children with SEN; these are mainly for low incidence disabilities and often run by voluntary bodies.

This study adds to previous work by its focus on children with specific speech and language difficulties (SSLD) and in particular on their parents' perspectives. The research combines both qualitative and quantitative methods, using each to cross-validate the other. The special educational needs system in the U.K. does not require

diagnostic categories; SSLD and SLI are both commonly used by practitioners to refer to children with primary language problems (Lindsay et al, 2002). Although their nonverbal intellectual ability is normal and they have no major sensory impairment, these children have substantial language impairment, typically in both expressive and receptive language domains. This group of children is particularly interesting because, by the nature of their problem, they bring together professionals from both health (speech and language therapy) and education. Also, their communication difficulties are typically not identified until they are 2 years or older. However, there is evidence of a mismatch in the understanding of these children's problems and their requisite needs as indicated by speech and language therapists and educational psychologists (Dockrell, George, Lindsay, & Roux, 1997) and gaps in teachers' knowledge and expertise to meet the children's needs (Dockrell & Lindsay, 2001). This study provides evidence on parental perspectives regarding the effectiveness of inclusive education. This is explored as a wider system issue, beyond the school alone, to include education and health services provision. It goes beyond the examination of each to address the integration of services.

Method

The present study was part of a longitudinal study conducted in two local education authorities (LEAs) and two regional special schools for children with severe speech and language difficulties in the UK. One LEA is a large urban community in the north of England with one health trust, population 531,000; the other spans two health trusts and covers both rural areas and a series of small towns, population 599,000. This project focused on a group of 69 children with specific speech and language difficulties (SSLD) selected when they were in Year 3 (about 8 years). An initial survey of all educational (school) psychologists, speech and language therapists

and schools' Special Educational Needs Coordinators in the two LEAs identified 133 children with SSLD, from whom a subsample of about 30 from each LEA was derived. The 59 selected children were supplemented by 10 children with SSLD attending regional special schools. There were 52 boys and 17 girls, a gender disparity typical of that found in samples of children with SSLD (Leonard, 1998). All children were on their school's special educational needs register, and 54% had a statement of special educational needs under the Education Act 1996. The children had substantially delayed development on a number of language and educational measures which ranged in mean age scores from 4 years 4 months to 6 years 1 month at mean chronological age of 8 years 3 months (Dockrell & Lindsay, 1998). The longitudinal study, using a mixed methods design, has examined the nature of the difficulties, including language and literacy, experienced by these children and the services provided to meet their needs. The present study of parental perspectives complements an investigation of the perspectives of the children's teachers (Dockrell & Lindsay, 2001).

Qualitative methods have become established within educational and psychological research (Miles & Huberman, 1994; Denzin & Lincoln, 2000), and more recently within special education (Bailey et al, 1999; Grove & Fisher, 1999; Palmer et al, 2001; Seery et al, 2000; Wesley, Buysse, & Tyndall, 1997). The use of individual and group interviews and focus groups allows a more flexible approach to data gathering, and provides the potential for richer information, which may extend the scope of the study beyond the original research questions (Anzul, Evans, & King, 2001; Pugach, 2001). Qualitative methods also represent a different epistemological approach, treating the participant as a partner, providing an interchange of views between two or more people, and emphasising the research as socially situated (Lewis

& Lindsay, 2001). However, the quality of research using qualitative methods has been criticized, including analyses sponsored by government agencies in the UK (Tooley & Darby, 1998). To address the limitations of both qualitative and quantitative methods a number of researchers have used a mixed methods approach, tailoring methods to different types of question within the research design (Bennett et al., 1997). The present study primarily used qualitative methods supplemented by data from teacher-completed rating scales and standardised assessments.

Participants

Participants were the parents of 66 out of 69 children who agreed to be interviewed. The parents had 21 children attending special schools (10 residential, 11 local) and 45 in mainstream. All children in special schools had active speech and language therapy involvement, as did 5 of the 6 children in mainstream schools with designated special provision, and 70% of those integrated individually into mainstream schools. The nature of this varied with intensity being greatest in special schools that had speech and language therapists on the staff, working with teachers and providing direct therapy. Those in mainstream schools received therapy from visiting therapists, typically no more than once a week and often much less frequently. The majority of interviews were carried out with mothers only (73%). In 21% of the interviews both parents were present. The four remaining interviews occurred with the father alone (n=2) or mother and grandmother (n=2).

Measures

The present paper focuses on the parental perspectives as gained at interview (see Procedure), but also draws upon the results of the standardized questionnaire completed by the parents, the Strengths and Difficulties Questionnaire (SDQ), a revision and extension of the Rutter parent and teacher questionnaires (Goodman,

1994, 1997). The SDQ comprises five scales: emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial. Each scale comprises five items which are marked “not true”, “somewhat true” or “certainly true”. Each of the five scales can result in a score from 0 to 10. The scores of the first four scales can be summed to produce a total difficulties score (range 0-40); the prosocial scale provides a separate score for positive behavior. Goodman (1997) has presented evidence for the concurrent and predictive validity of the SDQ as well as standardization data for the cut-offs for each scale and the total difficulties score to indicate children as likely psychiatric “cases” with 80% “normal”, 10% “borderline” and 10% “abnormal” in each case. Further information on the relationship between parent- and teacher-completed SDQ, together with measures of self esteem, language and attainment are presented in Lindsay and Dockrell (2000).

Procedure

The parents were sent the SDQ by post about two weeks prior to the visit to their home by one of the two junior researchers to conduct the interview. The completed questionnaires were collected after the interview had concluded.

The parents’ views of their children’s development were obtained by open-ended semi-structured interviews. A schedule of major topic areas was devised by the researchers from a review of the literature and pilot interviews with parents of children with SSLD who were not part of the current cohort. The development was aided by the project’s steering group which included a representative of the main voluntary body for parents of children with language difficulties in the UK (Afasic). Main topic questions were supplemented by probes, which were used if information was not produced spontaneously.

The parent interview focussed on the following areas: identification and assessment of the child including their primary and secondary needs, the child in relation to their peers and siblings, strengths and difficulties across the curriculum, school life and home life including social relations, self esteem, what the child likes to do, extra support provided in school, professionals involved with the child, their relationship with the child's schools and professionals, thoughts about the child's future and the optimal provision for him/her, and thoughts regarding their experiences.

Parents were introduced to the interview by the researcher noting that the project was considering children with a wide range of difficulties, from those who have a few problems to those with many and severe problems. The interviewer then explained that as parents know most about their children, we would be speaking to them as the first step in the project. They were asked for permission to tape the interview, and were assured that all information was confidential and that neither they nor their child would be personally identified.

Interviews were undertaken in the parents' homes and typically lasted about 1 to 1½ hours. The interviewer took the lead from the parent allowing them time to talk about their own experiences and salient issues related to each area. These issues serve as the means of organizing the results.

Interviews were transcribed by the researcher who carried out the interview. The authors read the interviews to develop an initial coding frame based on the interview questions. The junior researchers, who had degrees in psychology, coded the interviews using the ATLAS/ti programme for computer-based qualitative interview analysis (Muhr, 1997). The authors, junior researchers and a third, independent researcher with a degree in Child Development, read all the interviews to develop a revised set of codes with 5 main issues and subcategories. The 5 main issues were: the

child's special educational needs, the initial identification of the child's problem, the type and quality of the support their child was receiving, the wider impact of the child's difficulties on the family, and their hopes, plans and concerns for their child's future. There were subcategories for each issue, e.g. 'views on their child's special educational needs' included the following subcategories: difficulties with language, literacy problems, behavioural difficulties, social relationships (where a positive peer relationship subcategory was also included), attention and hyperactivity, and acting out behaviour. The junior researchers coded all interviews for the issues and subcategories; both of the authors read a 10% sample of the interviews and interrater agreement on subcategories was 92%. The subcategories were used in reporting the results.

Results

In this section we report the emergent issues together with indications of their frequency and comparisons between the parents of children in mainstream and special schools. Where appropriate results from the Strengths and Difficulties Questionnaire (SDQ) are also reported using chi square to compare the distribution of scores (normal, borderline, abnormal) with the 80:10:10 ratio expected from the standardization (Table 1).

<Table 1 about here>

Parents' Views of their Children's Special Educational Needs

Parents were aware of the children's language difficulties and a range of other needs that their children experienced. Eighty-five percent recognized their child's primary problem was with language, while a minority considered this secondary to

other difficulties. Over half the parents also highlighted literacy problems that were confirmed by conventional reading measures (Dockrell & Lindsay, 1998; 2002). Behavioral difficulties were reported by over one-third of parents, similar to the 37% who rated their child “abnormal” on the total difficulties score of the SDQ, a statistically highly significant difference from the expected distribution $\chi^2(2, N = 60) = 61.85, p < .001$, Effect Size Index $w = 1.02$, representing a large effect (Cohen, 1998). The difficulties identified at interview comprised several sub-categories indicating the complex nature of the impact of communication difficulties on this domain.

There was variation in the parents’ perceptions of the children’s social relationships as evidenced by the interview and SDQ data. A quarter (27%) identified problems at interview, characterised by the comment “I just wish she could make friends, - she’s on her own all the time”. A higher proportion (46%) rated peer problems as abnormal on the SDQ (Table 1). However, many of the children were reported at interview to be positively involved in friendship groups both at home (41%) and school (59%). Of particular interest with respect to inclusion, similar proportions of parents of children in mainstream and special schools (over 80% in each case) reported that there were no negative aspects concerning friendship groups in school.

The SDQ tended to highlight problems by the specific nature of the questions asked. For example, bullying was not raised specifically at interview but 22% of parents reported on the SDQ that it was ‘certainly true’ that their child was bullied and 27% that this was ‘somewhat true’, but with no difference between mainstream and special school. At interview, however, parents discussed their child holistically with positive comments as well as those expressing concern. Strengths were also reported

in prosocial behavior as indicated above; indeed, this was the only scale on the SDQ where there was no statistically significant difference compared with the standardization sample, $\chi^2(2, N = 64) = 2.02, p = .37$.

The next most frequently reported concerns during the interviews were about attention and hyperactivity (26%), and with acting out behavior (23%): “He is very hard to make sit still” and “His concentration is poor.” Concerns about concentration and attention were also revealed, and more frequently, by the SDQ, where 45% of parents rated their children as “abnormal” on the hyperactivity scale, statistically significantly above the expected rate compared with the standardization sample $\chi^2(2, N = 65) = 89.31, p < .001$, Effect Size Index $w = 1.17$. Parents also noted concerns about acting out behavior with 37% rating conduct problems abnormal on the SDQ, $\chi^2(2, N = 66) = 57.81, p < .001$, Effect Size Index $w = 0.94$. In each case the effect size is large. The latter domain was typically presented as either a result of the child’s communication difficulties: “He used to get angry because he couldn’t get his words across” or as a comorbid characteristic: “He’s got a temper and if he can’t express himself sometimes it shows itself that way.”

The children in mainstream ($M = 6.45, SD = 2.62$) were rated as having statistically significantly more problems with hyperactivity on the SDQ than children in special provision ($M = 4.82, SD = 2.17$), $t(65) = 2.57, p = .013$ (two-tailed), $d = .70$. The mainstream children ($M = 3.23, SD = 2.33$) were also rated as having more conduct problems on the SDQ than children in special provision ($M = 2.09, SD = 1.60$), $t(66) = 2.05, p = .044$ (two-tailed), $d = .58$. Finally, the children in mainstream ($M = 17.00, SD = 7.57$) were rated statistically significantly higher than children in special provision on the SDQ total difficulties score ($M = 12.76, SD = 4.89$), $t(60) = 2.63, p = .011$ (two-tailed), $d = .68$.

Both the interviews and SDQ indicate that this sample of children with SSLD have a range of comorbid difficulties, including high levels of hyperactivity, poor concentration and impaired peer relationships, in addition to the expected language and educational problems. The greater prevalence of these problems in mainstreamed children raises important questions about inclusion, including whether failure to meet their language and educational needs was resulting in these behavioural difficulties. The use of both methods has furthermore not only produced cross validation but also useful complementary information: the SDQ focussed parents on specific characteristics and difficulties while the interview facilitated a more holistic representation of the child, including positive features.

Initial Identification of the Problem

The second issue concerns identifying developmental difficulties during early childhood. Parents reported having played a key role in identification, but this had often been a frustrating process. Almost half (47%) reported that they were the first to notice a problem. Parents were acting on their own suspicions that something was wrong, often influenced by knowledge from family history. A quarter (25%) reported either a parent or a sibling having some form of speech or language difficulty: “It runs in the family so we picked it up” (mother) or “I went to a speech therapist when I was a young chap for stuttering when I was about five” (father).

Professionals were often seen as dismissive, telling parents to come back later. This could happen more than once and so result in a very lengthy process, in some cases delayed until the child was attending nursery school (kindergarten): “My only grievance is that things didn’t happen sooner” and “We went to the child development unit, they said he was just fine.” There was also concern that nursery had not noticed anything wrong: “I think nursery should have picked up on it.”

These findings indicate the importance of parents in early identification, but also highlight the need for partnership. Parental expertise may be enhanced by previous experience with an older child. Optimal identification processes require the joint involvement of parents and professionals in partnership, with professionals prepared to address parental concerns positively.

Meeting the Child's Needs

The parents identified concerns about meeting their child's needs which were classified into seven categories. There were statistically significant differences between parents of children in mainstream (n = 21) and special school (n = 45) in three of these categories, all having implications for inclusion (Figure 1).

<Insert figure 1 about here>

Problems with placement were raised statistically significantly more often by parents in special schools, $\chi^2(1, N = 66) = 8.63, p = .003$, Cramer's V = 0.33 which accounts for 11% of the variance. These parents reported having to fight hard to secure special school placement for their child. Such battles could be prolonged and upsetting, as shown by these two parents: "It was me who campaigned his corner, who fought, who wrote letters" and "I think there has to be a shake up down there, because to go through the trauma you've got to go through for 18 months to get somebody to a school...it was very distressing."

However, securing the appropriate levels of support within the school was a more frequent problem for mainstream parents $\chi^2(1, N = 66) = 9.47, p = .002$, Cramer's V = 0.38, which accounts for 14% of the variance. Examples of concerns include: "The plans are sound but they just never seem to get done"; "The school would like to do more but have not the time nor the resources"; and "They said that he

needs specialised schooling really and they can't offer it to him and I can't offer it because I am not a teacher.”

By corollary parents of children in mainstream provision were also more likely to express concern about school-based problems including class size and school organisation $\chi^2(1, N = 66) = 4.34, p = .037$, Cramer's V = 0.26 which accounts for 7% of the variance.

Both groups were equally concerned about earlier problems with identification, with 41% of all parents reporting such difficulties, financing of appropriate provision (17%), and the time available for discussion and dissemination of information (18% overall): “Unless we approach we don't know anything.” Both groups also expressed concern over frequent changes in speech and language therapist resulting in a lack of amount and consistency of speech and language therapy. In addition, mainstream parents felt that the child did not get enough expert help from SLTs, who were reported to visit infrequently and leave work for the teacher or teaching assistant to do with the child rather than undertake direct therapy.

These findings indicate different experiences, and battles for parents of children in mainstream compared with special schools. Special school parents had fought to gain these services against a system which was mainly based on inclusion. Parents of children in mainstream supported this policy, but were unhappy with the services actually provided for their children. A move to even greater levels of inclusion will require attention to the level of service provided if parents are to be satisfied.

Impact on the Family

The children's special needs affected families in a range of different ways, in some respects independent of the nature of the schooling. Communication difficulties

were one source of stress for parents: “I used to get really depressed, I used to find it really hard trying to communicate with him...I couldn’t understand why we were like we were.”

Impact on siblings was also mentioned, resulting from communication difficulties: “He used to get very frustrated ...if he couldn’t find the right words to ask her [sister] to move he’d just get hold of her hair and drag her across the room”; or in terms of being fair, as exemplified by a mother talking about her younger typically developing child’s successes:

I didn’t want her to do it [succeed in a swimming assessment]. I was dreading it in a way. It sounds awful because obviously I want her to do well but I just didn’t want his confidence to be knocked either.

Residential schooling could be a problem: “I think it will be harder on his brothers. Their brother is being sent away, and they are going to miss him.” However, siblings were also a source of extra support: “She’s quite capable of telling them why she’s screaming or why she’s doing that, she’s very good with her.”

Other impacts were related to the child’s schooling. Forty-seven per cent of the parents reported active involvement in supporting their child’s language and learning needs, the nature of which was partly determined by the proximity of the school. Where the child was included into a local school, parents often visited and worked in the school: “I used to go in and teach him every day.” Others worked with the child at home:

She gave us things to do every night, trying to make him pronounce sounds that he had difficulty with... We would have to get him to learn words. We would do things like cut them out and put them on a bit of paper and we would

play cards with him...I would say to him what is that and sometimes he remembered and other times he didn't but that was all things we had to do.

This extra involvement might have repercussions on the child and family: "The trouble is you end up doing so many things after school and you think 'poor child.'"

Parent support within the school could also have drawbacks:

Because we have to help him because he's got learning difficulties, because we go up to the school every day to help him at school, the other children say 'why are your mum and dad here to help you? They shouldn't be here'. And that gets to him.

The need for guidance was also apparent: "We go through his folder with him and that but I really don't know how to do it properly."

Having a child with SSLD had an impact on the family as a whole. This could include difficulties within the family, with siblings for example, but the active involvement of almost half the parents in the children's education provides another source of stress, as well as a potential for positive, collaborative action with professionals. However, such practice needs to be collaboration based on knowledge and expertise if it is to be effective. Parents have much knowledge but not necessarily the skills to address some of their children's problems. Unless professionals support them in their work with their child parents can be exposed, unsuccessful and frustrated as they struggle to devise effective educational interventions.

The Future

Parents also expressed their hopes, plans and especially their concerns for the future. Once more these comments have relevance to inclusion. For example, 8 out of 10 of parents whose children were attending residential special provision saw the child's educational future in special schooling, and were preparing for future battles:

We know that after this September we will have to start fighting in order to secure his place (for secondary school). I have already written to my barrister in London saying that we will be starting this fight and if we need his services ...that is the only way we are going to do it.

The other two had a “dream” about their child returning to mainstream but commented that this was not a “realistic option”. “Ideally it would be great if it all came together and she could integrate into a normal school and be near home. Realistically I see her being here until she is 16.” Parents of children in mainstream, however, overwhelmingly wanted this to continue. Indeed only one parent with a child in mainstream referred to a perceived benefit of special school: “If he went to special school nobody could say anything about him being different.”

The main concerns for the parents of children in mainstream provision focused on two issues. First, parents referred to their hopes for their child overcoming their difficulties, whether with communication, social skills: “Well I hope her speech gets all right, you know. I suppose it will eventually” or literacy: “If she could just learn to read and write.” A number of parents of children in mainstream were concerned that as their child became older they would be ridiculed and become more aware of their difficulties, and that this would “get them down.” This could be aggravated by the extra support provided:

I hope that ... he won't need it [extra help] because I think it is more difficult for them when they are in big school if they are getting help from the other kids. More so than at his age because I don't think they realise when Y goes off for help, but when he goes to the big school I think they do. So I am hoping that he will be all right by the time he gets to big school.

Secondly parents hoped that their child could continue to attend mainstream school and that levels of support would continue:

I know he probably won't ever be able to catch up to their level but you know at least if he can keep going and the school keeps having faith in him and don't hold him back again. That's the only thing I'm worried about that after so long they are going to say there is no more we can do for him he has got to back to a special needs school.

The strong commitment to the current system by parents of children in both mainstream and special schools poses a dilemma for policy makers. A move towards greater inclusion will antagonise those parents whose children attend special schools, and must also be supported by appropriate resources to meet the aspirations of parents who support inclusion.

Discussion

This study described the perspectives of parents of children with specific speech and language difficulties attending both mainstream and special schools, including residential special schools. These views are considered with respect to the role of parents in the education of children with disabilities and inclusive education in particular.

The study is relatively small scale, with a sample size of 66 parents, and is limited to parents of children with specific speech and language difficulties. However, the sample was drawn from two different areas, one largely urban, the other a mixture of small towns and rural, and represents a random selection of children with SSLD in those areas. Also, the confidence that can be placed in the results is boosted by the effect sizes for the analyses of Strengths and Difficulties Questionnaire data, and by the consistency between the quantitative and qualitative evidence.

Legislation demands that parental views be taken into account in the U.K., U.S. and other countries. This is an issue of parental rights for involvement in decisions about their child. However, the importance of parental perspectives goes beyond rights to the efficacy of the operation of the system. These parents were key figures in the initial identification of their child's problems and had a sound understanding of their children's strengths and needs as evidenced by the concordance between the parents' perspectives and the standardised measures. The high level of reported incidence among family members highlights the increased risk for children in some families but also the possible sensitivity to identification by parents (Bishop et al, 1999). However, the parents considered they were often not listened to, both at the outset and later, and that they had to fight hard for appropriate support services or entry to an appropriate school. Difficulties in identifying appropriate provision are likely to reduce the early identification of favourable environmental niches to support development. Thus despite these parents' real concerns about the needs of their children, early appropriate provision was often not forthcoming.

Perspectives of parents of children attending mainstream or special schools indicate the complexity of the inclusion issue. This is often presented as a question of rights but, as Lindsay (1997) has argued, that is insufficient. Both the surmounting of barriers and the efficacy of the education provided must also be considered (Buysee, Wesley & Keyes, 1998; Manset & Semmel, 1997; Mills, Cole, Jenkins, & Dale, 1998). Inclusion may be in tension with another important value, the promotion of informed choice. Many parents in this sample felt ill-informed about the ways in which their children's needs were being met at school. There was a clear division with respect to inclusion between parents of children in mainstream and those in special schools, with each favouring the type of provision currently attended by their child.

The development toward a system of total inclusive schooling would remove the right of choice from parents who seek special education. A further dimension, however, is efficacy of the education provided. The majority of the mainstream parents wanted their child to continue in mainstream, but many were concerned that the support provided was inadequate. Parents of special school children had often battled to gain a special school place but were now content with the amount and nature of support made. Hence, while there is less adequate support in mainstream there will be a dilemma for parents, requiring them to choose between the inclusive ideal of mainstream and special school provision that they consider to offer better resources to optimise educational progress

For parents of children with speech and language needs a further factor is the provision of speech and language therapy. Mainstream parents were concerned about both its amount and the type of delivery. In special schools speech and language therapists worked on site and could collaborate on programs. In mainstream, however, a consultation model of practice had been developed with SLTs advising teachers. Many parents were suspicious of this lack of direct therapy, a method which is appropriate for 8 year old children with severe speech and language difficulties, a concern also reported in a national study of speech and language needs in the U.K. (Law et al., 2002). At present, too little is known about teachers' implementation of interventions following consultation (Noell & Witt, 1999). Parents also had concerns for the future. In general those in special provision viewed continuation as a realistic option while those in mainstream had serious doubts about the support available at secondary school (usually attended from age 11 years). This diversity of opinion indicates the complexity of parental views on inclusion and in particular the different bases of opinions. Some parents emphasize value positions concerning normality,

while others give higher priority to improving language and educational abilities (Palmer, et al, 1998).

The present study extends the evidence previously available on younger children and those with either severe developmental delays or learning disabilities, reporting the perspectives of parents of children with specific speech and language difficulties at about 8 years, in their fourth year of compulsory schooling in the English school system. The children's difficulties were not obvious at birth nor in the early months, unlike children with severe and profound sensory, physical and intellectual developmental impairments. Their problems are not limited to speech and language, however. This group is at risk of significant educational, social and behavioral difficulties (Bishop, 2001; Lindsay & Dockrell, 2000; Lindsay, Dockrell, Letchford, & Mackie, 2002; Tomblin, Zhang, Buckwalter, & Catts, 2000). They require programs that address both educational and speech and language therapeutic goals.

Regarding parents as partners has been an increasingly important cornerstone of British government policy (e.g. Department for Education and Skills, 2001) and professional practice. However, there are several models of partnership. The current study questions the rhetoric of parent partnership from identification to provision. Parents were certainly involved in identification but decisions on the nature and extent of the provision generally remained the domain of professionals unless parents were prepared to fight for what they felt was appropriate; interestingly, these tended to be parents seeking a special school place. Parents were also concerned about the time taken to assess and decide on provision. Under these circumstances, the concept of partnership, whatever the good intentions of professionals and managers, becomes strained. This is partly a matter of communication and partly results from real conflicts

in the system, including financial priorities. True partnership requires more creative and effective approaches (Buysse, Wesley, & Skinner, 1999; Law et al, 2000).

Parents have an important role in mediating the development of children with developmental difficulties. Bronfenbrenner's ecological systems theory provides a useful approach to conceptualising their involvement and the present study provides evidence at each of the four levels. At the *microsystem* level parents contribute directly to intervention programs, both at home and at school. They also experience and can report on the interaction of the child's difficulties with the family. Parents are also involved in the *mesosystem* where their concerns about the implementation of inclusion by schools and speech and language therapists, including the latter's consultation model, provide important evidence. When professionals decide to change working practice because they consider the new method to be more effective and/or efficient, they need to gain the support and understanding of key stakeholders, in this case the parents. At the level of the *exosystem* parental perspectives provide important information to guide local strategic policy formation and implementation for the education and health systems. Finally, at the *macrosystem* level, parents' perspectives on the working of support systems, including inclusion, provide relevant and important information to influence value systems and national laws. The determination of some parents to continue to have their children's needs met in specialist provision is an important message for policy makers.

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Table 1

Parents' ratings of their children on the Strengths and Difficulties Questionnaire

	% Normal	% Borderline	% Abnormal
Emotional symptoms	63.1	4.6	32.3
Conduct problems	47.0	16.7	36.4
Hyperactivity	43.1	12.3	44.6
Peer problems	40.0	13.8	46.2
Prosocial	84.4	4.7	10.9
Total difficulties	41.7	21.6	36.7

Note. N = 66

Figure Captions

Figure 1.

Percentage of parents with children in mainstream and special provision who identified problems in meeting their child's educational needs.

Figure 1.

