AN INVESTIGATION OF THE ARRANGEMENTS FOR THE PROVISION OF EDUCATION FOR PUPILS WHO ARE OUT OF SCHOOL BY REASON OF ILLNESS

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Signed ....Susan M. Dawes.....

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ABSTRACT

This thesis reports on a study which investigated the impact of the decision-making process under the remit of the Education Act 1996 s. 19, on local education authority (LEA) arrangements for educating children out of school by reason of illness in order to contribute to policy development in the area of parental involvement. A multiple site case study of the administration of exceptional provision in English LEAs was conducted. Fifteen contrasting LEAs were contacted. Seven LEAs volunteered (two shire counties; one metropolitan district; one unitary and three London). Twenty one LEA professionals who were responsible for hospital and home tuition services, and 35 parents of 35 children (24 children residing in case study LEAs; 11 children residing in non case study LEAs) volunteered to participate in the study. In-depth qualitative data were collected between March 1998 and March 1999 by means of semi-structured interviews and document collation.

Overall, the data from parents suggested that diversity existed in the type and quality of provision, but less diversity existed in the quantity of provision that pupils received. Consistency existed in the pragmatic nature of factors related to the outcomes described by parents, and the data from LEA documents and professionals' perceptions. Enabling legislation and inconsistent levels of accountability allowed LEA professionals substantial discretion in decisions about the type of provision that pupils received and the quality of the arrangements. The diversity of family provision contributed to the diversity of the outcomes for pupils also.

The data from LEA professionals suggested that the main effects of professional decision-making in the administration of provision were rationing and displacement of responsibility to the school and parents. Given the pragmatic nature of factors responsible for the diversity in the type and quality of LEA provision that pupils received, together with evidence of rationing the quantity of resources allocated, the study concluded that the determining factor influencing professional decision-making was inadequate resources to fund LEA provision.

The data from LEA documents, professionals and parents suggested that the main effects of the informal involvement of parents in professional

decision making was parental influence on the type and quality of provision, but not the quantity of LEA provision. Given the limiting factor of inadequate resources and the lack of influence of parents on the quantity of LEA resources allocated, it was likely that financial pressure within the LEA caused the displacement of responsibility for provision to schools.

The discourse of participants suggested that professionals were in control of the decision-making process and parents accepted responsibility to liaise between stakeholders. The diversity of parents' needs was related to the effectiveness of the parent to influence decisions or situations that impinged on the type of provision and quality of the arrangements that pupils received.

The implications of the findings for decision-makers and possible areas for policy development are discussed.

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1 INTRODUCTION

1.1 Background to the study

The process of arranging educational provision for children out of school because of illness was of particular interest to the author. Her professional role encompassed different aspects of the education service, as a teacher, former parent advisor to the National Association for the Education of Sick Children (NAESC), advisor trained in SEN law by the Independent Panel for Special Educational Advice (IPSEA) and SEN governor in a secondary school. In addition to her professional roles the author had experience of the parental role as carer and at times, home educator. Career experience working in the pharmaceutical industry, gave the author additional insight into the issues pertinent to the health and education of children.

The fundamental assumption that 'no person shall be denied the right to education', set out in Article 2 of the First Protocol of the European Convention on Human Rights, now embodied in English legislation under the Human Rights Act 1998 Schedule 1, underpinned the beliefs and values of the author. The author believed that education was intrinsically valuable, contributing positively to the quality of life of a child. Observations recorded by the author, confirmed the need to keep education going

through periods of dislocated schooling, if a child was to fulfil his or her academic potential (Davies, 1998).

Fundamentally, the author believed that parental involvement in a child's learning made a difference to the scholastic achievement of a child. However, the author accepted that not all professionals or parents of sick children shared those beliefs and that ultimately the process of professional decision-making and the involvement of parents, would shape the outcomes for pupils who were absent from school because of illness.

1.2 Statement of the problem

Significant medical advances in the treatment of many chronic disorders of childhood have resulted in greater survival and return to normal life and schooling (Parliament. House of Commons Health Committee, 1997a). This has resulted in a corresponding increase in the responsibility of parents as carers and the need for medical, educational and social services.

Recently research interest has turned to the provision of education services. Larcombe (1995) conducted research into needs and services necessary to facilitate reintegration of children into school following absence on grounds of health in England. The National Association for the Education of Sick Children (NAESC, 1995, 1997a, 1999) has mapped educational provision throughout the UK. Qualitative studies conducted by Bolton (1997) in

England followed by Closs and Norris (1997) and Norris and Closs (1999) in Scotland, have reported stakeholder perceptions.

Fundamentally securing the educational entitlement for a child is a legal duty of individual parents, but it is the duty of the local education authority (LEA) to arrange the provision of suitable education in England. In practice, joint guidance issued by the Department for Education and the Department of Health (DfE and DoH, 1994) and evidence from research in England (Larcombe, 1995; Bolton, 1997) suggested that the location of responsibility for provision is perceived to oscillate between the LEA, the school where the pupil is registered and parents.

Larcombe (1995) and Davies (1998) alluded to attitudinal barriers to services based on the assumption that children absent from school on grounds of health are incapacitated to the extent that they cannot benefit from teaching:

> By definition, children treated for a chronic disease in hospital do not enjoy 'normal' health. Many will remain on medication for months, years, perhaps even for life. This does not mean, however, that they are 'sick', but that they are different. They will consider this situation to be normal for themselves. Many doctors recommend that these children return to normal schooling as soon as possible so that at least part of their lifestyle is normal. (Larcombe, 1995, p. 18)

Research conducted by Bolton (1997) and Closs and Norris (1997) taken together with the published accounts of participants (Hawkins, 1999; Hegarty, Lyke, Docherty and Douglas, 2000) have illustrated that individual children out of school because they are 'ill' do in fact obtain

benefit from teaching. Thus, 'sick' children cannot be categorised as ineducable. Furthermore professional (Harvey, 1998) and parent accounts (Mason, O'Sullivan and Cullen, 2000) have suggested that reasons for a child requiring out of school provision is more to do with the pragmatic concern of the school coping with a child having significant medical needs than with a child's incapacity to learn because of illness. The legal issue of liability and fear of teachers or the LEA being prosecuted by parents, should problems occur with the care and safety of children with medical needs, is noted as one reason for prolonged absence from school by Mason et al. (2000).

The process of identification is crucial to the way individuals gain access to services. Simply put, the characteristics of the population of children out of school by reason of 'illness' entitled to provision under the Education Act 1996 s. 19, codified as 'sick children' by departmental guidance (DfE and DoH, 1994) and recognised as having medical needs (DfEE and DoH, 1996a, 1996b), are not routinely addressed within the remit of special educational needs (SEN) in England. In addition, children having special educational needs are a subcategory of the population served under the Education Act 1996 s. 19. This raised the question of whether the lack of clarity of the definition of the client group influences decision-making. Such a fundamental issue raised questions regarding the administration of services for children absent from school. One significant factor influencing

outcomes for children is the part that parents play in the process of identification of need and the identity of provision. A disparity exists between the formal structures enabling the participation of parents in the decision-making process pertinent to the identification of needs and provision leading to a Statement of special educational needs in England and the informality of the decision-making process pertinent to arranging provision for children out of school in England. In Scotland, where the law is different, Closs and Norris (1997) reported that an individual record of needs is opened for a child with SEN.

The size of the population of sick children who require teaching is uncertain but approximately 3,000 pupils are taught in hospitals on a typical day and about 105,000 during the course of an academic year (NAESC, 1996). Roughly, 10,000 pupils receive home teaching or tuition at an education centre during a year (NAESC, 1996). The reason for the discrepancy in numbers between the hospital and home settings is not clear. Research conducted by NAESC (1995, 1997a, 1999) has shown that educational provision across the country is patchy and very much dependent upon where a child might live. The numbers of hours of tuition offered vary from one LEA to another. Often Home teaching is restricted to five hours or less per week and only supplied once a child has been away from school for a period of four weeks (NAESC, 1995, 1997a, 1999). During the interim period, department guidance advised mainstream

schools of their responsibility to provide education (DfE and DoH, 1994). Structures operate around criteria of eligibility, based on length of absence (NAESC, 1995, 1997a, 1999). Children reaching the point of recognition by the service and referred for teaching in the home are low in number.

The current climate of financial constraint has led service providers to adopt practices that restrict the supply of educational provision. NAESC (1995, 1997a, 1999) identified different eligibility criteria operating in UK local authorities, a finding, which Lipsky (1980, p. 105) might suggest, means that 'rationing' is taking place. Under these circumstances, the administration of services enhances the power of systems and diminishes opportunities for children and families to be in control (Malcolm, Peake and Walker, 1996). Adler and Asquith (1993) suggested that a high level of professional discretion conferred power towards decision-makers and a low level of accountability to the client consumer. In practice the curtailment of discretionary decision-making in favour of statutory entitlement has become a contentious issue for professionals (Hudson, 1997a; Simmons, 1996, 1998; Gross, 1996; Vincent, Evans, Lunt and Young, 1996). Research conducted by Riddell, Brown and Duffield (1994) reported that middle class parents of children recognised as having special educational needs are perceived as having the ability to gain resources for their children, and if necessary appeal against LEA decisions to the Special Educational Needs Tribunal (SENT) (SENT, 1997a). Conversely, Douglas,

Hulson and Trompeter (1998) reported that parents of sick children tend not to worry about matters that are beyond their control. Nonetheless, the lack of information reported by Mason et al. (2000) and Goodinge (1998) and perceptions of conflict reported during the Statementing process in research conducted by Cornwell (1987), Galloway, Armstrong and Tomlinson (1994) and Bowers (1995) are noted as barriers to services.

The quality of the arrangements for 'exceptional' provision is dependent to some extent on parental persistence, as the onus falls on them to adopt a liaison role between stakeholders (DfE and DoH, 1994). Parental resources are significant also, since the observations recorded by Davies (1994, 1998) and Mason et al. (2000) and research conducted by Closs and Norris (1997) show that individual parents may become the sole provider of education. The accounts provided by Mason et al. (2000) have illuminated their role as parents in fulfilling their obligation to secure educational provision for their offspring. In pursuing a Statement or record of special educational need, or documentation of some kind, Mason et al. (2000) attempted to secure the necessary provision to meet the child's care needs as well as educational needs.

Thus, a synthesis of research and participant accounts illuminated a likely problem existing in the process of arranging educational provision and suggested a need for research about the decision-making process in determining the identification of, and allocation of resources for, children

who were out of school because of 'illness'. Head teachers' and school governors' perceptions of their prime responsibility to arrange provision for their registered pupils and the ultimate responsibility of the LEA to arrange and resource that provision further complicates decision-making. Nevertheless, decision-making is unlikely to occur in a vacuum and policy initiatives and processes may exert some influence.

Recently the labour government placed the education of children out of school high on the political agenda (White Paper, 'Excellence in Schools', DfEE, 1997e). In promoting a policy of inclusion, the government has declared its goal to reduce the number of Statements of special educational needs that are issued (Excellence for all children: Meeting Special Educational Needs, DfEE, 1997a).

Tension in policy implementation is evident. The Law Lords (1998) clarified the meaning of the primary legislation under the Education Act 1996, s. 19, and in so doing, set the scene for a change in policy and thus decision-making. Furthermore, Parliament amended the legislation under the Education Act 1997 s. 47, shortly before the election of the labour government in May 1997. Essentially, the general duty to provide education under the Education Act 1996 s. 19 has changed to one that is owed to the individual and to some extent falls in line with special educational provision. The change in policy is all the more significant as provision arranged under the Education Act s. 19, is not restricted to a

specific location. Exceptional provision may be deployed for any child of compulsory school age, if necessary, to enable them to receive suitable education, whether they are absent from or attending school.

1.3 Aims and relevance of the study

The focus of the research concerns the process of arranging educational provision under the Education Act 1996 s. 19, in English LEAs. The prima facia research question sought to gain knowledge of professionals' and parents' perceptions of the decision-making process concerned with identifying pupils and arranging provision and how the process determined outcomes for pupils, who because of illness require provision 'otherwise than at school'.

The research aims to examine the diversity of arrangements and identify factors responsible for that diversity. The research aims to investigate the effects of professional decision-making in the administration of provision and the effects of parental involvement in the process of professional decision-making on outcomes for children. Identification of professional and parent perceptions of the decision-making process in their LEA will enable the study to contribute to policy development in the area of parental involvement.

The research study is timely, as the DfEE have consulted on revisions to departmental guidance, 'The Education for Sick Children' (DfE and DoH,

1994) and the SEN Code of Practice (DfE, 1994). Furthermore, the Special Educational Needs and Disability Bill [Lords] (Parliament, 2000b) has attained recently the status of an Act of Parliament. The proposed new section 316A(d) refers to provision arranged for a child who is admitted to a community or foundation special school which is established in a hospital.

Chapter two reviews the literature pertinent to the processes of policy and the decision-making process, in the context of influence, the context of policy text formulation and the context of practice regarding decision-making in arranging educational provision for children out of school because of illness.

2 LEGISLATION, POLICY AND PRACTICE

The relationship between legislation, developing case law, policy and practice changed during the course of the study. For this reason it was necessary to review the text of the legislation and policy in the light of processes of policy, in order to identify the implications of the results for policy development.

In this chapter, the literature is reviewed in two sections. Section one reviews the literature illuminating the nature, content and implications of enabling legislation on decision-making pertinent to the education of children who are out of school because of illness and sums up the current status of the legislation. Section two reviews the literature illuminating likely factors influencing professional decision-making and evidence of effects and outcomes of policy in LEAs.

2.1 Legislation, policy and processes of policy

2.1.1 Enabling legislation

In the same way that Goacher, Evans, Welton and Wedell (1988) explicated the notion of good practice as a fundamental assumption underpinning the implementation of the Education Act 1981, so it was likely that enabling legislation pertinent to the administration of education otherwise rested on goodwill:

> While the 1981 Education Act, through its relationship with the 1944 Act, includes within its framework the possibility of sanctions against non-compliant LEAs, it is not at all clear what form such sanctions would take and even less clear what consequences their imposition might bring about. Therefore, essentially, the Act is enabling rather than coercive. Inherent in such a system is the assumption of 'good practice' as well as that of goodwill. (Goacher, et al., 1988, p. 2)

In order to understand the significance of enabling legislation in the administration of provision it was necessary to review the text of the relevant Education Acts.

State responsibility for educational provision otherwise than at school, for sick children can be traced to the primary legislation residing within the Statutory System of Education under the Education Act 1944 s. 56. The backbone of the system for compulsory education was organised around the institution of the school and education otherwise than at school. The LEA had direct responsibility for children who were entitled to have special arrangements to receive education when absent from school:

> If a local education authority are satisfied that by reason of any extraordinary circumstances a child or young person is unable to attend a suitable school for the purpose of receiving primary or secondary education, they shall have the power with the approval of the Minister to make **special arrangements to receive such education otherwise than at school.** (Education Act 1944 s. 56, Author's emphasis)

From 1944 to 1994, departmental guidance about a child's entitlement to a specific type and quantity of provision received little mention in legislation or policy statements. However, in 1950, the government of the day established a fundamental principle guiding resource allocation. A maximum quota of teaching time was identified as ten hours a week:

> A Manual of Guidance, Special Services No 1, published in 1950, suggested that 'the amount of individual tuition given per week will naturally depend on the child's ability and aptitude and on his physical condition'. It also suggested that the tuition should not exceed five sessions per week unless there were very special circumstances. A 'session' has never been defined but has usually been interpreted by LEAs as two hours, making a **maximum of 10 hours a week.** (DES and HMI, 1989, p. 1, Author's emphasis)

All was quiet in the policy arena until over forty years later, the principle guiding resource allocation changed from entitlement to special arrangements for a standard quota of teaching time to 'full time or part-time' education under the Education Act 1993 s. 298. The parameters guiding the identification of eligible pupils changed also from being "unable to attend a suitable school" to a broad classification which encompassed "illness, exclusion from school or otherwise" for children who required arrangements to receive suitable education:

> Each local education authority shall make arrangements for the provision of **suitable full-time or part-time education at school or otherwise than at school** for those children of compulsory school age who, by reason of **illness, exclusion from school or otherwise**, may not for any period receive suitable education unless such arrangements are made for them. (Education Act 1993 s. 298[1], Author's emphasis)

The legislation was subsequently amended and the words 'full-time or part-time' were deleted from the face of the Act (Parliament, 1997b):

> Each local education authority shall make arrangements for the provision of suitable education at school or otherwise than at school for those children of compulsory school age who, for reason of illness, exclusion from school or otherwise, may not receive **suitable education** unless such arrangements are made for them. (Education Act 1996 s. 19 (1), as amended by s. 47 Education Act 1997, Author's emphasis)

A child was entitled to 'suitable education' Parliament defined suitable education:

> In this section 'suitable education', in relation to a child or young person, means **efficient** education suitable to his **age, ability and aptitude and to any special educational needs he may have.** (Education Act 1996 s. 19(6), Author's emphasis)

The child would receive education anywhere and by any means, according to individual circumstances. The responsibility for arranging provision changed also as a minor amendment (No.114) of the Education 1997 Bill further changed the definition of 'school' under the Education Act 1996 s. 4 (Parliament, 1997c). The function of the school as an institution, now encompassed exceptional provision under the 1996 Act s. 19, in addition to providing primary, secondary and sixth form education. Thus, the effect of the enabling legislation bound the school formally, rather then as gesture of goodwill, into the type of arrangements for educational provision for children out of school. Arguably, sharing responsibility for provision with the school enabled LEAs to move away from segregated provision for sick children.

A further change in the law occurred when the Law Lords clarified the meaning of the legislation in 1998 and determined that the statutory duty (s. 19) was owed to the individual rather than to children as a group (Law Lords, 1998). The significance of the judgment regarding the context of practice is discussed more fully in section 2.1.3.3.

During this same period from 1944 to 1994, the rights of the child changed significantly under the different framework of special educational needs. Under the Education Act 1944, the statutory categorisation of handicap, codified the term 'delicate' as a generic term which encompassed medical conditions and identified children who potentially required special educational 'treatment' and segregated provision (DES, 1978, para 2.46 p. 20 and p. 380):

> Delicate pupils, that is to say, pupils not falling under any other category in this regulation, who by reason of impaired physical condition need a change of environment or cannot, without risk to their health or educational development, be educated under the normal regime of school. (DES, 1978, p. 380, Handicapped Pupils and Special Schools Regulations 1959, para. j)

The Warnock Committee questioned the rationale underpinning statutory categorisation (DES, 1978) as a means of determining a segregated placement for children. As a result, the Education Act 1981 (now re-enacted as the Education Act 1996 part four s. 312) established the foundations for a system of special education which linked the identity of special educational provision to the concept of special educational 'needs' rather than to the statutory classification of handicap. Evidence of special educational needs turned on a relative concept of a 'learning difficulty' which was further defined as a 'difficultly in learning' or 'disability' such that it was necessary for the LEA to arrange provision that was generally additional to, or different from, educational provision available in the school where the child was registered.

Although the Warnock Committee affirmed a child's need for continuity of educational provision (DES, 1978, para 8.89 and para 11.41) and recommended "for administrative purposes, all education in hospital should be regarded as special educational provision" (DES, 1978, para 8.78), the Education Act 1981, made no reference to the organisation of education otherwise than at school as a service. This raised the question about decision-making in determining the kind and quantity of resources deemed appropriate for the child in hospital or in the home. Was decision-making based on the principle of access to suitable education or on needs?

In order to understand the significance of enabling legislation on professional decision-making it was necessary to review the literature illuminating the processes of policy operating within a system of education, in the light of political, social and economic factors.

2.1.2 Balancing control between central and local government

In education policy, the substantial power of the LEA relative to the government department, described by Regan (1977) and Goacher et al. (1988) was gradually undermined by the conservative government, as state control increased and policy was decided at the centre with responsibility for implementation delegated to the periphery (Bowe and Ball, 1992; Bottery, 1998). Batho (1989) argued that centralised control enabled politicians considerable influence on the education service, with the

Department for Education asserting itself as a pro-active constituent of policy.

The conservative government held power from 1979 to 1997. However, at a time when the power of the LEA had diminished, the direct responsibility of the LEA towards sick children increased, as arranging education otherwise than at school became mandatory under the Education Act 1993 s. 298. Policy relevant to the administration of individual provision was determined centrally (Education Act 1944 s. 56; Education Act 1993 s. 298; DfE and DoH, 1994; Education Act 1981), but the literature suggested that parents of children with Statements of SEN influenced policy at the local level also (Croll and Moses, 1998; Parliament, 2000a).

2.1.3 The policy process

Bowe and Ball (1992) suggested that policies develop as the operational statements of the beliefs and values underpinning a particular ideology. Under the conservative government the effects of policy became manifest as a contracting welfare state situated in a competitive world (Bottery, 1998).

The election of the labour government, in May 1997 set the scene for a shift in values underpinning the foundation of policy. Rather than suggest that children excluded from school should be 'disqualified' from education (Parliament, 1997a, Lords Hansard 10th February 1997, col. 70) a proposal

tabled under the conservative government during the passage of the Education 1997 Bill, the labour government held the opposite view. In due course, the labour government pledged "that LEAs should be moving towards a full timetable for every child, with a clear focus on reintegration wherever possible" (DfEE, 1998c, p. 1).

Under the conservative government, Bowe and Ball (1992) suggested that policy generation at the centre allowed for little consultation with education practitioners, who were to be the unquestioning implementers of that policy, a characteristic 'top down' model of implementation (Hill, 1997b, p. 128). Conversely, the innumerable consultation documents that emanated from the DfEE during the first term of office of the labour government, indicated that a switch to a consensus style of policy making had taken place and implied that a 'bottom up' model of implementation was aligned to a specific policy goal (Hill, 1997b, p. 138).

Bowe and Ball (1992) and Hill (1997b) suggested that the appearance of a linear relationship between policy formulation and implementation obscured the turbulence of the policy process. This caused the author to reflect on previous research she had undertaken, concerning control mechanisms operating through positive and negative feedback loops within the mammalian endocrine system (Davies, 1976), and which resonated with how Bowe and Ball (1992, p. 10) saw the dynamics of the policy process operating through the interpretations of a series of 'texts'.

Bowe and Ball (1992, p. 10) suggest that "The translation of education policy into legislation produces a key text (the Act). This in turn, becomes a 'working document' for politicians, teachers, the unions, and the bodies charged with 'implementing' the legislation". Thus, the enabling legislation reviewed in section 2.1.1 become operational statements of values, which in turn become statements of intent in 'working documents'.

The way that individuals interpret policy texts influences decision-making and the actual working practice of professionals. Thus Hill (1997a) suggests that a study of the policy process would be incomplete if it did not consider the work of Lipsky (1980) and the street level influence of bureaucrats in determining effects and outcomes of policy. Nonetheless, Hill (1982) and Hudson (1997a) have criticised the contradictions and inconsistencies of Lipsky's thesis.

Hill (1982) noted the overly narrow view of the corruption of professionals' ideals in responding to pressures arising from policy goals or a lack of resources, with Lipsky advocating formalised accountability as a control mechanism. Hill (1982) suggested that bias, rooted deeply in American culture, promoted formal structures of accountability only, and criticised Lipsky for omitting mechanisms of informal and loosely structured control of professional administration. Hudson (1997a) further noted that Lipsky (1980) did not systemically attempt to link his analysis to a broader

perspective influenced by the social, political and economic framework and thus failed to connect micro and macro sociological concerns.

A reading of Hill (1997b) and Bowe and Ball (1992), writing from a United Kingdom perspective, illuminated the ebb and flow of policy, turning on cumulative interpretations and decisions within the different contexts of policy making. Bowe and Ball (1992, p. 20) represented their conception of the policy process ideas in Figure 2.1.

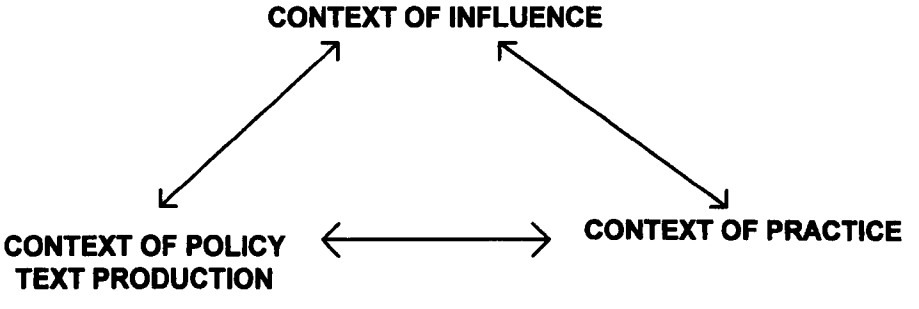


Figure 2.1 Contexts of policy making

2.1.3.1 The context of influence

Bowe and Ball (1992) argue that public policy is initiated in the context of influence. It is here that concepts are discussed and where interested groups seek to influence, often from narrow dogmatic standpoints. This may be through formal or informal channels of communication. The author has contributed her voice to the context of influence, serving as a confidential witness, to the Parliamentary House of Commons Health Committee (1997b). Furthermore, the author has provided the DfEE with an

explication of the training needs of teachers pertaining to children with medical needs (Davies, 2000a) and disseminated preliminary findings from the current study directly to members of the SEN division, DfEE (Davies, 2000b).

Government thinking underpinning the type and quantity of provision allocated to sick children was evident in Parliamentary debates. The issue of 'suitable education' became a topic of debate in the House of Lords (Parliament, 1997a, 1997b, 1997c, 1998). The noble Peers pursued amendments under the Education 1997 Bill (Parliament, 1997b, 1997c) and the School Standards and Framework 1998 Bill (Parliament, 1998), intended to change the primary legislation of the Education Act 1996 s. 19. The drive to rectify the problem of exclusion from school was interwoven with arranging suitable education for sick children. Tensions were evident in the Parliamentary debates, as Peers argued to reinforce a child's entitlement to receive full time educational provision, suitable to age, ability, aptitude and any special educational needs of the child. However, government ministers defended the legislative requirement to ensure that provision was cost effective, in order to rationalise public expenditure.

Warnock (1997, Lords Hansard 3rd March 1997, col. 1512) expressed her deep concern over the rejection of the amendment intended to secure full-time education "simply on ambiguity of the expression of 'full-time education'". However, she conceded:

> To calculate how many hours of education in the week are full time equivalent would be difficult. (Warnock, 1997, Lords Hansard 3rd March 1997, col. 1512)

Inherent tensions between the duty to provide suitable education and the efficient use of public resources provoked strong feelings among the noble Peers:

> If the amendment is not accepted, there must be some provision in the Bill to make it positively illegal to provide only two hours' education in the week for a child, with no further supervision or supervised activity. (Warnock, 1997, Lords Hansard 3rd March 1997, col. 1512)

Nonetheless, conservative government thinking was focused on alleviating the financial burden on LEAs by promoting a solution which would divert the responsibility for educational provision for pupils excluded from school away from the LEA into the further education sector and work. The incoming labour government followed the same direction in policy. Parliamentary decision-making regarding exceptional provision under the Education Act 1996 s. 19 was informed more by the pragmatic necessity to ensure efficiency of educational resource allocation than adherence to any principle:

> To secure that excluded pupils and others out of school such as sick children are entitled to full-time education. There is no disagreement that excluded pupils need full-time education- if anything they need more than other pupils. The fact that they are not provided with full-time education is a matter of resources, not principle. Out-of-school education does not have to conform to the national curriculum. One can include activities such as work experience, which may well be very good for children. Failure to make this provision places parents in the invidious position of being in breach of their legal duty to secure their children's full-time education. (David, 1998, Lords Hansard 8th June 1998, cols 242-243)

Davies (1998) commented on the implications of the prevailing attitude of the government in the context of influence on provision for sick children:

> In March 1997, Lord Henley argued against an amendment intended to secure full-time education for children not in school, suggesting that "full time education may not be appropriate" for children in hospital. Baroness Blackstone echoed the same argument in June 1998 when referring to reports from the Social Exclusion Unit. The attitude seems to be nothing can be done to maintain education provision for sick children in hospital or at home. (Davies, 1998)

2.1.3.2 The context of policy text production

The context of policy text production is different to the context of influence in that it seeks to present policy in a more consensual form, having gathered views from a wider range of people (Bowe and Ball, 1992).

In the context of the present study, the DfEE issued statutory guidance pertinent to Education Act 1996 s. 19 first as a consultation circular, in January 1999 and then as two documents in July 1999 (DfEE, 1999d, 1999e, 1999f). The consultation document and final drafts referred to the 'Tandy' judgment (Law Lords, 1998) and illustrated clearly the step change in government thinking about the quantity of provision suitable for sick children in response to events occurring in the context of practice:

> Sick children should be enabled to benefit from as much education as their illness allows. Depending on individual circumstances, this could range from little or no provision for a child who is seriously ill, to a full timetable for other children. DfEE will review the Department's guidance on the education of sick children (Circular 12/94) later this year and, as part of that process, will consider the support that should be provided for children out of school because of illness or injury. (DfEE, 1999f)

As a result, the DfEE initiated further consultation the following year (DfEE, 2000f).

Regarding the legislative framework of special educational provision and the policy goal aimed at reducing the amount of segregated provision arranged for disabled children, civil servants sought the views of various stakeholders. Many consultation documents were issued, such as the 'Excellence for all children: meeting special educational needs' (DfEE, 1997a); 'Draft guidance on LEA Behaviour Support Plans' (DfEE, 1997c); 'Draft Guidance-Social Inclusion: Pupil Support' (DfEE, 1999d); 'Draft guidance. School Attendance and the role of the Education Welfare Service' (DfEE, 1998g); 'Draft Revised Code of Practice' for special educational needs (DfEE, 2000c) and 'Consultation document: SEN and Disability Rights in Education Bill' (DfEE, 2000b), to name some notable examples.

The Green Paper 'Excellence for all children' (DfEE, 1997a) provoked considerable public interest. Over 3600 responses were analysed by the Department (DfEE, 1998d). The initial consultation (DfEE, 1999c) on revising the SEN Code of Practice (DfE, 1994) received 1700 responses (DfEE, 1999a) which taken together, implied that proposals to change Part Four of the Education Act 1996 was a political issue.

The literature illuminated tensions between the context of policy text production and the context of practice. Whereas Green (1998), arguing on

behalf of the Department and defending the Green paper (DfEE, 1997a), emphasised the intention to provide high quality provision with less emphasis on the need for Statements as a main goal of policy for children with special educational needs, Wright (1998) challenged the rationale which supported a reduction in the number of children receiving Statements.

A substantial length of time elapsed between the publication of the Green Paper, 'Excellence for all children' (DfEE, 1997a) and the publication of a consultation document for the revised SEN Code of Practice (DfEE, 2000c). The delay between declaring inclusion as the main policy goal and providing a consultation document about operational procedures raised the question whether a 'bottom up' approach to policy making was in reality preparing the context of practice for change. The reason being that the DfEE had signalled that education otherwise was to be a key factor in the administration of provision (DfEE, 1999c) under the revised SEN Code of practice. Government thinking about the proposed new section 316A(d) of the Special Educational Needs and Disability Bill [Lords], (Parliament, 2000b) confirmed that education otherwise provided when a child is admitted to a community or foundation special school which is established in a hospital, fell within the remit of the special educational needs framework of administration.

2.1.3.3 The context of practice

Here the actors have an opportunity to re-define policy yet again. Bowe and Ball (1992) suggest that policy is not rigidly received and implemented, but subject to interpretation and re-creation.

Regan (1977, p. 93) suggested that factors concerning the "effective use of resources" in the context of practice informed the terms of reference for the Warnock Committee (DES, 1978) and more recently, Parliamentary debates reviewed in section 2.1.3.1 suggested that public expenditure was a critical issue for government.

The literature illuminated concerns about the effect of an individual's value position and subjective judgment influencing the interpretation of policy texts. Roaf and Bines (1989) were concerned that:

> The relativism of needs as currently understood can lead to haphazard and unequal provision. (Roaf and Bines, 1989, p. 9)

Whereas Warnock (1991) criticised the link between needs and the identity of provision:

> In the light of the concept of need, then, equality was seen as equality of entitlement, not identity of provision. (Warnock, 1991, p. 148)

Simmons (1996, 1998) defended the necessity of a formal link between needs and the identity of provision. Nonetheless, Warnock (1998) has become extreme in her views. She expressed her deep regret about the role of her committee initiating a system of administration which endorsed the

differential entitlement of children to special educational provision specified on a Statement, during Parliamentary debates:

> I think the question of who has a Statement and who has not is increasingly irrelevant. On my deathbed I shall continue to regret that my committee ever introduced that distinction, but that is by the way .(Warnock, 1998, Lords Hansard 3rd Feb 1998, col. 592)

Whereas Richards (1998) asserted that social welfare provision under the Chronically Sick and Disabled Persons Act 1970 (CSDPA) and special educational provision under the Education Act 1996 was predominately determined by the principle of need, Robinson (1998) asserted that the relationship between entitlement and cost effective provision under the Education Act s. 19, was governed by educational criteria alone. Tensions between entitlement to suitable education for a child out of school because of illness and public expenditure, led to the legality of a LEA decision to cut home tuition across the board, being settled by the 'Tandy Judgment' (Law Lords, 1998). Beth Tandy was aged sixteen, mildly dyslexic and of compulsory school age until February 1998, had suffered from myalgic encephalomyelitis (ME) since the age of seven. Beth received home tuition under the provision of a Statement of special educational needs, from 1992 until the LEA ceased to maintain the Statement in 1995. After that, the LEA arranged home tuition under the Education Act 1993 s. 298. The LEA's provision was the prime source of education for Beth. In September 1996, the LEA decided to reduce home tuition from five to three hours per week, across the board, because of financial difficulties. In formulating that

policy and following the decision through to the individual, the LEA had applied a rigid decision based on financial considerations. Davies (1998) commented:

> The duty to arrange education for sick children should not be compromised by an LEA pleading poverty. (Davies, 1998)

Lord Browne Wilkinson, speaking on behalf of the Law Lords in 1998, noted the unenviable position of the local authority, in discharging its duty to arrange exceptional provision in a climate of fiscal constraint:

> The control exercised by Central Government over local authority spending through the Local Authority Standard Spending Assessment was reducing public expenditure but at the same time not relieving local authorities of statutory duties that were imposed upon them by Parliament when different attitudes prevailed. (Law Lords, 1998)

The Tandy judgment (Law Lords, 1998) clarified essential points regarding the status of the statutory duty. Firstly, the duty was owed to the individual rather than to children as a group. Secondly, educational criteria determined the type of provision, without the necessity for a prior assessment of need. Thirdly, the LEA duty to arrange and provide educational provision was independent of the availability of financial resources.

The literature illuminated a heated debate among legal commentators concerning the impact of the Tandy judgment (Law Lords, 1998). Richards (1998, p. 25) described the arrangements under the Education Act 1996 s. 19 as a "hard duty", having primacy over legislation embodied as a discretionary power and argued that the judgment held significant implications for the administration of special educational provision. She

explained her concern by citing the legal authority of the Gloucestershire judgment (Law Lords, 1997) regarding the Chronically Sick and Disabled Persons Act 1970 (CSDPA). This landmark judgment set a legal precedent in needs led provision for individuals, and linked the principle of need to the availability of local authority resources.

Richards (1998, p. 25) was concerned that LEAs would shift resources away from discretionary applications in order to fulfil the "hard duty" under the Education Act 1996 s. 19. Richards (1998) was alarmed to point out that in the extreme, exceptional provision would draw resources away from statutory assessment procedures and undermine the LEA's capacity to maintain Statements for children who were on the roll of mainstream schools. She argued however, that the House of Lords had allowed a concession, suggesting that resources could be taken into account when determining the way exceptional provision was arranged. Robinson (1998) neutralised Richards' sense of alarm, suggesting that she was not justified in asserting that the House of Lords made a concession, since Parliament has stated explicitly in section 19 that LEAs must provide educational provision suitable to the age, ability, aptitude and any special educational needs a child may have, in the most cost effective manner. Ruebain (1999) advanced the debate further reaffirming the necessity of a statutory assessment of needs and the specification and quantification of provision to meet those needs in part three of a Statement. He argued that in principle

the identification of needs was determined independently, irrespective of LEA resources. In reality, clarity in the identification of needs laid the foundation for clarity in the type and quantity of provision specified in part three of a Statement.

Another twist in policy occurred in July 2000. The judgment in the cause of Phelps (Law Lords, 2000) laid the foundation for developing case law based on the principle that professionals have a duty of care in the execution of their duties. On the one hand, Rabinovitz (2000) viewed the judgment as beneficial to children, whereas Hart (2000) writing on behalf of the teaching profession was reticent about the implications for teachers and professional decision-making.

2.1.3.4 Discretion and power

Adler and Asquith (1993) compiled a review of the literature regarding discretion and power and suggested that a high level of discretion conferred power to professional decision-makers and a low level of accountability to the client consumer. However the notion of power as a fixed state, which resulted in a dichotomy between the position of the decision-maker and the client consumer was to some extent inconsistent with the theoretical literature pertaining to organisational behaviour and power as a process (Robbins, 1984; Handy, 1985; Lee and Laurence, 1985).

Lee and Laurence (1985, p. 129) defined power as the capacity to affect people, things, situations and decisions. This definition implied that influencing decisions or situations represented a state of flux. Handy (1985) suggested that the capacity of the individual to influence decisions or situations, will change, as the membership of the constituency within which power is exercised, changes. This raised the question whether professionals and parents, positioned in a network of organisations namely the LEA or school, draw on different sources of power in order to influence decisions or situations.

Robbins (1984), Handy (1985) and Lee and Laurence (1985) illuminated that a range of factors determined the actor's influence. Robbins (1984) suggested that the actor's source of power and the strength of the power base were determining factors and suggested that the actor's characteristics determined four sources of power. First, the formal position of the actor in a structured hierarchy; second personal resources of articulation, domineering personality or 'charisma'; third, expert or specialist knowledge and fourth opportunity, being in the right place at the right time. Whereas Handy (1985) argued that the power source, particularly personal or expert had to be plausible and credible, Robbins (1984) noted that access to information was a factor derived from the actor's power base.

The literature pertaining to parental involvement in professional decision-making emphasised a dichotomy in power relations between professionals

and parents. Tomlinson (1982) theorised the relationship between parents and professionals in terms of unequal power relations, with parents exercising little influence on decisions. Writing before the implementation of the Education Act 1981, she emphasised the acceptance by parents, of their dependency on professional expertise and support. However section 2 of the '81 Act enabled the LEA to take account of the wishes of the child's parents and consequently changed the position power of parents. Goacher et al. (1988) suggested that the '81 Act initiated a new paradigm of administration, with parents participating in decision-making as client consumers, with formal rights to play a part in the identification of special educational needs.

Time moves on but recent research conducted by Wolfendale (1997a, 1997b), Todd and Higgins (1998), Fylling and Sandvin (1999) and the critical speculation of Malcolm, Peake and Walker (1996) has emphasised the persistent notion of a power differential existing between children and parents and professional decision-makers. For example, qualitative research conducted by Fylling and Sandvin (1999) questioned twenty-six teachers and fourteen parents about the notion of partnership. Two roles were identified for parents: first 'implementer', following up aims and measures set by the school with very little influence on how things are being done, and second, 'clients' when teachers see parents as part of the child's problem. The researchers argue that both roles placed parents in a

subordinate position to teachers. Taken together with the perception of stigma attached to special education, the researchers concluded that a socially defined relationship had the effect of restraining parents in their actions.

The literature has theorised parental power in terms of individual and collective action. Research conducted by Vincent (1996) considered individual and collective empowerment in the context of policy. Vincent (1996) questioned sixteen teachers and fifty working class parents, about the problem of acute teacher shortages in 1990-1991, which lead to some children spending prolonged periods at home without educational provision. She found that parents took no concerted collective action. Only six individuals out of the fifty parents mentioned the possibility of writing or telephoning the LEA, and just three of this six attended a public meeting arranged by the National Union of Teachers to consider the problem. Six parents chose the exit route and removed pupils from the school. Exceptionally, two parents of children with special educational needs contacted the local press. Since parents took no collective action, Vincent (1996) concluded that parents in the study were not empowered as individuals in citizen state relations.

Conversely, almost twenty years previously large numbers of parents expressed their concern about the quality of education offered at the William Tyndale Junior School. Initially the Head teacher was

unresponsive, adopting an adversarial stance when confronted with collective parental action. However, once parents voiced their complaints in public the events came to the nation's attention through media interest and a formal inquiry was convened (Auld, 1976).

Ranson (1986) emphasised the role of the individual in broader citizen-state relations suggesting that the agency of the citizen was a vital component of accountability in education. Nonetheless, the critical review compiled by Woods (1988) suggested that parental participation in decision-making should be exercised in the spirit of responsibility and citizenship. Vincent (2000) has located the notion of parental agency within themes of citizenship, participation and collective action, concluding that the particularity of parental agency and inequalities in participation rendered these themes fragile and partial. These different facets of participation raised questions about the meaning of empowerment.

Writing from a philosophical standpoint, Fielding (1996) suggested on the one hand, that the notion of empowerment can be traced back to studies of processes of power, emphasising neutrality, and operating within a values vacuum, a concept which he criticises for it naivety because of the propensity for manipulation. On the other hand, he explicates the significance of a more value-laden position underpinning the meaning of empowerment aligned with the individual's motivation to gain emancipation, through the democratic process, and noted the significance

of appropriate structures to support the transmission of 'voice'. Finally Fielding (1996) questioned the easy dichotomy in power relations between stakeholders, putting forward a more fluid view of power exercised among stakeholders, and rejected the notion of individual power as a fixed state.

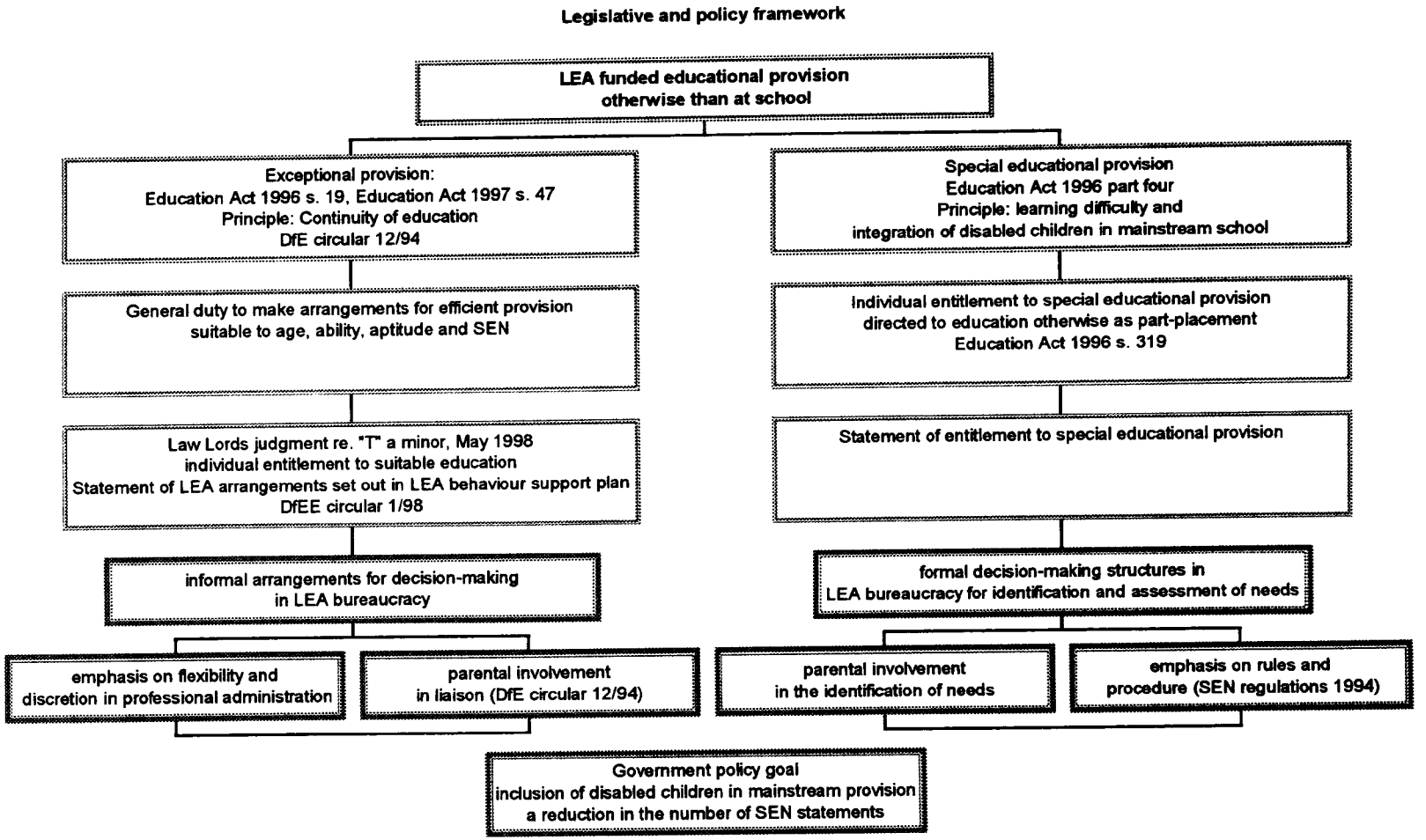
Given the implications of a multiplicity of power relations between stakeholders in the context of practice and the dichotomy of power relations, which are structured by the Education Act s. 19, led the researcher to consider an alternative vehicle for the exercise of power by parents of sick children. If choice and participation were missing dimensions of policy involving parents, then the question remained whether parents would resort to 'voice' or draw on their own resources in order to influence decisions or situations about the arrangements for education. There were signs that the government was developing a new infrastructure based on information and communications technology (ICT) aimed at inculcating a learning society (DfEE, 1997b). This raised the question of whether ICT would have some bearing on the capacity of parents to influence situations in order to enhance opportunities for learning in the home.

2.1.4 Summary: The legislative and policy framework

Figure 2.2 summarises the legislative and policy framework relevant to the identification of children needing exceptional or special educational provision reviewed in section one. The Special Educational Needs and

Disability Bill [Lords], (Parliament, 2000b) new section 316A(d) refers to provision arranged for a child who is admitted to a community or foundation special school which is established in a hospital. The proposed change to the law has linked arrangements under the Education Act 1996 s. 19 with the special educational needs framework under part four of the same Act in a concrete way, with significant implications for professional decision-making.

Figure 2.2 Summary of the legislation and policy framework for exceptional and special educational provision



Heward and Lloyd-Smith (1990) commented that legislation has an impact on special education policy. However, the principles underpinning the identification of children and resource allocation differ substantially between different the frameworks of administration for exceptional and special educational provision. On the one hand, the child is entitled to cost effective suitable education, while on the other hand, a child is entitled to provision that any special educational needs identified by statutory assessment calls for. The specification of the type and quantity of provision written on a Statement enabled parents to ensure that a child receives the necessary provision, underpinned by their right to appeal against LEA decisions to the Special Educational Needs Tribunal. However a reading of the decisions (SENT, 1997b, 1998) suggested that the choice of administrative framework used to allocate education otherwise provision for children with medical conditions was a contentious issue.

A significant difference in the identification of children eligible for provision within the two different frameworks is the part the parent plays in the identification of need. Consequently, the formal participation of parents in professional decision-making regarding special educational provision had implications for the processes of policy operating in the context of practice.

Following the recommendation from the Disability Rights Task Force (1999), the principles underpinning the Disability Discrimination Act 1995

(DDA 1995) regarding the civil rights of children to have access to goods and services, is to be applied to education. At the draft stage of the Special Educational Needs and Disability Bill (2000), the definition of disability under the DDA 1995 linked the identification of children within both frameworks. This represents a positive step forward from the previous application of the DDA 1995 to goods and services other than education (DFEE, 1997d), since it is likely to strengthen access to educational provision. The literature suggested that the process of identification and verification of the individual's eligibility for additional resources is important to know because it illuminates the principles underpinning professional decision-making in the context of practice.

Fundamentally, the literature reviewed in section one suggested that enabling legislation renders the processes of policy fluid. In section two, the literature is reviewed in order to illuminate the context of professional decision-making and factors likely to influence the outcomes and effects of policy.

2.2 The LEA context of decision-making

2.2.1 Market forces and a competitive environment

Much has been written about the Education Act 1998. It was the government's intent to improve the quality of education and raise standards of achievement among schoolchildren. The critical speculation of Ball (1993) and Ranson (1993) viewed the introduction of Local Management of Schools and Open Enrolment as creating a 'quasi' educational market, which essentially exposed schools to forces of competition that were beyond their control. Large scale empirical research conducted by Woods, Bagley and Glatter (1998) confirmed that schools were operating in a more uncertain market-like environment.

Brown (1990) recognised that the actions of parents were essential to the processes of policy. He coined the phrase 'parentocracy' when he proposed that a new ideology had emerged as a vehicle for state control over education without responsibility, typically characterised by the slogans of 'parental choice', 'educational standards' and the 'free-market', in which he predicted, a gradual move towards privatisation of services would occur. Brown (1990, p. 66) developed his argument, suggesting that "the defining feature of educational 'parentocracy' is not the amount of education received, but the social basis upon which educational selection is organised". He predicted that 'parentocracy' would increase educational inequalities.

Empirical evidence indicating the effects of a market-like environment for schools, has emerged in the literature. Research conducted by the DfE (1995), Parsons (1996), Parsons and Howlett (1996) and Dawson (1997) suggested that market forces have caused a rise in the number of children excluded from school and a greater diversity of provision, with more disadvantaged children losing out. The emphasis on exam results and league tables has fostered a competitive climate, to the extent that research conducted by Bagley, Woods and Glatter (1996) and Woods et al., (1998) suggests, has led schools to adopt a differential response to groups of clients and where academic learning has displaced the traditional caring role of the school.

The notion that 'parentocracy' has increased educational inequalities has permeated the literature pertinent to the administration of special educational provision. The critical speculation of Corbett and Norwich (1997, p. 384) argued that parental empowerment and the pursuit of entitlement to special educational provision favoured the middle classes, by fostering "a climate in which those who are alert to opportunities are able to gain resources". Empirical research conducted by Knill and Humphreys (1996) and Vincent, Evans, Lunt and Young (1995), and the critical speculation of Evans and Vincent (1997) suggests that choice, operationalised through the placement rights of parents, has led to inequalities in resource allocation at LEA level. Research conducted by

Gross (1996) suggested that parental empowerment goes against the ethos of equitable entitlement for all children if resource allocation for special educational provision is disproportionably skewed by the ability of parents to exert pressure on professional decision-making. This raised the question whether formal procedures, enabling parents to participate in professional decision-making regarding the identification of need, have favoured children from privileged backgrounds as the research conducted by Riddell et al. (1994) and Duffield, Riddell and Brown (1995) in the field of specific learning difficulties has suggested. In this respect the literature shows a changing perspective about who should be involved in decision-making about the identity of provision to meet a child's special educational needs (DfE, 1992; Harris, 1997; Evans, 1998).

Another element of broader policy initiatives, evident in the literature was the rationalisation of public expenditure in terms of educational outcomes. Literature pertinent to policy initiatives, such as 'Fair Funding', 'Target setting and 'raising standards' has focussed research attention on ways of measuring the efficiency of the educational process and the efficient use of resources (Vignoles, Levačić, Walker, Machin and Reynolds, 2001; Crowther, Dyson and Millward, 1998; Marsh, 1998, 2000). 'Best Value Performance Indicators' were mooted as a means of establishing the quality of service provision for sick children, and the Department was considering

the feasibility of an appropriate outcome measure pertinent to provision for sick children (DfEE, 2000f).

A body of literature illuminated critical concerns about the effect of local management of schools on the distribution of resources between the LEA and school. Research conducted by Vincent, Evans, Lunt, and Young (1994) suggested that resource allocation for students having special educational needs was tipped in favour of pupils with severe and complex needs, with Statements. As the number of Statements maintained by LEAs has continued to rise (Audit Commission, 1992; DfEE, 2000e) the literature has reflected a growing concern about the cost of spending on SEN provision, to the extent that Bowers (1996), Gardiner (1997) and Marks (2000) concluded that LEA spending was out of control. Marks (2000) argued that the financial cost of sustaining a system of special educational provision was potentially undermining the funding of the statutory system of education, to the extent that he proposed a radical solution to the issue of SEN spending:

> **Has the concept of the individual pupil's Statement of Special Educational Need, in its present form outlived it usefulness? Should the concept of defining specific categories of disability be revived...? (Marks, 2000, p. 36)**

2.2.2 Sick children: a rising population?

Following a substantial enquiry into the specific health needs of children and young people, the Parliamentary House of Commons Health Committee (1997a, para 119) concluded that the increasing efficacy of

medical treatments had led to a corresponding decrease in child mortality rates. The committee raised concerns about the absolute number of children injured in accidents generally; the increase in the prevalence of asthma; and the 'problems of success', suggesting that the incidence of varying degrees of disability or need for care in school age children has increased.

Prescott-Clarke and Primatesta (1999a) carried out a cross sectional survey where a random sample of children aged between two and fifteen and young people aged between sixteen and twenty four, were questioned in order to evaluate the health of young people during 1995-1997 for the Department of Health. Over 8,000 adults and nearly 7,000 children were interviewed. For the year 1996-1997, members of the survey team Boreham and Prior (1999), classified the 'self reported health' of participants', but parents answered on behalf of children aged 2-12 years, whereas children aged 13 and over were interviewed:

> 10% of males and 9% of females aged 2-15 reported a longstanding illness that limited their activities. In both sexes those aged 12-15 were more likely to report a limiting longstanding illness than those aged 2-11, but there was no other significant variation by age. (Boreham and Prior, 1999, section 2.3.1)

Following the report of the Parliamentary House of Commons Health Committee (1997a, 1997b) Acheson (1998) summarised a substantial weight of statistical data and other evidence, identifying key determinants of ill health as factors associated with income, education and employment as well as to the material environment and lifestyle. Acheson (1998)

recommended a holistic approach to policy development, which encompassed education, to rectify inequalities in health. The Department of Health transformed his committee's recommendations into an all-embracing plan of action (DoH, 1998).

2.2.3 Social deprivation and child health

The literature suggested that a relationship between child health and social deprivation existed. Boreham and Prior (1999) reported that among young people aged 2-24:

> No strongly marked differences in the prevalence of limiting longstanding illness were seen by social class. There were some variations by region, but they did not form consistent patterns. (Boreham and Prior, 1999, section 2.3.2)

However, among children aged 2-15 social class was a factor:

> Among those aged 2-15, prevalence of limiting longstanding illness was higher in the bottom quintile of household income than in higher income quintiles. (Boreham and Prior, 1999, section 2.3.2)

Research conducted by Roberts and Power (1996) suggested that social class was a significant correlate with the incidence of child mortality arising from injury. The death rate noted for lower social economic groups (social class five) increased to being five times higher than for social class one between in 1989-92, from a rate of three and a half times higher between 1979-83.

2.2.4 Parental involvement in the care of sick children

The literature suggests that parents are involved in the care of sick children in hospital and in the home and a change in hospital policy and practice has enabled parents to maintain continuity of child care at first hand (Date, 1986; Johnson, 1990; Evans, 1992; Belson, 1993). As the national health service has changed to accommodate parents, the attitudes of health care staff towards the presence of parents in the anaesthetic room (Kain et al. (sic.), 1996) and in the recovery room (Hall, Payne, Stack and Stokes, 1995) have been shown to be positive. The role of parents in health care has extended and parents are expected to implement specialised nursing procedures themselves, when caring for their children in the home (Parliament. House of Commons Health Committee, 1997b, para 30-32; DoH, 1998a). The literature suggests that parents carry a substantial burden of responsibility as partners in health care provision in addition to their duty to cause their children to receive education under the Education Act 1996, s. 7. Given these two areas of responsibility, the author questioned whether parents have the personal resources to support a child's learning activities in the home, or influence decisions in the route to provision.

2.2.5 Pupil and parent perceptions of education for sick children

A small body of literature illuminated pupil and parent perceptions of education for sick children. Qualitative self reported data were gathered by means of semi-structured interviews and/ or focus groups by Bolton (1997)

and Mukherjee Lightfoot and Sloper (2000a) in England, and Closs and Norris (1997) in all twelve regional counties of Scotland. Bolton (1997) surveyed one hundred parents in England followed by interviews with fourty-six parents. Mukherjee et al. (2000a) questioned thirty-three pupils with chronic medical conditions who attended mainstream secondary school, fifty-eight parents of primary and secondary age school children and thirty-four primary and secondary school teachers. Closs and Norris (1997) questioned sixteen parents. 'Framework' analysis (Ritchie and Spencer, 1994 p. 173) was a common strategy used by Closs and Norris (1997) and Mukherjee et al. (2000a). A synthesis of the research suggested that pupils (and their parents) expressed a strong desire to receive education when unable to attend school. Parents perceived that education maintained a sense of 'normality' contributing positively to a child's quality of life. Moreover, Closs and Burnett (1995) commenting on the views of parents and teachers reported that children with terminal illness wanted to follow the usual curriculum because it was challenging, interesting and appropriate for them to do so.

2.2.6 Type of LEA arrangements and provision

The time that children spend in hospital has fallen, from an average length of stay of seven days, in 1973, to an average of three days in 1994-1996 (Audit Commission, 1993, p. 43; Parliament. House of Commons Health Committee, 1997c). The number of registered hospital schools in England

and Wales has fallen steadily from one hundred and twenty in 1955 (DES, 1978, para 2.56) to sixty-nine in 1988 (HMSO, 1995), nineteen in 1995 (NAESC, 1995) and fifteen in 1997 (NAESC, 1997a). As health care provision has moved into the community (Audit Commission, 1993; Parliament. House of Commons Health Committee, 1997b, 1997c) increasing proportions of children required access to educational provision in the home.

In 1989, Her Majesty's Inspectorate recognised the potential impact of the trend towards community health provision on Hospital and Home Teaching Services (DES and HMI, 1989) and recommended that LEA policies should promote the amalgamation of Hospital and Home teaching services. This raised the question whether the type of organisational structure for LEA services was an important factor influencing outcomes for children.

Fassam (1982) conducted the first large-scale study of educational provision in hospital in England and reported that LEA arrangements had developed in a piecemeal way, resulting in patchy provision. Large scale research conducted by NAESC, mapping LEA offerings of provision (NAESC, 1995, 1997a, 1999), showed that a diversity of LEA arrangements continue to exist, with Hospital and Home teaching services organised as discrete units, or as a combined service, or managed under the auspices of special education needs, pupil support, or pupil referral units.

The accident of where a child lived determined the type of educational arrangements offered to a child in hospital or in the home.

2.2.7 Quantity of provision

In 1997 and 1998 educational provision offered in hospital ranged from 'full time' to no teaching (NAESC, 1997a, 1999). Provision offered in a teaching centre, or in the home ranged from an upper limit of ten hours per week to three hours per week.

Of the forty-six children interviewed by Bolton (1997) almost half the children who received teaching in hospital failed to receive provision in the home in England. Similarly in Scotland, where provision was discretionary under Scottish law, research conducted by Closs and Norris (1997) suggested that children received scant provision in hospital or in the home. The level of unmet need for the service remains unreported in the literature.

2.2.8 Quality indicators

Departmental guidance has stressed continuity as a central tenant underpinning the arrangements for educating sick children (DfE and DoH, 1994). Qualified teachers have been the mainstay of curriculum delivery in hospital and in the home (NAESC, 1996) and anecdotal evidence in the literature suggested that information and communication technology was penetrating hospital provision (Ryan, 1998; Boydle, 1998; Johnson, 1998; Russel, 1998).

2.2.8.1 Professionals' knowledge and understanding of the educational needs of sick children

Research conducted by Eiser and Town (1987) suggested that a lack of knowledge serves as an impediment to teachers' understandings of the educational needs of sick children. For example, some 57% of the 147 teachers questioned by Eiser and Town (1987) believed that asthma had a 'psychological component'. These findings find accord with research conducted by Mukherjee et al. (2000a). The main findings of the research suggested that teachers' lack of knowledge and understanding of the needs of sick children was a key factor responsible for the diversity of support offered to children with chronic illness attending mainstream schools. This raised the question of whether teachers in mainstream school had appropriate knowledge and understanding to play a role in the identification of children who required additional educational provision.

2.2.9 Professional administration

Lipsky (1980) illuminated the dilemma of the individual in public services in terms of the conditions of work and the practices and routines of the 'street level bureaucrat' which had the effect of rationing services in order to distribute scarce resources in a population. Practices included limiting access and demand and inequality in administration.

Access to information about services was a persistent theme in the literature (Goacher et al., 1988; Vaughan, 1989; Wolfendale, 1997a, 1997b; Closs and Norris, 1997; Goodinge, 1998; Mitchell and Sloper, 2000). The research conducted by Goacher et al. (1988) confirmed that few LEAs alerted parents to their legal rights to make representations and submit written evidence, or provided encouragement and support to parents to do so. The research showed that scant written guidance existed to assist parents to make their views known. Wolfendale (1997a) reported the findings of a government funded research project on parent partnership schemes. The research showed that only three of the sixty-seven LEAs in the sample informed parents of their legal right to contribute their views during the statutory assessment process. Seventy seven per cent of LEAs encouraged parents to express their views verbally or in writing, fifty per cent of LEAs did this positively or strongly. In the case of parents negotiating access to services to disabled children and their families Goodinge (1998) reported, on behalf of the Department of Health social services inspectorate, the results of a multi-agency inspection in which a total of 420 families were questioned:

> To be fully involved in decisions about their child's care, parents need to have information about the assessment process and the full range of provision for children in their area. Families frequently found information difficult to obtain and were often confused about where to get it. This was because they were unaware which agencies were responsible for which services. (Goodinge, 1998, p. 33)

The literature contains some documentary evidence of the unintended effects of rationing. The Warnock Committee was alive to the waiting period experienced by children in hospital before LEAs allocated provision for financial reasons (DES, 1978, para 8.80). A questionnaire survey conducted by Fassam (1982) suggested that of the eighty two per cent of LEAs that responded nationally, fifteen per cent said that provision in hospital had been adversely affected by budget cuts. Fassam (1982) believed the statistics underestimated the magnitude of rationing as fifty-eight hospital administrators from thirty-six LEAs reported that the service had been cut. Furthermore, several LEAs reported that inequalities in administration existed in the allocation of provision offered to certain categories of children only. This raised the question whether rationing was an effective control mechanism enabling the equitable distribution of resources within a population.

2.2.9.1 Roles and responsibilities

The arrangements for the education of children out of school encompass the LEA, the home and the 'home school' (DfE and DoH, 1994). Lipsky (1980) argued that a division in responsibility among stakeholders caused ambiguity in role expectations. He traced the root cause to ambiguity and conflict between different policy goals. In the current study the prime responsibility of the school governors and the ultimate responsibly of the LEA created a division of responsibility for provision arranged under the

Education Act 1996 s. 19. Secondly, goal ambiguity arises at the point of identification of the child within the legislative framework of exceptional provision and special education under part four of the same Act.

Lipsky (1980) located the notion of role expectation among stakeholders. He identified three sources: in peers and others who occupy complementary role positions; in reference groups, which operationally define role expectations; and the consensus of public opinion about role expectations. He maintained that clients were not the primary reference group of street level bureaucrats, the reason being, in the present study, that pupils and parents do not define street level bureaucrats' roles. For these reasons he concludes, firstly, that the effectiveness of the organisation may be impaired and thus, it is feasible that pupils would fall through the net between LEA and school provision. Secondly, street level bureaucrats may be resistant to client demands, to the extent that disputes may arise concerning the participation of clients in decision-making and having a voice in policy.

The research literature showed that Lipsky (1980) made a valid point in his assessment of the implications of ambiguous role expectations of professionals supporting children with medical conditions in mainstream school. Mukherjee et al. (2000a) concluded that ambiguity in roles and responsibilities of school teachers influenced the identification of pupils,

often leaving children with chronic illness outside the remit of the SEN Code of Practice (DfEE, 1994).

Lack of time was one factor working against professionals cited by Mukherjee et al. (2000a) but the literature suggested that motivation was a critical issue also. Tomlinson (1982) suggested that assumptions about an overriding spirit of benevolent altruism, providing the motivation for principle decision-makers working with parents in the assessment of special educational needs, was unrealistic. In the field of social services, Hudson (1997b) echoed similar concerns suggesting that an assumption of professionals' propensity to co-operate with other organisations, in response to an alert of individual or community needs, was unrealistic.

Hudson (1997b) suggested that the most powerful motivation of decision-makers concerned the realisation of organisational goals. Lipsky (1980) and Hudson (1997b) have commented that welfare organisations do not normally possess or control the entire complement of resources needed for their goal accomplishment. In the face of inadequate resources, organisations may enter into exchanges with one another to acquire needed resources. However he suggested that the scope of exchange operating within a network could lead to exploitation of the immediate environment.

The literature has illuminated the notion of 'exchange', simply put as the give and take in relations between different organisations, and which Hudson (1997b) suggested was fruitful because it focused on the balance of

power between stakeholders. Levine and White (1961) have used 'exchange' as a conceptual framework for the interorganisational relationships between health care providers in their study of the significance of referral routes, while Benson (1975) used the notion to explain the flow of resources within an interorganisation network as a political economy.

2.2.9.2 Delegation of LEA services

In a press release issued by the Government, Byers (1998) alluded to the increasing pressure bearing down on LEAs to increase the proportion of the budget delegated to school. The government intended that 'Fair Funding' (DfEE, 1998j) would improve the delegation of monies to school.

Fletcher-Campbell and Cullen (1999) surveyed one hundred and four LEAs and collected qualitative data in five case study authorities in an investigation of the impact of delegation on LEA Support Services for Special Educational Needs. They suggested that delegation had not led to the demise of centrally funded services, but services nonetheless were affected in different ways. For example, a service for low incidence sensory impairment had closed because of a trough in numbers, with the resultant dissipation of professional expertise in one LEA. In another LEA the possibility of competition from other agencies working to support pupils at stage three of the SEN Code of Practice, meant that the organisation as a whole was more focused on providing a high quality service to schools. An

increase in demand from schools for the stage of support funded centrally by the LEAs (in the form of Statements) was related to a lack of schools taking responsibility for the earlier stages of support, which was funded through the delegated budget. Overall, delegation influenced the amount of SEN support LEAs offered to schools from centrally funded services.

2.2.9.3 Involving parents in professional decision-making

Although the literature has addressed the involvement of parents of children having SEN in the decision-making process occurring at the level of the LEA, a very small body of literature exists looking at the involvement of parents of sick children in professional administration. Closs and Norris (1997) commented on the findings arising from qualitative research:

> Within the families interviewed one of the most clear indicators of parental influence on education was the extent to which parents were willing to be co-ordinators, supervisors, or even sole providers of education for their children when their condition prevented school attendance, sometimes throughout sustained or frequent intermittent absences. (Closs and Norris, 1997, p. 100)

Bolton (1997) alluded to parents' passive engagement in professional decision-making and communication.

Research conducted by Cornwall (1987) and Galloway et al. (1994) prior to the enactment of the Education Act 1993, showed that tensions in the relationship between professionals and parents arose when a process of participation and partnership influenced the use and allocation of resources.

Of parents experienced in the procedures of SEN assessment and annual review, Bowers (1995) reported perceptions of adversarial relationships between parents and officers of LEAs. Bowers questioned 35 parents, (31 women, four men) and reported that 34 parents recounted negative experiences. Perceptions of bureaucratic practises included, inaccessibility to LEA officers, ignoring parents' views, using threats and being untrustworthy. One strategy identified in the literature by Simmons (1997) and Evans (1999) to enable the participation of parents in the decision-making process for special educational provision, was advocacy, particularly where the spirit of partnership had broken down.

Lipsky (1980) suggested that bureaucratic administration imposed costs on clients who were seeking service. Time, money and personal resources were likely to be important factors contributing to clients' success in securing the provision of services. One aspect of children experiencing sustained absence from school, reported by Bolton (1997) and Closs and Norris (1997) was the perception of loneliness and isolation from supporting services whilst in the home. This raised the question whether parents negotiated access to state provision as individuals or received support from others.

2.2.9.4 Communication and liaison

Eiser and Town (1987), Eiser (1993), Mukherjee, Lightfoot and Sloper (2000b) and Mitchell and Sloper (2000) have all emphasised the

importance of communication between parents, medical services and schools, in giving education professionals accurate information regarding the child's medical condition. Parents questioned by Bolton (1997), Closs and Norris (1997), Norris and Closs (1999) and Mukherjee et al. (2000a) said that communication with school was informal.

The informal nature of liaison and communication led the researcher to consider the identification of need for teaching in terms of 'need gratification' underpinning a theory of motivation suggested by Maslow (1987). A discrepancy between the actual state and the desired or preferred state of being activated a motive or need. As the discrepancy between the actual and the desired state increased, the drive strength increased. The stronger the drive, the greater the perceived urgency of response, particularly where the service was personally relevant and the consumer was highly involved. The need activated was associated with a hierarchy of levels and considered fundamental physiological needs at the lowest level. Mukherjee et al. (2000a) suggested that the practicality of home school liaison was troublesome for parents and teachers. Pupils and parents in their study wanted schools to set up systems to ensure that work was sent home and teaching support given to pupils in catching up, rather than being left to copy up work from peers.

This raised the question whether parental involvement in the identification of needs at the operational level was an effective means of gaining recognition by the school or a Hospital and Home teaching service.

2.3 Chapter summary

The literature reviewed in section one illuminated the nature of enabling legislation and the processes of policy operating in the context of influence, policy text production and practice regarding decision-making in arranging educational provision for children out of school because of illness. It showed it is likely that pressures brought to bear through political and socio-economic policy and by parents influence professional decision-making. A body of research illuminated professionals' and parents' perceptions of the decision-making process in the administration of special educational provision, but no research has focussed on the decision-making process regarding exceptional provision under the Education Act 1996, s. 19.

Exploring professionals and parents' perceptions of the decision-making process is complex and demanding: the literature suggested that a multitude of interacting factors exist, both within the legislation and without and situated both within the decision-making process at LEA level and without. It is important to know what factors are likely to promote or hinder the administration of provision to meet the needs of pupils, so that the implications of the results are communicated to the appropriate agency.

Essentially the process of arranging provision for children out of school raises questions about the roles and responsibilities of the school governing body where the child is registered, the LEA and the parent. The literature suggested that two interrelated facets of the decision-making process existed in terms of professional control and parental influence on the process of identification of need and the allocation of provision. Thus, the research questions must address the involvement of stakeholders in the process of identifying and arranging provision for children. What is the impact of professional control and parental influence on the identification of pupils who need teaching in hospital or in the home and the provision arranged?

The study reported here sought to identify outcomes and effects of decision-making, factors responsible, and the impact of power relations between professionals and parents in order to ascertain the impact of the decision–making process on outcomes for children. This is important to know in order to contribute to policy development in the area of parental involvement.

The literature suggested qualitative data was valuable in research concerning decision-making in the administration of special educational provision and processes of policy, and in identifying issues concerning the education of sick children. The implications of using a qualitative design in the current study are discussed in chapter three.

3 EDUCATIONAL AND APPLIED POLICY RESEARCH

The research explores issues pertinent to the definition of suitable education under the Education Act 1996, s. 19 and salient themes raised in the literature discussed in chapter two. In this chapter the paradigmatic context of educational and applied policy research is discussed and the selection of a qualitative design is justified. Philosophical issues underpinning the subject object relations existing between the researcher and the researched and the implications of epistemological theory on the quality of research are discussed.

3.1 The research question, focus and aims of the study

3.1.1 Research question

The prima facia research question sought to gain knowledge of professionals' and parents' perceptions of the decision-making process concerned with arranging provision for pupils 'otherwise than at school'. The literature reviewed in chapter two suggested that a multitude of interacting factors exist and that the relationship between professional control and parental involvement in decision-making influences outcomes for children. Thus, the research questions sought to ascertain the impact of the decision-making process on outcomes for children.

3.1.2 Focus of the study and research design

The focus of the study was the process of arranging educational provision in seven English LEAs. Qualitative data were required in order to study the process of arranging provision. The reasoning underpinning this decision is discussed more fully in relation to policy research generally (section 3.2); the particular methods chosen for data collection (section 3.4); and the implications for data analysis (section 3.5).

A multiple case study design was chosen. As the decision to arrange provision rests ultimately with the LEA, the case definition was defined as the LEA. The rationale underpinning the sampling frame is discussed in section 3.3.

A replication strategy was used to enable some assessment of consistency of procedures across LEAs and consistency of processes influencing outcomes for children (Miles and Huberman, 1994, p. 29). Documents, professionals' and parents' self-reported information and perceptions and substantial background information published by NAESC (1997a, 1999) supported the triangulation of data and the internal and external validity of the research findings. These issues are discussed more fully in section 3.7 and 4.4.4.

3.1.3 Aims

The study aims were:

- to examine the diversity of arrangements made for provision (Aim 1)

- to examine factors responsible for that diversity (Aim 2)

- to investigate the effects of professional decision-making in the administration of provision (Aim 3)

- to investigate the effect of parental involvement in the process of professional decision-making (Aim 4)

-to identify professional and parent perceptions of the decision-making process in their LEA (Aim 5).

3.1.3.1 The aims operationalised as observable objectives of the study were:

- to categorise the diversity of outcomes for pupils (Aim 1 operationalised)

- to describe outcomes of decision-making on the administration of educational provision (Aim 2 operationalised)

- to identify determining factors that influence decision-making and promote (or hinder) the administration of provision to meet pupils' needs (Aim 3 operationalised)

- to inform an analysis of the actual exercise of discretion with an understanding of the structural position of the LEA as provider and its relationship to a broader social, political and economic framework (Aim 4 operationalised)

- to contribute to policy development relating (directly or indirectly) to parental involvement in the decision-making process (Aim 5 operationalised).

3.1.3.2 The form of the argument

The form of the argument which is advanced in the thesis and evaluated in the light of empirical evidence, is presented in Figure 3.1. Empirical evidence provided basic reasons (R1, R2 etc). Deductive reasoning supports a conclusion which in turn forms a reason to support a further conclusion. The form of the argument finds accord with the relationship between the logic of real arguments and empirical evidence, discussed by Fisher (1988) and Phelan and Reynolds (1996).

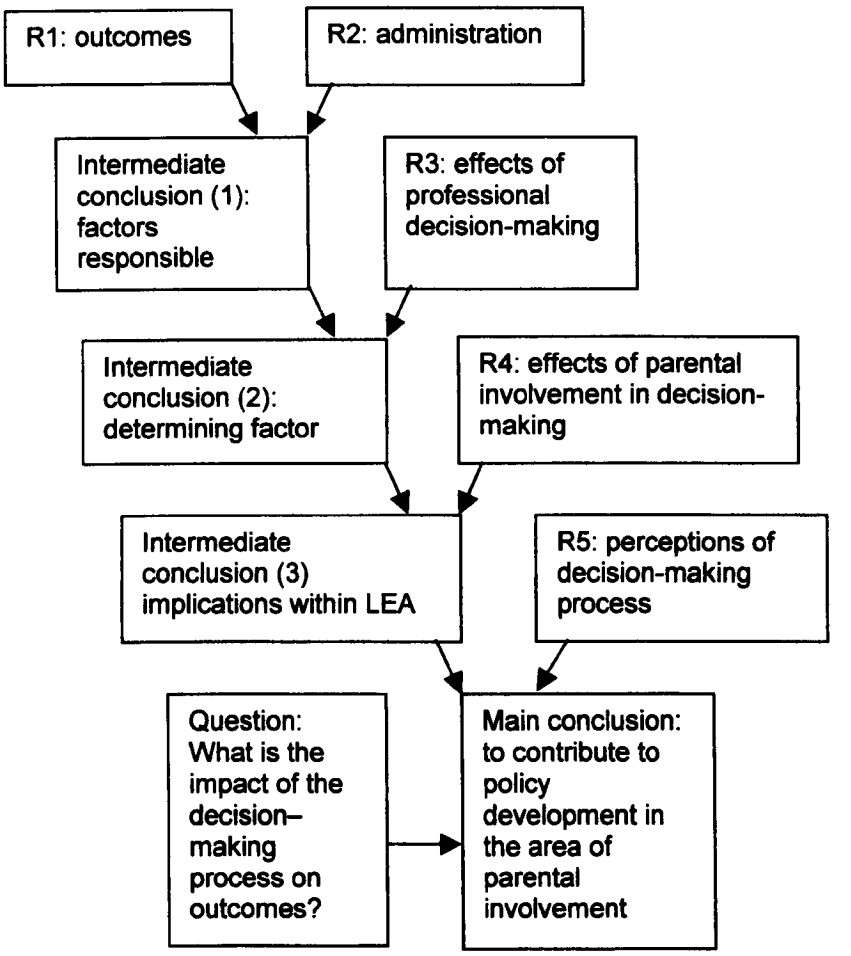


Figure 3.1 The form of the argument

3.1.3.3 Background information

The relationship between argument and evidence was strengthened by a platform of pre-existing large scale research which provided substantial background information about the current state of LEA provision, the size of the client population (NAESC, 1996) and the type and quantity of intended offerings arranged by individual LEAs nationally (NAESC, 1995,

1997a, 1999). An illustration of the level of background information supporting the present study is located in Appendix 9.1. The strength of these large-scale studies lay in their capacity to answer research questions about what was provided and to how many children, nationally. Thus, the current study built on previous large-scale quantitative and qualitative research that supported triangulation and corroboration of self-reported information.

3.2 Policy research and the processes of policy

Qualitative data was required because the literature reviewed in chapter two suggested that the relationship between outcomes for children, factors responsible, effects of professional administration and parental influence was complex and multi-factorial.

Power (1992) and Bowe and Ball (1992) suggested that researching educational policy is fraught with discontinuity and difficulty. The literature reviewed in section 2.1.1. suggests that the very nature of enabling legislation allows substantial discretion in the interpretation of the Act and policy texts, to the extent that policy intention and the effects of policy were rarely the same. Bowe and Ball (1992) explicated three areas of difficulty in conducting research. First processes of policy are invisible; second, outcomes of legislative policy are non-specific; and third effects are typically diffuse. However in contrast to the explorations and analyses of the impact of the Education Reform Act 1988 discussed by Bowe and

Ball (1992) and Power (1992), a specific outcome indicator of policy, under the Education Act 1996 s. 19, was identifiable. An outcome indicator categorised as tuition hours received by individual pupils functioned to track decisions and illuminate intended and unintended effects.

The notion of identifying intended and unintended effects as outcomes of policy raised the question about the suitability of an epistemological paradigm chosen for the collection of data. Martin and Sugarman (1993) and Salomon (1991) have traced the philosophical assumptions underlying different methods of empirical enquiry beyond a division resting solely on the numerical or textual nature of data, to epistemological origins derived firstly from Aristotelian science and correlation type designs and secondly, the testing of hypotheses, characteristic of the Galilean science. Given that the substantive nature of unintended effects was unknown, the notion of testing a hypothesis by falsification was rejected in the present study. Furthermore, the literature showed that children reaching the point of recognition by the LEA service were low in number (NAESC, 1996) and led the researcher to reject a large scale quantitative survey requiring a statistically viable population for analyses.

The literature reviewed in chapter two suggested that qualitative data were instrumental to research concerning the administration of educational provision for individuals. Although the literature has illuminated substantive issues pertinent to the education of children with chronic illness

(Bolton, 1997; Closs and Burnett, 1995; Closs and Norris, 1997; Norris and Closs, 1999; Larcombe, 1995; Mukherjee et al., 2000a), limited systematic knowledge of key issues influencing the process of arranging exceptional provision for children out of school because of illness existed. Conversely, the literature has illuminated the perceptions of parents participating in professional decision-making relating to special educational provision (Bowers, 1996; Cornwell, 1987; Vincent et al., 1994, 1996) and therefore the study extends existing research from a contrasting legislative framework. The methodology used in the current study followed the precedent of existing research.

It was likely that outcomes and effects would be a function of the relationship between situation and context factors. The situation of pupils and families and factors pertinent to the context of LEA decision-making suggested that qualitative data was required in order to identify what was provided for pupils and the type of factors responsible for outcomes and effects (Ritchie and Spencer, 1994).

The purpose of the qualitative design was to elucidate how a process of decision-making contributed to outcomes and effects and why. Qualitative data were needed to illuminate the factors influencing the process of arranging provision and introduced notions of classification, association and exploratory analysis, which aligned the methodology within the epistemological origins of Aristotelian science. The implications for

qualitative analyses and the philosophical assumptions underpinning the relationship of the researcher and the researched are discussed below in section 3.6.

3.3 Rationale for the sampling frame

At the time of planning the study NAESC (1977a, 1999) had complied a directory of provision for 116 LEAs in England and Wales in 1997, rising to 138 LEAs in 1998 following local government reorganisation. A multiple site case study was chosen to reflect a diversity of LEA contexts in England (Miles and Huberman, 1994; Foster, Gomm and Hammersley, 1996). Policy studies conducted by Vincent et al. (1994, 1996) illustrated that multiple case sampling was useful in selecting a diversity of contexts. As these studies focussed on decision-making processes, LEAs were unmatched. In a study of school SEN policies, Thomas, Tarr, Webb, and Taysum (1996) used criteria for sample selection based on size and geographical spread of LEAs in order to gain representation to a larger population of schools. Taking on board the rationale underpinning the multiple case sampling frame used by Vincent et al. (1994, 1996) and the use of two criteria by Thomas et al. (1996), the present study echoed a similar rationale. In the present study, a purposeful sample of LEAs was selected against two criteria. First, shire and urban LEAs to give a geographical spread in England, second, a diversity of 'service arrangements' as categorised by NAESC (1997a). Heterogeneity of LEA

contexts was sought, as the study focussed on the process of arranging provision for children.

An opportunity sample, comprising a cluster of parents residing in case study LEAs was sought. Parents residing in non case study LEAs were sought in order to evaluate inherent sampling bias within the volunteer LEAs, compared with non-volunteer LEAs. The parent sample in its entirety informed the analysis of factors responsible for diversity of outcomes arranged for individual pupils arising from individual situations and families.

Foster et al. (1996, p. 66) suggest that "multi-site investigations, where sites are selected by means of sampling decisions that are designed to represent relevant kinds of heterogeneity within the population" support empirical generalization. Thus transference of empirical findings about administrative processes in the case study LEAs A-G, to LEAs H-R was feasible given the level of specification for individual LEAs in the Directory of Current Provision in England and Wales 1997, 1998 published by NAESC (1997a, 1999). All participants were volunteers. The notion of random sampling from a definitive population of parents was untenable in practice and representation to a larger population based on empirical evidence of outcomes for individual pupils was invalid. Furthermore Riddell et al. (1994) reported that the recruitment of parents for a study of parental empowerment was skewed by self selection and the differential response to

invitations depending on whether LEA professionals or a parent support group acted as gatekeepers. Thus, the researcher accepted that consistency of LEA processes defined the substantive element of transferability.

In the current study a match in underlying theory was operational at the level of the Education Act 1996, s. 19 and s. 319 paragraph (1)(b) by the commonality of 'education otherwise' provision arranged under the administration of exceptional and special educational provision. Miles and Huberman (1994) and Foster et al. (1996) suggested that a match to underlying theory supported the generalization of findings on grounds of theoretical inference.

3.4 Rationale for the qualitative methods selected for data collection

The aim of the research was to illuminate the dynamics of processes, so it was important to apply an ethnographic approach to 'in vivo' data collection that disturbed the context as little as possible in order to provide accurate data. Document collation and semi-structured interviews were used. The process of field research is discussed more fully in chapter four.

A sterile 'in vitro' approach to data collection, such as questionnaires, or the projective techniques used in focus groups used by Davies (1993) that were stripped of natural context, was considered inappropriate to the goals of the current study.

The aims were operationalised through the following methods used for data collection:

First, standardised semi-structured interviews with LEA professionals gathered perceptions of the LEA arrangements. Standardised semi-structured interviews with parents of children with medical needs, with and without a Statement of special educational need, gathered perceptions of outcomes for individual children (Aim 1).

Second, a standardised data collection pro forma gathered situational data from parents. Standardised semi structured interviews with LEA professionals and document collation gathered contextual data regarding LEA policies and eligibility criteria applied to resource allocation, in each LEA (Aim 2).

Third, standardised semi-structured interviews gathered professionals' perceptions of determining factors that influence decision-making and promote (or hinder) the administration of provision to meet pupils' needs (Aim 3).

Fourth, relevant documents were collected to gather contextual data pertinent to the context of LEA decision-making and its relationship to a broader social political and economic framework. LEA documents were gathered in hard copy or from LEA Internet web sites (Aim 4).

Fifth standardised semi-structured interviews gathered professionals' and parents' perceptions of parental involvement and influence on professional decision-making (Aim 5).

There has been a steady growth in the use of qualitative methods for applied social policy research (Ritchie and Spencer, 1994), research concerning processes of policy (Rist, 1994; Hill, 1997a), research concerning educational inequalities (Foster et al., 1996) and ethnographic analyses concerned with power and participation (Gitlin, Siegel and Boru, 1993). Ritchie and Spencer (1994, p. 173) distinguished applied policy research from 'basic' or 'theoretical' research, because the purpose of the applied policy research was "to meet specific information needs and its potential for actionable outcomes".

The objectives of the study became operationalised through the form of the interview questions. Open-ended questions gathered data about the form and nature of what children received. Open-ended questions gathered data about professional administration in order to identify the reasons for, or causes of, what existed. Open-ended questions examined what influenced the effectiveness of what exists, for example the part that parents play in professional administration.

However identifying factors responsible for diversity required the research design to address the questions of ethics, in terms of safeguarding the integrity of participants. Given the nature of the substantive field

concerning children with a medical condition the recommendation of Gitlin et al. (1993), to incorporate into a research design ethnographic participant observation, was rejected because children and their families were situated in hospital or in the home and extensive observation was likely to be intrusive. Whilst Davies (1997) suggested that participant observation ultimately placed the anonymity of participants at risk, a research design incorporating a multiple case study reduced that risk.

Although desirable, it was not feasible for the researcher to record observations regarding the type, quantity and indicative quality of the provision that pupils received and thus, as Foster et al. (1996, p. 56) explained, informant's accounts provided "second hand information". Nevertheless the literature reviewed in section 2.2.2. showed that reported data underpinned the health survey in England where 8,000 adults and nearly 7,000 children were interviewed. Parents answered on behalf of children aged 2-12 years in order to provide data about their child's health and well being (Boreham and Prior, 1999). A statistical analysis was used to test the reliability of trends identified in the data. In the present small scale study, parents answered on behalf of children in order to provide data about the arrangements for the provision of education for their children presented in section 5.1. Corroboration with primary and secondary sources served to establish researcher confidence in the accuracy of the reported

data for each child. The identification of themes in section 5.1 was supported further by triangulation with the case study LEAs A-G.

3.5 Rationale for the qualitative analysis of the study

At this point in the study, it was important to introduce strategies to control the effects of the researched on the researcher, during the process of analysis. The philosophical issues underpinning this metaphorical separation and implications for the quality of the research is discussed in section 3.6. The discussion leads to a consideration of the aims, operationalised as the analyses of the study.

First, the contextual data were organised to identify the form and nature of the arrangements and what provision English LEAs provided. Data abstracted from LEA documents and transcripts were sorted and categorised as type, quantity and by quality indicators. A process of triangulation between LEA professionals' and parents' perceptions and primary and secondary documentary sources corroborated factual data. A profile of data relevant to each child was indexed in a computer database Access®. Fields of data were sorted and categorised to aid further analysis ('Framework analysis' Ritchie and Spencer, 1994, p. 173). The number of hours of visiting teaching that pupils received was used as an outcome indicator of diversity and was charted as an additional check on the internal reliability of the theme (Aim 1).

Second, situational factors pertinent to pupils and families, were abstracted from contextual data and indexed in the database Access®. Charted fields of indexed data, were then compared and analysed for factors, using the presence or absence of provision as an outcome indicator. Factual data relevant to the context of LEA administration were abstracted from documents and transcripts and checked by a process of triangulation. Contextual data were transformed into themes and charted to show consistency or inconsistency in administrative processes between English LEAs and the degree of professional control over the administrative route for provision (Aim 2).

Third, an analytic inductive analysis of professionals' perceptions identified themes illuminating intended and unintended effects of professional decision-making. The identified themes then informed a hypothetical–deductive analysis of parent perceptions (Miles and Huberman, 1994). Data abstracted from parent transcripts were indexed in a computer database Access® (Aim 3).

Fourth, an analytic inductive analysis identified themes illuminating the intended and unintended effects of parental involvement in the process of professional decision-making (Aim 4).

Fifth, a discourse analysis illuminated professionals' and parents' perceptions of parental involvement in the process of professional decision-making and parental influence on professional decision-making within the

context of the LEA (Potter and Wetherell, 1987, 1994). Discourse analysis was used because the interpretation of intentions and situated actions required an appreciation of the way in which words were used to capture key features of experience (Aim 5).

A computer word processor, Word 2000® was used as a basic analytic aid. Interview transcripts were coded and raw data were transformed into themes. Analyses of content (Ritchie and Spencer, 1994) and discourse (Potter and Wetherell, 1987, 1994) provided a typology of qualitative data sets, which were categorised to aid interpretation. Data from documents were electronically scanned, transformed into Word2000® by an optical character recognition program Textbridge® and cross-referenced. The analysis encompassed various sized 'chunks' in the data. Once qualitative analysis was exhausted using Word2000, a strategy recommended by Stanley and Temple (1995), a dedicated computer program that was suitable for this particular study was selected. Burgess, Pole, Evans and Priestley (1994) used a relational database (NUDIST®) as a tool for their multi-site case study analysis. In the current study Access® was chosen because of its compatibility with the Microsoft Windows® operating system and the computer programs Word2000® and Excel2000®. Data abstracted from transcripts was indexed and charted as fields in the database.

The descriptive characteristics of the diversity of provision (Aim 1) and factors responsible (Aim 2) were analysed and explored using 'hours of provision allocated' as an outcome indicator. Data from multiple case English LEAs were sorted and classified according to different patterns and configurations and some cross case comparison was undertaken. The integrated use of the Microsoft Windows operating system for Access2000® and Excel2000® facilitated exploratory analyses, simple descriptive statistics and graphic presentation of findings. The computer was used as a tool to support the reliability of analytic procedures in order that other researchers, given the same access to data, could replicate the study. It was accepted that the LEA context where the fieldwork was undertaken was likely to change and thus complete replication, given access to the same snapshot of English LEAs and participants would be uncertain.

Thus, the research design incorporated applied policy research (Ritchie and Spencer, 1994) to identify the form and nature of what exists and reasons for what exists. The analysis of parent and professional discourse (Potter and Wetherell, 1987, 1994) illuminated the propensity of the actions of professionals and parents to influence the outcomes for children. A process of reflection illuminated the meaning of the findings in order to identify the implications of the results for decision-makers.

A recurrent theme in the methodological critique offered by Power (1992) and Mizen (1994) was the notion of a gap between empirical investigations conducted at ground level and the theoretical explanations proposed at the level of political ideology or cultural explanations. On the one hand, Mizen (1994) criticised the methodological weakness of research using participant observation conducted by Hollands (1990) suggesting that claims to knowledge proposed at the micro level fail to support hypotheses at a macro level because a gap existed in the empirical evidence. On the other hand, Power (1992) contends that exploratory studies of effects that have sought explanations within the sociology of education, have failed to enhance our understanding of the relationship between education policy and the degree of continuity and/or change in educational processes and outcomes.

This study was not searching for causality within cultural explanations grounded in ideology or politics, an approach clearly favoured by Hollands (1991) but within explanations concerned with the process of decision-making. The focus of the study looks at the process of arranging provision in English LEAs. Empirical data relevant to the situation of pupils and families and the LEA context of decision-making were gathered. Thus, the current study has incorporated a snapshot of empirical data collection, set across a review of relevant texts, illuminating the context of influence, the context of policy text production and the context of practice. In so doing,

the 'policy trajectory' approach favoured by Ball (1997, p. 266) closed the gap between empirical data collection in the context of practice and the contexts of influence and policy text production.

3.6 Philosophical issues in educational research

In the field of research concerning processes of policy, Hill (1997b, p. 27) advised researchers to provide a "realist description" of the world. Likewise Foster et al. (1996) advised researchers to retain value neutrality in substantive research illuminating educational inequality, suggesting that factual evidence and value arguments should be separated. Gitlin et al. (1993, p. 194) take a different standpoint suggesting "the danger for us, is not 'going native', but detachment. The question is not whether the data are biased; the question is whose interests are served by the bias". The researcher has considered these two philosophical standpoints. Foster et al. (1996 p. 34) suggests that a 'problem of justification' is likely when making a claim to knowledge, if a judgment about the validity of the claim is based on a different epistemological foundation to the research.

In this study, the subject-object relationship between the researcher and the researched raised the question of whether fundamental epistemological principles were in conflict. In the opinion of the researcher, a Gadermerian perspective is useful in illuminating the tensions between truth and method:

> As we see it, the problem of method is entirely determined by the object- a general Aristotelian principle- and the important thing for us is to examine the curious relation between moral being and moral consciousness that Aristotle sets out in his Ethics. (Gadamer, 1989, p. 313)

Gadamer (1989) has provided a useful analysis of the hermeneutic relevance of Aristotle:

> The alienation of the interpreter from the interpreted by the objectifying methods of science, characteristic of the hermeneutics and historiography of the nineteenth century, appeared as a consequence of false objectification. My purpose...is to help us realise and avoid this. For moral knowledge, as Aristotle describes it, is clearly not objective knowledge- i.e. the knower is not standing over against a situation that he merely observes; he is directly confronted with what he sees. (Gadamer, 1989, p. 314)

Gadamer has questioned contemporary interpretations pertaining to the status of research findings and claims of generalisation of conclusions, suggesting that Aristotle's position on 'natural law' is highly subtle:

> Certainly he [Aristotle] accepts the idea of an absolutely unchangeable law, but he limits it explicitly to the gods and says that among men not only statutory law, but natural law is **changeable**. For Aristotle, this changeability is wholly compatible with the fact that it is "natural" law". (Gadamer, 1989, p. 319, Author's emphasis)

Gadamer develops the discussion further by illuminating different ways of knowing and forms of knowledge; for example technical knowledge arising from substantive technique and moral knowledge arising from deliberation with oneself, suggesting that technical knowledge is particular and serves particular ends:

> Certainly if technical knowledge were available, it would always make it unnecessary to deliberate with oneself about the subject. (Gadamer, 1989, p. 321)

Thus the commonality between the researcher and the researched would suggest that seeking 'technical' knowledge, would be compatible with a Gadermerian perspective of Aristotelian science and would subsequently engage the researcher in a process of reflection, to illuminate the meaning of findings arising from the study. However, the meaning assigned to the findings would reflect to some extent the position of the individual researcher and the status of systematic knowledge in the field of research. In this connection, Lincoln and Denzin (1994) and Sparkes (1995) endorse the authority of the researcher as an authentic representation of voice, given the crisis of representation brought about by the separation of the researcher and the researched.

Difficulties with the notion of a supra 'universal objective reality' led Salomon (1991) to argue that the validity of a conclusion falls only within the parameters of the study, and the "untenability of any notion of absolute truth" led Garratt and Hodkinson (1998) to question the notion of definite criteria for judging qualitative research.

Nevertheless, Foster et al. (1996, p. 55) advocated that sufficient evidence must be provided in order to support the plausibility of claims to knowledge beyond reasonable doubt. Accepting a claim to knowledge would depend also on the "likelihood of error" in the process of data collection and analysis and it follows the credibility and reliability of the

findings. For these reasons, a pilot study was conducted in order to identify sources of error in the proposed methods and a resolution to those conflicts.

3.7 The quality of educational research

Professor David Hargreaves commented in the 1996, Teacher Training Agency (TTA) Annual Lecture (1996, p. 4) that it is the "gap between researchers and practitioners which betrays the fatal flaw in educational research" because the researchers, not the practitioners determine the agenda. Essentially Hargreaves emphasised the desirability of evidence-based research, and in so doing initiated a lively debate concerning judgments about the quality of educational research (Ball, 1997; Hammersley, 1997; Hargreaves, 1997). A critical review of 264 published educational research articles complied by Tooley and Darby (1998) raised questions as to whether the conduct of research was academically rigorous. A review of educational research reported by Hillage, Pearson, Anderson and Tamkin (1998) suggested that dissemination of a substantial body of educational research was too far removed from practitioners and criticised educational research because it failed to draw conclusions that had an impact on teaching practice or policy.

In the present study, particular research tools were developed for data collection and analysis, a practice recommended by the British Educational Research Association (2000). The pilot study refined the methodology so

that the tools and techniques were suitable for the distinctive nature of educational research conducted within the present study.

3.8 Pilot Study

A pilot study was conducted in England, during the months of April –June 1997, in order to test the feasibility and reliability of the research design and to develop strategies to control the likelihood of effects of the researcher on the researched and effects of the researched on the researcher.

3.8.1 Access to participants

The integrity of the design rested on gaining access to valid data. A network of contacts was established. Appropriate strategies to introduce the study and gain access to LEA professionals and parents were developed during this initial phase (Burgess, 1984). Purposeful strategies were identified to build relationships, trust and rapport, before the interview took place, during the interview and post interview (Hitchcock and Hughes, 1989). Strategies to minimise procedural reactivity and personal reactivity were identified, during each phase of communication with participants, by post, telephone and during the face-to-face interview as suggested by Foster et al. (1996). An introductory letter giving details of the purpose of the study, the interview protocol and a pro forma to be returned to the researcher giving informed consent and background information was revised to suit a professional and parent audience (Appendix 9.3 and 9.4).

3.8.2 Documents

A pilot collation of policy documents from one urban and one shire LEA was carried out.

3.8.3 Interview protocol

Unstructured interviews with professionals responsible for Hospital and Home teaching were carried out in one shire and one urban unitary LEA during the design phase (April, 1997) in order to ascertain an appropriate depth of questioning required to yield the data needed for the study. The protocol was standardised during this initial phase and the form of the open-ended questions decided. Interview questions were tied closely to the objectives of the study.

Trial interviews with LEA professionals responsible for Hospital and Home teaching and special educational provision and one parent were conducted in one shire and one urban unitary LEA (June, 1997) in order to test the pace and flow of the interview. Trial interviews were recorded on audiotape and transcribed.

A trial analysis of the interview transcripts showed that the initial protocol required amendment. The initial design used five questions, supplemented by a list of prompts, but the trial interviews showed that participants required little if no prompting to provide information required by the study in all but one specific objective regarding parental involvement (Aim 5).

The use of prompts was rejected and an open-ended question "what part do parents play?" added to the revised protocol (Appendix 9.2).

The conduct of the interview was then revised and tested again with an LEA officer. In order to enable participants to take control of the pace and flow of the interview, participants used a copy of the interview questions as a guide. Interjection of the researcher was to be confined to a check on what was said. The use of prompts or probing questions that may be interpreted as seeking explanations about why participants behaved as they described, were avoided, in order to be considerate of the Code of Ethics underpinning research conducted with humans (Oxford Brookes University, 2000). The pilot study showed that participants were relaxed with the absence of prompts and probes and disclosed information and perceptions of sufficient depth and authenticity to proceed to the main study with the revised protocol.

3.8.4 Trial analysis

A coding scheme was developed to aid interpretation of the data. Codes were identified as type, quantity and quality indicators leading to categorisation of the outcomes, administration and effects of professional administration.

3.9 Chapter summary

This chapter described and justified the research design and the choice of methods employed for data collection, data transformation and analysis. The chapter has raised questions from philosophical and epistemological standpoints about the quality of educational research. These questions will be addressed in chapter four which will report the conduct of the research.

4 CONDUCTING EDUCATIONAL RESEARCH

Following the completion of the pilot study, described and evaluated in chapter three, the main study commenced. The present chapter describes the characteristics of the LEA sample and parents of children who were profiled in the study. The process of data collection, transformation of data, the identification of themes and the tools used during the analysis is described. It was considered important to report how the methodology worked in practice so that other researchers could replicate the methodology, avoiding potential pitfalls as necessary.

4.1 Negotiating access

4.1.1 Phase one: negotiating access to LEAs

English LEAs within a 75-mile radius of Oxford Brookes University were identified to meet the purposeful sampling criteria of urban and shire geographical locations and type of service organisation, in order to support heterogeneity in the sampling of the multi site case study, using a published directory of provision for England and Wales (NAESC, 1997a).

LEA personnel responsible for Hospital and Home teaching were identified from the directory of provision (NAESC, 1997a). Opportunity to take part in the study was provided, by post, to named managers in fifteen English LEAs. A letter of invitation provided information about the study, the

interview questions, request for specific documents, a reply pro forma and stamped addressed envelope (Appendix 9.3).

Nine LEAs responded by post. Two LEAs responded by telephone. A non-response was recorded for four LEAs. LEAs gave three reasons for declining to take part in the study: staff shortages, ongoing policy review and the issue of participation was being discussed within the hierarchy of administration so that the individual LEA manager was unable to take a decision. Seven English LEAs volunteered to participate in the study. Contact by telephone followed all positive responses received from LEAs. The reason given for participation was the agreement to provide a digest of the findings to each LEA.

4.1.1.1 Characteristics of the purposeful sample of English LEAs

Two Shire, two Metropolitan boroughs and three London boroughs (one inner and two outer) volunteered to participate in the study. Information relevant to each LEA specified in the Directory of Provision (NAESC, 1997a, 1999) illuminated different types of service organisation existing between LEAs (Appendix 9.1). Table 4.1 illuminates the degree of heterogeneity in the LEA sample.

Table 4.1 Characteristics of LEA sample

Characteristics of the LEA sample: Data Source: NAESC (1997a)	
A-Shire	No hospital units. LEA tuition service managed from regional centre
B-Shire	Separate Hospital teaching units. Home schools organised Home teaching
C-Unitary	LEA tuition centre based in Pupil Referral Unit (PRU), combined Hospital and Home teaching service
D-Metropolitan	Registered Hospital (special) school with Hospital centres, teaching units and Home teaching
E-London (outer)	LEA tuition service (PRU based), combined Hospital and Home teaching service
F-London (outer)	LEA tuition service, combined Hospital and Home teaching service
G-London (inner)	No Hospital units, LEA tuition service, teachers work from special school base

4.1.1.2 Characteristics of the sample: LEA professionals

Data were collected from 21 professionals between March 1998 – March 1999. The role and exact number (n) of the professionals is given below.

LEA managers who were responsible for Hospital and Home teaching (HT Manager) were interviewed: face-to-face, semi-structured interviews were recorded on audiotape for LEAs A (1), B (1), C (4), D (2), E (1), F (1), G (1). LEA managers who were responsible for the allocation of special educational provision were interviewed because SEN was a subcategory of the population of children out of school because of illness: face-to-face, semi-structured interviews were recorded on audiotape in LEAs B (1), C (1) and G (same as manager for G-LEA home teaching service). A telephone interview was recorded on audiotape in F-LEA (1). The content

of telephone conversations with SEN managers in D and E LEA (2) were recorded as interview notes. LEA professionals and teachers were interviewed: semi-structured telephone interviews were conducted for the purpose of triangulation and were recorded on audiotape or as interview notes (5). All interviews with LEA decision-makers that were recorded on audiotape were transcribed.

4.1.1.3 Characteristics of the sample: LEA policy documents

Four types of documents were collected: Hospital and Home teaching policy and/or documents in LEAs A; D; C; D; F; G; special educational needs policies in LEAs A (contains section for education otherwise), B; C; F; G; learning support policy in LEA-E, and LEA behaviour support plans in LEAs A; B; C; D; E; F; G.

4.1.2 Phase two: negotiating access to parents

Opportunity to take part in the study was provided through a range of strategies (Table 4.2). Three medical support groups published a research request in their newsletter, which was distributed nationally. Hospital and Home teachers, a charity, which donated computers to sick children and professionals from the case study LEAs, passed on a letter of invitation to individual parents. Two mothers introduced their spouse to the study.

Table 4.2 Recruitment route: parents

Recruitment route: parents
Personal contact from LEA manager responsible for Hospital and/or Home teaching (10)
Personal contact from Hospital or Home teacher (9) [3]
Personal contact from two children's charities (1) [4]
Gatekeeper passing on introductory letters to a third party organisation (0)
Readership of research requests placed in carer and professional journals published nationally by Contact a Family (distribution 1000+), Action for Sick Children (distribution 700) and The British Epilepsy Association (distribution 1000+) September 1998 (1) [3]
Personally known to one interviewee (1+ spouse)
Personally known to the researcher [1+ spouse]
Key: (n) parents residing in case LEAs = 23 [n] parents residing in non-case LEAs = 12 Total number of parents = 35

Two hundred and thirty introductory letters were issued to individuals who had contact with parents in case LEAs in September 1998. Letters were passed directly to parents in person or by post and through a third party, but it was not possible to ascertain how many letters actually reached parents or the response rate. A direct approach from a gatekeeper known to the parent proved more successful than any other procedure.

Parents returned the pro forma (Appendix 9.4.1 and 9.5.1) by post or contacted the researcher through a telephone answering service. Each parent then received a standardised letter seeking their informed consent regarding participation in the study and background information needed to ascertain whether the volunteer was a parent of a child who was out of school because of illness (parent selection criteria section 4.1.2.1). Access was negotiated successfully with 35 parents. Two prospective participants

who contacted the researcher did not meet the sample criteria, and did not enter the study.

The mother of Diane responded by telephone and explained that she would provide a written account only, declining to be interviewed because it triggered painful memories, which were emotionally upsetting. Parents' decisions regarding the terms of their participation in the study were respected in accordance with ethical principles governing research with humans.

The motivation of parents for participating in the study was noted to aid an assessment of reliability of the data collected. Reasons given were: as a favour to the LEA manager or personal contact who was held in high esteem by parents; as part of a quality evaluation review of services provided by the LEA; a desire to raise awareness of the need for services for sick children; a desire to obtain information about educational provision at school or otherwise that at school; bereaved parents believed that education for a child with a life limiting condition was important to the child's quality of life.

4.1.2.1 Characteristics of the opportunity sample: parents

Data were collected from 35 parents between November 1998 and March 1999 (Appendix 10.1.3). Twenty-seven mothers and three fathers were interviewed alone, both parents of Lee and Brian were interviewed

together. The mother of Diane provided a written account. Thirty four of 35 parents who participated in the study were interviewed between November 1998 and March 1999 (Appendix 10.1.3). Parents chose face-to-face interviews in their own home (18); the workplace (2); or conducted by a loudspeaker telephone (16) for pragmatic reasons determined by the participant and the researcher. Thirty two parents gave permission for the interview to be recorded on audiotape.

The criterion for the selection of a parent was based on parental self-reported information about a pupil having experience of being out of school because of 'illness'. The definition of 'illness' given in Dorland's Medical Dictionary (1977) as "a condition marked by pronounced deviation from the normal healthy state" was used in the study. All thirty five parents who participated in the study met the selection criteria.

4.1.2.1.1 Pupil profiles and demography

Parents reported information on behalf of pupils, drawing on the number of half day absences noted on school reports.

Table 4.3 shows the medical condition (reported with informed consent) and the pattern of absence, which was categorised according to the eligibility criteria specified for LEA provision in departmental guidance (DfE and DoH, 1994). Raw information reported for each pupil is presented in Appendix 10.1.1.

Table 4.3 Pattern of pupil absence

Alias	Age	LEA ID	Condition reported by parent	Absence pattern Continuous (> 4 weeks) Intermittent (< 4 weeks)	SEN state.mt
Jonathan	10	A	leukaemia	continuous & intermittent	yes
Simon	16	A	medical	continuous & intermittent	no
Steven	15	A	orthopaedic	continuous	no
Debbie	10	A	orthopaedic	continuous & intermittent	no
Dan	7	A	leukaemia	continuous & intermittent	no
Miak	14	B	cranial tumour	continuous	no
Sally	14	B	M.E.	continuous	no
Chloe	14	B	M.E.	continuous	no
David	15	B	cystic fibrosis	intermittent	no
Mark	14	B	cystic fibrosis	intermittent	no
Ben	17	B	cystic fibrosis	intermittent & continuous	no
Louise	16	B	M.E	continuous	no
Gary	13	B	cancer	intermittent & continuous	no
Jack	13	B	chronic asthma	intermittent	no
Mary	14	B	diabetes	intermittent	no
Karen	13	B	disability& asthma	continuous & intermittent	ceased Y6
John	5	C	leukaemia	continuous & intermittent	no
Sue	9	D	missing data	continuous	yes
Richard	20	D	M.E.	continuous	no
Becky	14	E	glandular fever	continuous	no
Novid	14	E	orthopaedic	continuous	no
Paul	14	G	sickle cell anaemia	continuous	no
Alan	6	G	epilepsy	intermittent	yes
Lee	14	G	medical	intermittent & continuous	no
Nicola	7	H	riley-day syndrome	continuous & intermittent	yes
Jill	15	I	M.E.	continuous	ceased Y9
Liam	18	J	psychiatric	intermittent & continuous	no
Diane	17	J	school phobia	continuous & intermittent	no
Gareth	14	K	heart condition	continuous	yes
Michael	13	K	orthopaedic	continuous	no
Nigel	13	L/M	leukaemia	continuous	no
Peter	16	N	leukaemia	continuous	no
Daniel	14	O/P	autistic sp. ADHD	continuous	yes
Brian	14	Q	debilitating migraine	intermittent	no
Max	5	R	leukaemia	continuous	no

All but two families had one child with chronic illness, the exceptions being two families who had two children, each with a chronic illness. Chloe and Louise; Ben and Mark were siblings. All but two pupils experienced a physical or mental impairment, which had a substantial and long-term effect, on the pupil's ability to attend school regularly, lasting more than one year. Two pupils, (Becky and Steven) incurred a single episode of absence, which, at the time of the fieldwork, the prognoses were unknown. Two pupils, Max and John had died shortly before the fieldwork.

The sampling plan was considerate of the accepted standards of research and medical ethics, as it did not require disclosure of a pupil's medical condition although the majority of parents did volunteer this information.

4.1.2.1.2 Pupil placement

The majority of pupils profiled in the study were on the roll of a mainstream school for compulsory schooling. Alan was on the roll of a special school. Two pupils, Daniel and Liam were without a school placement for a substantial period and were educated solely under the auspices of the LEA tuition service for education otherwise. Four pupils had transferred from mainstream schooling to the further education sector.

4.1.2.1.3 Parent resources

The nature of family provision was related to a number of socio-economic factors, indicated by the child's entitlement to free school meals; mother

working outside the home; the type of domiciliary abode; job occupation of the main wage earner of the parent (Appendix 10.1.2). Since Foster et al. (1996, p. 53) suggested that social class categories are "notoriously problematic" because of different classification systems and concepts, further categorisation of the socio-economic status of the parent sample was not attempted.

4.2 Collecting the data

4.2.1 Data collection pro forma

A data collection pro forma was sent by post to professionals and parents before the interview took place in order to collect background information that was important to the study (Appendix 9.3 and 9.5).

4.2.2 Field notes

Background information abstracted from school reports, SEN Statements and observations of the family situation and LEA context were recorded in field notes (Appendix 9.6.3). Some parents provided copies of these documents and corresponded with the researcher in order to provide further background information.

4.2.3 Carrying out the semi-structured interviews

Semi-structured interviews were conducted using interview questions specified in Appendix 9.3.1 and 9.4.1. Interviews were conducted in the

style of the 'listening ear' described by Ribbens (1989, p. 586) in order to check the effect of an imbalance in power between the researcher and the researched on what was said. The technique necessitated participants to talk freely without any pressure exerted using probes in order to simulate as naturalistic approach to data collecting as humanly feasible.

Previous research conducted by Davies (1993) suggested that the very nature of a sensitive topic could present a barrier to communication. Thus, as Hitchcock and Hughes (1989) have emphasised, pre-planning, the development of rapport before the interview and the type and style of social engagement face-to-face was important so that participants disclosed their perceptions. Since Foster et al. (1996) emphasised issues of personal and procedural reactivity biasing the quality of the data collected, strategies that were identified during the pilot study to minimise reactivity are described in sections 4.2.4 and 4.2.5.

4.2.4 Overcoming personal reactivity

The researcher generated a rapport with the participant by post and by telephone before the interview. Forwarding the interview questions to participants in advance of the meeting served more than one purpose. First, it provided opportunities to build trust and rapport with participants, emphasising with LEA professionals that the study fell within the remit of personal research; giving assurance that individuals and LEAs would be anonymous; and gaining informed consent. Second, professionals and

parents needed time to reflect upon their experiences, tune into the research topic, and prepare themselves for the interview, by gathering information from school reports for example. Third, travelling distances up to 75 miles, incurred some traffic delay and telephone calls were made to participants if the researcher was likely to be late.

On arrival at the office or home, the researcher engaged in a preamble discussion with the participants, based on shared experience as a professional or as a parent. The researcher dressed formally, carrying a briefcase when interviewing professionals in an office environment, but a casual style of dress was adopted when interviewing parents in the informal environment of the home and the briefcase was left in the car. Where it was clear to the researcher that the participant occupied a different demographic group, efforts were made to reduce personal reactivity, for example the car was parked a distance away from the parent's home.

4.2.5 Overcoming procedural reactivity

Procedural reactivity (Foster et al., 1996) was avoided by sending a copy of the interview protocol to the participant before the interview was arranged. Where participants requested a telephone interview rather than a face-to-face interview the research responded positively to those requests. The same interview protocol was used and the amplification of sound with a hands free telephone enabled an audio recording to be made. Where the telephone was used, the interview was conducted at a pre-arranged time

that was mutually convenient to the participant and the researcher. The quality of data recorded by means of the telephone and face-to-face interview was evaluated in the light of the critical review of both strategies reported by Frey and Mertens Oishi (1995) and is noted briefly in chapter seven.

All participants were given a copy of the interview protocol and were asked to speak to six open ended questions. The researcher assured participants that the interview protocol they had received in the post was the format for all interviews and the researcher would not stray beyond the questions that had been agreed. Permission was sought to record the interview on audiotape and participants were informed that following the interview the participant would be invited to edit the tape if they so wished.

Participants were invited to 'speak to the questions' using the guide as an aide-memoire. Participants controlled the interview pace and the order of response to questions, speaking freely. Interjection from the researcher was confined to reiteration of what was said to clarify meaning, as appropriate and where rambling occurred, to engage in conversation that was unrelated to the topic guide. Thus, the interview was consistent with both a social engagement and a research interview.

As a control on the authenticity of the account and to avoid introducing systematic bias due to personal pressure, the researcher did not probe in depth for explanations of participant actions or personal beliefs and values

underpinning their motivation. Thus, this differed from the interview technique used by Measor (1985) which placed an emphasis on the use of probes.

The unpredictability of illness for some pupils or other pragmatic factors meant that some interviews were cancelled at short notice. In these situations, a telephone interview was used and the same interview procedure followed and recorded on audiotape using the amplification and hands free facility of the telephone.

4.2.6 Post account authentication

Corroboration of specific information, for example the consistency of the policy implementation and tuition hours received, followed the interview. Accounts elicited within the case LEAs were corroborated for internal consistency of processes and against LEA policy documents. Corroboration was sought from an external source of data specified in the Directory of Provision (NAESC, 1997a, 1999).

4.3 Organising and transforming the data into themes

4.3.1 LEA documents

Documents were scanned electronically and converted into a Microsoft Word2000 document by an optical character recognition program Textbridge®. The find and replace facility of the word processing program was then used to amend the text so that information that could lead to the

identification of the LEA or an individual was removed. LEA web site pages with calendar dates were downloaded, the text amended and stored as indexed files on computer.

4.3.2 Interviews

All interviews conducted with decision-making professionals and parents were transcribed. A team of four assistants in addition to the researcher, worked on transcription. The researcher checked each transcript for accuracy. A sample of two hundred words of text was checked for error and incidence noted between the assistants. As the accuracy of transcription varied, the researcher repeated the transcription process and amended the text as required. Transcripts were returned to the participants, inaccuracies identified and the draft document retuned to the researcher with comments, as necessary.

4.4 Qualitative analysis procedures

Three type of qualitative analysis were employed: 'Framework' analysis (Ritchie and Spencer, 1994); a thematic analysis (Miles and Huberman, 1994) and 'Discourse' analysis (Potter and Wetherell, 1987, 1994).

4.4.1 Framework analysis

The process of 'Framework' analysis consisted of five stages. The stages included: familiarisation which involved listening to audio tapes, reading transcripts and documents and studying observational field notes;

identifying an initial thematic framework; indexing the framework against transcripts and systematically charting the data using Access® (Appendix 9.7); followed by interpreting the data through tracing patterns and associations in order to identify factors and over arching themes. The framework for analysis included a priori issues in the interview guide and emergent issues.

4.4.2 Thematic analysis

Themes were cross-referenced to the framework analyses of outcomes for pupils and professional administration. Descriptive codes were identified as first order constructs relevant to categories regarding decisions about the type, quantity and quality indicators of provision offered, factors responsible and effects of administration. A key word search using a Microsoft Word 2000 'find' procedure and a multiple cut and paste technique using the 'spike' sorted the verbatim text by codes to aid interpretation (Appendix 9.8). The result of each search was saved as a new file and stored in a named category folder. The process of analysis organised the data into folders and effectively transposed categories into themes, organised both as a hierarchy and as free issues. One sample transcript was checked for coder reliability of descriptive categories with a co-researcher working in the corresponding substantive field. At a later stage, the resulting findings were checked also with the same researcher.

4.4.3 Discourse analysis

Analysis focused on linguistic content that was pertinent to the outcomes for pupils and professional administration and linguistic form, in terms of grammar and cohesion. Potter and Wetherell (1994) considered it important to recognise that content and form became the same. Transcripts were analysed to reveal elementary rationalisations and justifications for the reported actions of participants regarding the type, quantity and quality of provision received or offered. Potter and Wetherell (1994) suggested that a qualitative analysis of quantification provided descriptive statistics illuminating variation of linguistic content or form. This element of discourse analysis supported the use of an outcome indicator based on the quantity of visiting teaching time that pupils received, illuminating invisible effects of decision-making.

4.4.4 Quality of the research process

Systematic controls on potential sources of error arising in the conduct of research explicated by Foster et al. (1996) were applied throughout the research process. The likelihood of a systematic trend of errors running throughout the study was controlled by using a replication strategy which included: preparing participants to gather information from primary sources such as school reports; using the standardised protocol and interview guide; avoiding the pressure of prompts; triangulation of primary and secondary sources and corroboration with the research literature. Participants were

contacted by telephone if the data contained gaps in the information that was required to fulfil the aims and objectives of the study. The rigor of the framework analysis supported the interpretive element of a thematic and discourse analysis and served to alert the researcher to haphazard interpretations occurring from unsystematic data retrieval.

4.5 Chapter summary

This chapter has explicated the conduct of the research and raised questions about the reliability and validity of the data collection and the process of analysis, illuminating potential pitfalls to avoid by future researchers working in this field. An evaluation of the methodology, the effectiveness of tools used and confidence in the conclusions that are drawn from the empirical findings is discussed in chapter seven. Chapter five presents the empirical findings of the research.

5 THE IMPACT OF THE DECISION-MAKING PROCESS

The identification of themes arising from the analysis of qualitative data is presented in five sections. In section one, the results of a framework analysis of the arrangements for educational provision received by thirty-five pupils who were out of school because of illness or injury is presented. It is important to know what was provided for each child in order to analyse factors associated with the outcomes. In order to understand the complexities of the decision-making process and its relationship to the outcomes experienced by individual pupils, in sections two to five the process of arranging provision in seven English LEAs is presented.

Section two presents the results of a framework analysis of Hospital and Home teaching policy documents and LEA behaviour support plans in seven case study LEAs A-G in order to identify factors responsible for the provision that pupils received. Professionals' perceptions of their conditions of work and routines of practice inform a thematic analysis of the effects of professional administration which is presented in section three. Taking the results of section two and three together, the implications are discussed in chapter six, section 6.3.1.

Section four presents the results of a thematic analysis illuminating the effects of parental involvement in profession decision-making, in a context where formal participation and parental choice is a missing dimension of

policy. The results of section four taken together with evidence of a limiting factor influencing professional decision-making, informs a discussion concerning the implications of discretion in professional administration, with an understanding of the structural position of the LEA and its relationship to a broader social, political and economic framework, in chapter six, section 6.4.1.

Finally, in section five, the results of thematic analysis of professionals' and parents' perceptions of the decision-making process are presented in order to contribute to policy development in the area of parental involvement, the implications of which will be discussed in chapter six, section 6.5 and 6.6. A summary is provided at each step in the analysis noting the key findings.

5.1 The diversity of arrangements for educating children who are out of school because of illness

This section presents the results of a framework analysis of the provision received by thirty-five pupils who were out of school because of illness or injury. A typology of the type and quantity of provision received and indicative quality of the arrangements existing between the Hospital, Home teaching service, school and home, for each child, is presented. The consistency and inconsistency of patterns in the data is explored in order to discover factors associated with the outcomes for children.

5.1.1 Type of provision

The type of provision arranged was categorised according to the setting for education, access to the curriculum in the home, and who was involved in supporting continuity with the school (DFE and DoH, 1994).

5.1.1.1 Accuracy of the data

A process of triangulation between the primary data source of the parents' and the professionals' perceptions showed substantial consistency regarding the type of provision arranged for pupils residing in the case study LEAs A-G. Telephone interviews with Hospital and Home teachers working in B, C, G, J and K LEA enabled some cross checking of the data. OFSTED reports, issued during the course of the study, for Hospital

schools and Pupil Referral Units (PRUs) pertinent to LEAs C, D and E further supported triangulation.

5.1.1.2 Hospital teaching

Table 5.1 LEA provision: Hospital teaching

Alias	Year group	LEA ID	LEA provision: Hospital teaching (per day)
Jonathan	5	A	session at bedside in isolation cubicle
Simon	12	A	session at bedside or 2 sessions in Hosp. school
Steven	10	A	not applicable -day admission/outpatient
Debbie	6	A	session at bedside
Dan	2	A	session at bedside, and in day clinic
Miak	10	B	session at bedside
Sally	10	B	not applicable - outpatient
Chloe	10	B	not applicable - outpatient
David	10	B	full day in ward school room if able
Mark	10	B	full day in ward school room if able
Ben	12	B	not available - admission to adult ward
Louise	11	B	not applicable - outpatient
Gary	8	B	session at bedside or full day in Hosp. school, if able
Jack	8	B	full day -ward based school room, if able
Mary	9	B	not available - admission to adult ward
Karen	8	B	teacher not available
John	R	C	session on ward when compulsory school age
Sue	5	D	session at bedside or full day in Hosp. school
Richard	adult	D	not applicable -outpatient
Becky	10	E	not applicable -outpatient
Novid	10	E	full day -ward based teaching
Paul	10	G	not applicable, outpatient
Alan	1	G	session at bedside
Lee	10	G	not applicable, outpatient
Nicola	2	H	session at bedside
Jill	10	I	not applicable - outpatient
Liam	12+	J	two sessions, in-patient or hosp. day unit
Diane	12+	J	two sessions, hosp day unit
Gareth	9	K	session at bedside
Michael	8	K	session at bedside
Nigel	8	L/M	full day plus Internet access
Peter	11	N	full day plus e-mail communication
Daniel	9	O/P	not applicable – out-patient
Brian	9	Q	not applicable - out-patient
Max	R	R	one session teaching/ guided play alternate days

Table 5.1 shows that most pupils (87.5%) who were admitted to hospital or received education at a hospital day unit, had access to teaching on the ward, in isolation cubicles or in a schoolroom, whether ambulant or immobile. Three pupils, Mary and Ben, who were admitted to an adult ward and Karen, who was admitted to a hospital where a teacher was not available, received nil provision in hospital. Curriculum delivery by means of information and communications technology (ICT) was available in a specialist paediatric centre attended by Nigel and Peter only.

5.1.1.3 Home teaching

Table 5.2 LEA provision: Home teaching

Alias	Year Group	LEA ID	LEA provision: Home teaching (per week)
Jonathan	5	A	1 teacher, set/marked work, English, maths
Simon	12	A	1 teacher during Y 9 & Y11, 10 then 9 GCSE subjects, computer compact discs, & transport to school in Y11
Steven	10	A	1 teacher, set/marked work, GCSE subjects, tutor delivers work between home/school, then transport to school
Debbie	6	A	1 teacher, set/marked work, English, maths
Dan	2	A	1 teacher, set/marked work, English, maths
Miak	10	B	1 teacher, GCSE English, maths, science, economics, tutor delivers work between home/school
Sally	10	B	2 teachers, set/marked work, GCSE English, maths, science
Chloe	10	B	1 teacher, set/marked work, GCSE English, maths, history
David	10	B	nil
Mark	10	B	nil
Ben	12	B	nil
Louise	11	B	1 teacher, then FE part-time placement, 2 GCSE subjects
Gary	8	B	1 teacher, at home or in school, English, maths, science
Jack	8	B	nil
Mary	9	B	nil
Karen	8	B	1 teacher at home or in school, set/marked work, English, geography, history, French, maths
John	R	C	1 teacher, set/marked work, English
Sue	5	D	nil
Richard	adult	D	nil
Becky	10	E	1 teacher, set/marked work, GCSE English, maths
Novid	10	E	2 teachers, set/marked work, English; geography & maths; transport to school
Paul	10	G	1 teacher, GCSE subjects, tutor delivers work between home/school, 'e-mate' computer
Alan	1	G	nil
Lee	10	G	nil
Nicola	2	H	nil
Jill	10	I	2 teachers, set/marked work, GCSE English, maths
Liam	12+	J	subject teachers visit, then transport to hospital unit – 9 GCSE subjects
Diane	12+	J	transport to hospital unit – set/marked work, 10 GCSE subjects
Gareth	9	K	1 teacher, set/marked work
Michael	8	K	1 teacher, set/marked work
Nigel	8	L/M	5 teachers, set/marked work, focus on English, maths, science

Alias	Year Group	LEA ID	LEA provision: Home teaching (per week)
Peter	11	N	1 teacher, set/marked work, broad curriculum GCSE
Daniel	9	O/P	1 teacher & ICT provider, maths, English
Brian	9	Q	nil
Max	R	R	nil

Table 5.2 shows that approximately two out of three pupils (66%) had access to Home teaching whether ambulant or immobile, at some stage during their episodes of absence. The diversity in the type of provision arranged by the LEA included curriculum delivery by distance /open learning contracted through an independent provider for Daniel. LEAs A, E and J arranged LEA funded transport for Simon, Steven, Novid and Diane who were able to attend school, or a tuition unit part-time. LEA provision arranged for Karen and Gary depended on the location of the pupil and followed the pupil into the school setting. Approximately one in three (34%), of the pupils profiled in the study did not have access to LEA funded teaching in the home.

5.1.1.4 School provision

Table 5.3 School provision

Alias	Year group	LEA ID	School provision
Jonathan	5	A	no involvement, (SEN provision in school only)
Simon	12	A	set/marked work, and part-time attendance Y11
Steven	10	A	set/marked work, resources, then part-time attendance
Debbie	6	A	no involvement
Dan	2	A	part-time attendance
Miak	10	B	set/marked work
Sally	10	B	set/marked work until home tuition arranged
Chloe	10	B	set/marked work, resources, IT access in school
David	10	B	set/marked work
Mark	10	B	set/marked work
Ben	12	B	no involvement
Louise	11	B	no involvement
Gary	8	B	set/marked work, part-time attendance
Jack	8	B	set/marked work
Mary	9	B	set/marked work, form teacher collates work, school friend delivers work between home/school
Karen	8	B	set/marked work, computer compact discs and resources
John	R	C	set work
Sue	5	D	set work
Richard	adult	D	set/marked work, part-time attendance,
Becky	10	E	set/marked work, part-time attendance
Novid	10	E	set/marked work, part-time attendance
Paul	10	G	set/marked work
Alan	1	G	no involvement (child sent home)
Lee	10	G	no involvement (student excluded)
Nicola	2	H	no involvement (SEN provision in school only)
Jill	10	I	no involvement
Liam	12+	J	no involvement then placement EOTAS for Y10-11
Diane	12+	J	1 day/week part-time attendance
Gareth	9	K	no involvement
Michael	8	K	set/marked work, resources
Nigel	8	L/M	set/marked work, e-mail communication
Peter	11	N	set/marked work and e-mail communication for some GCSE work
Daniel	9	O/P	placement EOTAS
Brian	9	Q	no involvement
Max	R	R	set/marked work

Table 5.3 shows that approximately two out of three pupils (63%) had access to homework and curriculum resources in the home provided by the school where the pupil was registered. A minority of pupils had access to part-time attendance at school, when ambulant or with the assistance of a wheelchair, at some stage during the episodes of absence. Three pupils only, residing in L, N and O LEAs, were reported to use e-mail or fax for sending and receiving schoolwork from the education provider.

5.1.1.5 *Family provision*

Table 5.4 Family provision

Alias	Year group	LEA ID	Mother working outside home	Family provision (* denotes charitable donation)
Jonathan	5	A	no	supervision, activities e.g. games
Simon	12	A	no	supervision, books*, computer, software
Steven	10	A	part-time evening	supervision, activities e.g. jig-saw games, computer, parent/peer delivers work between home/school
Debbie	6	A	no, then part-time	supervision
Dan	2	A	no	supervision, learning activities e.g. cooking, weighing ingredients, computer
Miak	10	B	no	supervision
Sally	10	B	part-time then no	some supervision then full supervision
Chloe	10	B	full-time	curriculum delivery RE, some books
David	10	B	no	supervision, visits to library, art gallery, computer, parent delivers work between home/school,
Mark	10	B	no	supervision, pupil collates work before planned absence, then parent delivers work between home/school
Ben	12	B	no	computer*
Louise	11	B	full-time	curriculum delivery RE
Gary	8	B	no then part-time	supervision
Jack	8	B	no	supervision, parent delivers work between home/school
Mary	9	B	part-time	supervision
Karen	8	B	part-time shifts	supervision, computer
John	R	C	no	supervision, learning activities e.g. reading, books, computer, parent delivers work between home/school
Sue	5	D	part-time	supervision and curriculum delivery
Richard	adult	D	no	parent delivers work between home/school
Becky	10	E	full-time	computer
Novid	10	E	no	supervision, 1 hr/ wk private tuition for science
Paul	10	G	no	supervision, parent /sibling delivers work between home/school
Alan	1	G	no then part-time	supervision, reading
Lee	10	G	no	supervision
Nicola	2	H	part-time	supervision, reading

Alias	Year group	LEA ID	Mother working outside home	Family provision (* denotes charitable donation)
Jill	10	I	no	supervision
Liam	12+	J	part-time	supervision when Liam is at home
Diane	12+	J	no	supervision when at Diane is at home
Gareth	9	K	no	supervision
Michael	8	K	no	supervision, computer*, sibling delivers work between home/school,
Nigel	8	L/M	no	supervision, computer*, parent delivers work between home/school
Peter	11	N	no	supervision, computer*
Daniel	9	O/P	no	supervision
Brian	9	Q	full-time	computer
Max	R	R	no	supervision, learning activities, computer* and software , sibling/parent delivers work between home/school

Table 5.5 shows that most parents provided teaching and learning accommodation in the home setting. Most parents supervised schoolwork in the home, with the exception of some parents of teenagers who were employed during the day. More parents of primary than secondary age pupils reported their engagement in tasks to support the child's learning. Parents reported that they purchased, borrowed, or were recipients of charitable donations, which enhanced the family provision of textbooks, a computer and software. Parents of Louise and Chloe, Ben and Mark, Miak, Richard and Steven said that expenditure on provision fell beyond their financial means. Conversely, for Novid, family provision included private tuition.

5.1.1.6 Special educational provision

Special educational provision specified on a Statement was directed to the school placement for Nicola and Jonathan and consequently had very little impact on the provision of Home teaching. Although Nicola's Statement guaranteed the necessary provision that enabled her to attend school, she did not receive LEA provision when absent from school, even though the duration of her absence extended beyond four weeks. For Jonathan, Home teaching, delivered by a qualified teacher, was arranged separately.

Daniel's Statement specified, in part four, 'Education Otherwise than at school' as the placement. Home teaching, together with an information technology package was specified as special educational provision in part three. Delivery by distance/open learning was contracted to a private company. The mother of Jill reported that Home teaching had been specified on the Statement, but the Statement was now ceased.

The findings illustrate that around one in three pupils (38%) who had experience of a Statement received nil provision in the home.

5.1.2 Quantity of LEA funded provision

The quantity of provision was categorised according to the number of hours of visiting teaching each pupil received in the home.

5.1.2.1 Accuracy of the data

Self reported data of parents and professionals showed substantial consistency in the case study LEAs A-G regarding the quantity of teaching that pupils received and the LEA offering, where specified (Table 5.5).

Table 5.5 Triangulation: quantity of provision

LEA	Parent perceptions	LEA perceptions and documents
A-Shire	Hospital -missing data for local hospital	Hours offered not specified
	4 or 5h home tuition	Hours offered not specified
	and/or part time attendance at school	
B-Shire	Full day in hospital schoolroom.	Full day in hospital schoolroom
	5h home tuition, 3h offered to child with ME;	5h home tuition (or less if medical condition was ME)
	and/ or part time attendance at school.	
C-Unitary	0.5h/day at bedside in hospital.	Ward based teaching a.m. Psychiatric provision 15h
	5h home tuition.	5h home tuition
D-Metropolitan	1h/day at bedside or full day in Hospital school.	1h/day at bedside or full day in Hospital school.
	Home tuition-missing data	Unit based teaching, hours not specified
E-London Borough	Full day in hospital school	Full day in hospital
	3h home tuition	3-5h home tuition
	& 3h part time attendance at school or 4.5h home tuition.	
F-London Borough	Hospital – missing data	4 mornings a week on ward, p.m./ discretionary
	Missing interview data. Written corroboration from 5 parents dated 1994/95.	1-5 hours home tuition
G-London Borough	No NHS Hospital	No NHS Hospital
	4.5h home tuition	4.5h home tuition

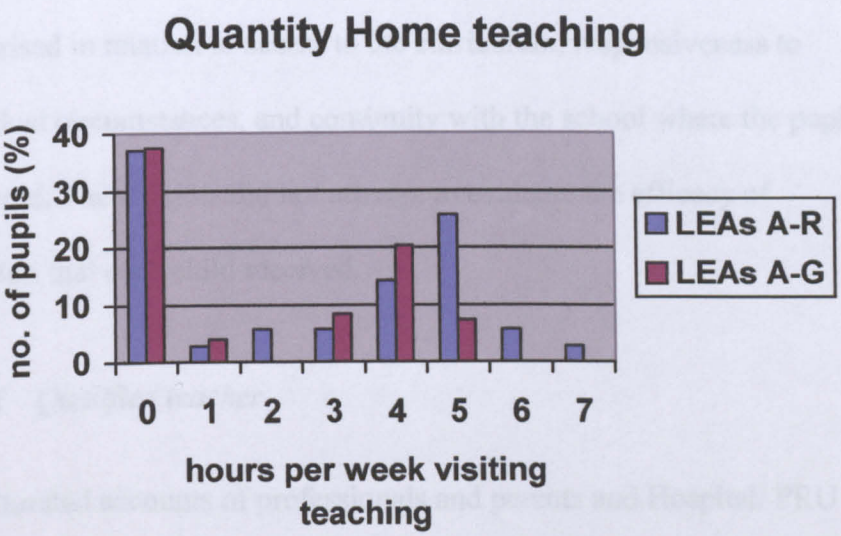
Most parents reported that the quantity of LEA funded provision allocated was fixed, once the arrangements were in place, until the venue for teaching moved.

Table 5.6 Quantity of Home teaching

Alias	Year group	LEA ID	Home teaching (visiting hours).	NAESC (1999)
Jonathan	5	A	5	Not specified
Simon	12	A	5	Not specified
Steven	10	A	4	Not specified
Debbie	6	A	4	Not specified
Dan	2	A	4	Not specified
Miak	10	B	5	5
Sally	10	B	3	Up to 5
Chloe	10	B	5	5
David	10	B	0	5
Mark	10	B	0	5
Ben	12	B	0	5
Louise	11	B	1	5
Gary	8	B	5	5
Jack	8	B	0	5
Mary	9	B	0	5
Karen	8	B	5	5
John	R	C	5	5
Sue	5	D	0	6
Richard	adult	D	0	6
Becky	10	E	4	10 max
Novid	10	E	3	10 max
Paul	10	G	4	4.5
Alan	1	G	0	4.5
Lee	10	G	0	4.5
Nicola	2	H	0	3-4
Jill	10	I	5	per need
Liam	12+	J	6	10
Diane	12+	J	0	10
Gareth	9	K	2	6
Michael	8	K	2	6
Nigel	8	L/M	5	5
Peter	11	N	6	4.5
Daniel	9	O/P	7	5-7 then 5
Brian	9	Q	0	3
Max	R	R	0	5

Table 5.6 shows that the quantity of hours received by some pupils was inconsistent with the maximum 'quota' stated in the directory of provision published by the NAESC for the year 1998 (NAESC, 1999). Thus, if a maximum quota corresponded to a ceiling on resource allocation, the findings of the study suggest that in some LEAs pupils received a notional amount of provision only.

Figure 5.1 Quantity of Home teaching



The quantity of LEA Home teaching fell within a narrow range categorised as nil to seven hours per week. Figure 5.1 shows that the most prevalent category of provision that pupils received was nil hours per week. A clear division existed between pupils who received LEA funded provision and pupils who did not. For pupils reaching the point of recognition of the service, four hours was the most popular allocation in the case study LEAs A-G and fell slightly below the most prevalent 'quota' of five hours received overall in LEAs A-R.

5.1.3 Quality indicators of educational arrangements

The indicative quality of arrangements (outlined in Departmental guidance DfE and DoH, 1994, and as suitable education in primary legislation) was categorised in relation to access to the curriculum, responsiveness to individual circumstances, and continuity with the school where the pupil is registered. The analysis did not attempt to evaluate the efficacy of provision that each child received.

5.1.3.1 Qualified teacher

Corroborated accounts of professionals and parents and Hospital/ PRU OFSTED reports (C, D and E LEA) suggested that a qualified teacher delivered the curriculum in LEAs A-G. Parents' perceptions were not accessed directly in F-LEA, but the LEA provided written client evaluation forms, which pre-dated the fieldwork. All parents perceived that a qualified teacher delivered the curriculum. However LEA offerings (5.3.3) included learning support assistants also and so, further triangulation was conducted with Hospital and Home teachers in LEAs B, C, G, J and K, who corroborated the accuracy of parents' perceptions.

Each of the pupils at Key Stages one and two, were taught by one teacher. Most pupils at Key Stages three and four were taught by one teacher in LEAs A, B, C and G, but a minority were taught by two or more subject teachers, in LEAs E and J. Most parents were complementary about the

professional practice of the Home teacher and perceived that a session of individual tuition, lasting between one and two hours was an intensive teaching and learning experience.

5.1.3.2 Breadth of curriculum access

Table 5.2 suggested that most parents perceived that curriculum delivery focused on a core curriculum consisting of English and Maths. Parents of Chloe, Novid, Becky and Peter raised concern that elements of GCSE coursework were missed during prolonged absence.

5.1.3.3 School homework

The quality of homework enhanced or constrained the effectiveness of school provision:

> **Some of the homework that did come, some of it was photocopied and wasn't clear. We couldn't read it. Some of it was obviously things that were done in the lesson and she had missed and she obviously couldn't do it. Which was very frustrating for all of us. Very frustrating. And her art tutor sent her some course work which she didn't understand. And I actually had to phone and try to get her to explain it. She very kindly offered to come to the house to explain it to Becky.**
> (Mother of Becky, fourteen year old girl with glandular fever, E-London LEA)

5.1.3.4 Responsiveness to the immobility or ambulance of the pupil

Most parents perceived that as the pupil's state of immobility changed, either by using a wheelchair, or progressive ambulance, the pupil moved from one educational setting to another. Where feasible, pupils moved from an isolation cubicle or bedside teaching to group teaching in hospital. LEA

provision followed the transition of the pupil from the hospital to the home and for a minority of pupils, to the school.

For those pupils who received LEA funded provision in the community, the data suggested that arrangements for provision were flexible and responsive to the changing circumstances of the pupil. For example, following discharge from hospital, Simon received five tuition hours in the home for a substantial period, followed by Home teaching and part-time attendance at school, culminating finally in full time attendance at school and LEA provision withdrawn. For Gary and Karen LEA provision followed the transition of the pupil from the home into the school:

> He was out of school so much and the home tuition wasn't working so I basically called a meeting and said well look, we've got to start targeting lessons, he's missing out a heck of a lot here and it's just not good enough basically. So what we did was target the maths English and sciences and he went into school for those lessons. But he had the home tuition tutor there with him like. (Mother of Gary, thirteen year old boy with cancer, B-Shire LEA)

Flexibility in the system enabled part-time attendance at school for seven of the pupils profiled in the study. However, a minority of parents perceived some inflexibility on the part of schools, in response to concerns for the safety of the pupil. Steven and Liam received home tuition even though they were ambulant, or progressed to being ambulant during their absence from mainstream school.

5.1.3.5 Delivery to individuals or a group

The venue of the Hospital school or a tuition centre was amenable to curriculum delivery to pupils as a group. A teaching service existed in hospitals located in B, C, D, E, and F LEAs. Educational provision was organised for groups of pupils for mornings or a full day, either on the hospital ward or in a schoolroom. If group tuition was not arranged on the ward or in a schoolroom, then individual tuition at the bedside, where it occurred, was time limited. Children in hospital who were taught as a group had access to more schooling hours than children who were taught individually.

In the home, the situation was different. Isolated pupils required provision. Pupils who were transported to a group setting had access to more tuition time than pupils who were taught individually in the home.

5.1.3.6 Linking provision: Family, LEA and school provision

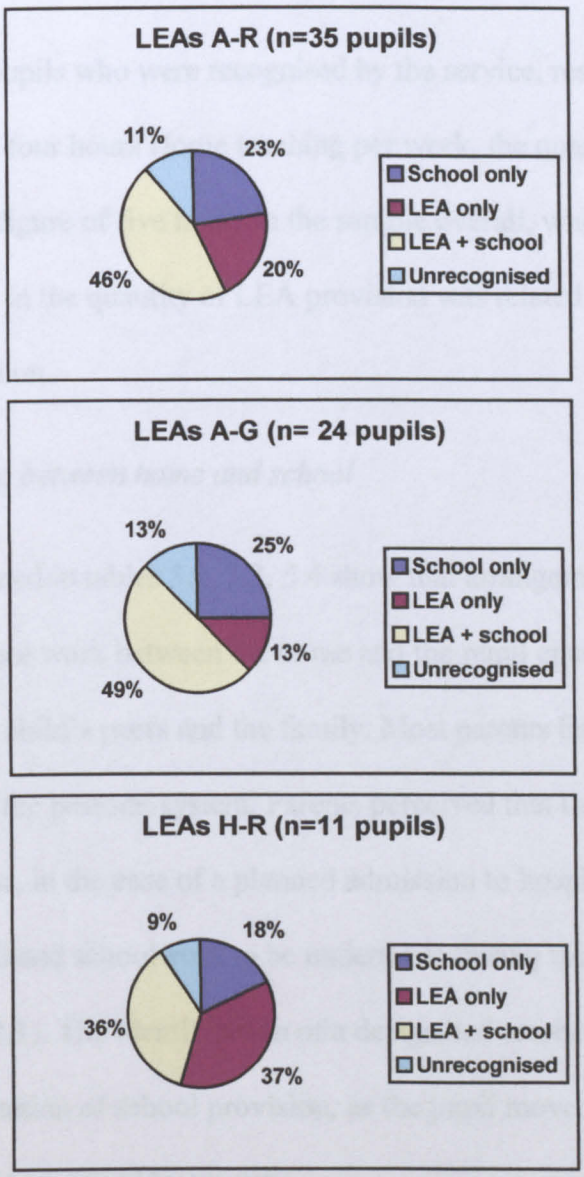


Figure 5.2 Linking provision between family, LEA and school

Fig 5.2 shows that most pupils maintained some contact with the school, but some pupils were isolated, receiving Home teaching as segregated provision, or remaining unrecognised by the LEA or the school. The school

was more prominent in the arrangements for children in the volunteer LEAs A-G than for children residing in non-volunteer LEAs H-R.

Whereas most pupils who were recognised by the service, residing in LEAs (A-G), received four hours Home teaching per week, the quantity was less than the modal figure of five hours in the sample overall, which implied that a reduction in the quantity of LEA provision was related to an increase in school provision.

5.1.3.7 Liasing between home and school

Findings presented in tables 5.2, 5.3, 5.4 show that arrangements for delivery of school work between the home and the pupil encompassed the home tutor, the child's peers and the family. Most parents liaised with school through the pastoral system. Parents perceived that the form teacher, the year head, or, in the case of a planned admission to hospital, the pupil themselves, collated schoolwork to be undertaken during the absence (Appendix 10.2.1). The identification of a designated teacher, responsible for the co-ordination of school provision, as the pupil moved through the school was an issue raised by parents:

> **When he went into the next year group, because its the upper school they changed year heads. Urmm and form tutors. And, nothing was arranged in year ten. I phoned up, about halfway through year ten and sort of expressed my concern. Because he was now doing his GCSEs. He was still having a lot of time off school. And I was basically told nothing could be done for him. ..... At the beginning of year 11, urmm I telephoned the education department, who told me to get in touch with the LEA tuition manager urmm. (Mother of Simon, sixteen year old boy with a medical condition, A-Shire LEA)**

> There is one lady with whom I had to discuss the options for GCSEs. I actually had to say to her, "can I contact you if there is a problem?" And they are not very keen to say, "yes I'm the one", you've got to tell them that you have a problem,..... and it is tying that person down, that they are going to be the one who you contact if there is a problem. (Mother of David, fifteen year old boy with cystic fibrosis, B-Shire LEA)

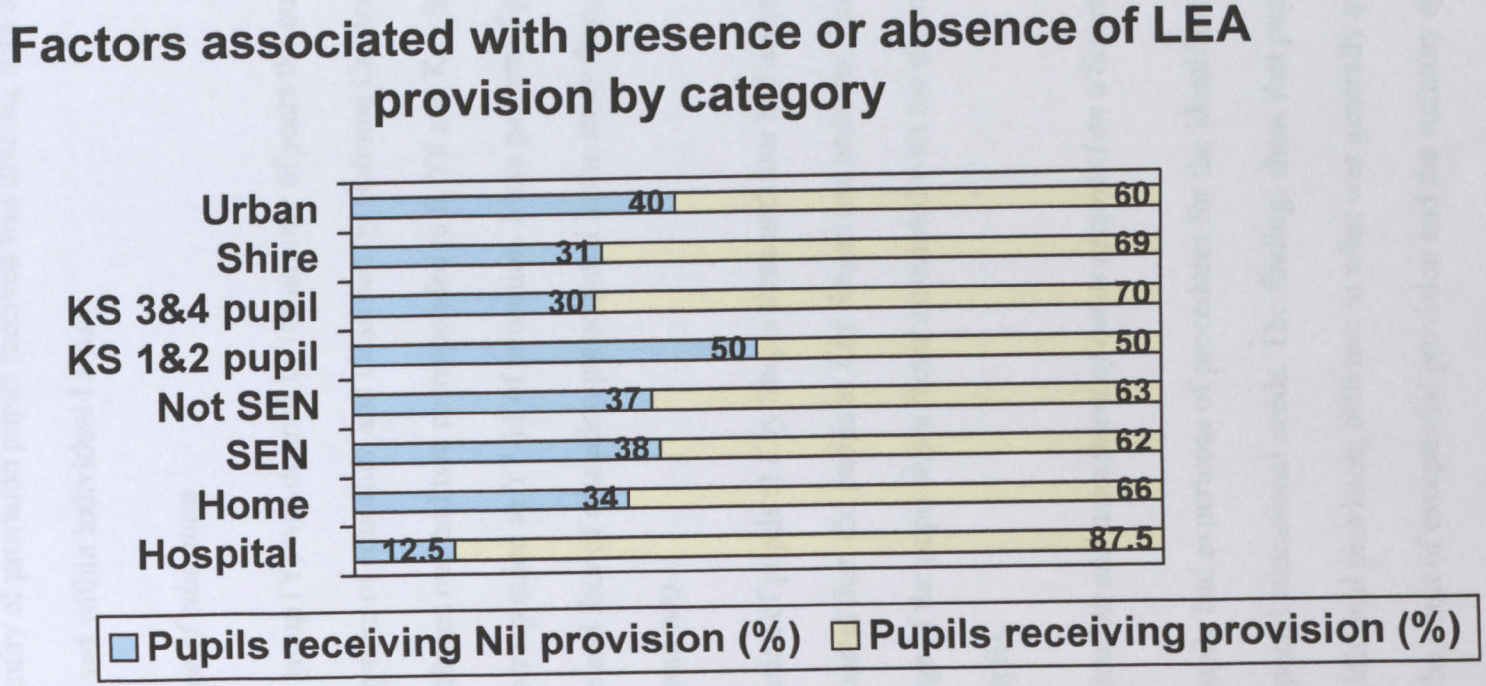
Professionals from different agencies supported parents in gaining access to a gatekeeper of the referral procedure (Appendix 10.2.1).

5.1.4 Factors associated with diversity

Figure 5.3 shows categorical factors compared in terms of whether pupils received provision or not.

Key to Figure 5.3 Category	**Total pupils per category (n=35)**
Urban metropolitan LEA	10 LEAs 15 pupils
Shire county LEA	6 LEAs 22 pupils
Key stage 3 & 4	27
Key stage 1 & 2	8
No SEN Statement	27
SEN Statement	8
Home setting	35
Hospital setting	24

Figure 5.3 Factors associated with the presence or absence of LEA provision by category



5.1.4.1 Urban/ metropolitan and shire/county LEAs

No clear pattern emerged between LEAs categorised as urban or shire county. The type and quantity of provision pupils received was diverse, between individual LEAs and within individual LEAs.

5.1.4.2 Key stage of education

The pupils' year group (Y) was defined by the number of years the pupil was in the statutory system of education and classified by National Curriculum Key Stage. Key Stages one and two corresponded to R-Y6 and Key Stages three and four corresponded to Y7-11 of education. More parents of pupils at Key Stages three and four of education participated in the study than pupils at Key Stages one and two.

A greater proportion of pupils at Key Stages three and four had access to teaching in the home, than did pupils at Key Stages one and two. The findings suggested that age of the pupil was a factor associated with the diversity of outcomes for pupils.

5.1.4.3 Identification and assessment of needs recorded on a Statement

A minority of pupils had experience of procedures for the identification and assessment of special educational needs. The findings show that pupils were identified for additional provision, different to what was generally available in school, within the remit of exceptional provision and the statutory system of

education. Thus, the administration of SEN provision was a minor factor in diversity of provision.

5.1.4.4 The setting for education

The difference in provision available in hospital compared with the home emerged as a major factor in diversity. The provision that children received depended on what was available.

5.1.4.5 Parental pressure

The accounts of parents illuminated a balance of parents' self- perceptions of their perseverance or passivity in their actions, undertaken to gain provision of homework from the school and a subsequent referral to the LEA (Appendix 10.2.2). An indicative judgment about the amount of parental pressure exerted by the family was made based on the presence or absence of indicators such as telephone calls, visiting school to make an enquiry about provision, or calling a meeting with professionals. Parental persistence seemed to be a consistent factor in the route to LEA provision, but Table 5.7 below, shows that the effect was ad-hoc, as some pupils gained access to provision, while others did not.

5.1.4.6 The pattern of absence

Pupils experienced intermittent periods of absence of less that four weeks, or prolonged continuous absence in excess of four weeks or both (Table 4.3). Pupils with episodes of absence of less than four weeks were less likely to meet the threshold criteria (DfE and DoH, 1994), even though an intermittent

pattern of absence existed which extended beyond one year. Thus, a stop/go pattern of absence was a factor in diversity.

5.1.5 Section one summary: outcomes

The findings show that pupils received a diversity of provision.

5.1.5.1 Type

Parents reported that pupils received different types of provision depending on whether the arrangements included Hospital, Home teaching, outreach from the school, family provision or special educational provision, as a discrete entity or in combination.

5.1.5.2 Quantity

The quantity of LEA funded provision fell within a narrow range of 0-7 hours Home teaching. Most pupils received nil provision, but for pupils recognised by the service, five hours visiting teacher provision allocated in the home was the most prevalent allocation.

5.1.5.3 Quality indicators of arrangements

In the absence of a qualified visiting teacher, accessibility of curriculum materials used for home study under the supervision of parents was an indicator of quality.

A qualified teacher delivered a narrow curriculum to pupils who were recognised by the service. Delivery to individuals changed to group teaching in accordance with the pupil's ambulance or immobility.

Diversity existed in the balance between the different types of provision that pupils received and the degree of curriculum linkage with the school.

5.1.5.4 Unmet needs

The diversity of outcomes included some unmet needs of pupils. Unmet needs were likely to exist where the quantity of provision allocated fell below the quota specified in the DfEE commissioned research (NAESC, 1999). Although most children had access to teaching in hospital, more pupils were at risk of failing to receive provision in the home.

5.1.5.5 Diversity related to where the child lived

5.1.5.5.1 Type

Pupils residing in most LEAs had access to teaching in Hospital, but Home teaching was patchier.

5.1.5.5.2 Quantity

For pupils recognised by the service the narrow range in hours of Home teaching received by pupils was consistent across the LEAs and less dependent on where the child lived. For pupils residing in LEAs A-G four hours home tuition was the most popular allocation, in contrast to five hours across LEAs A-R.

5.1.5.5.3 Quality indicator of arrangements

Most pupils were taught by a qualified teacher for the entire provision, but more than one subject teacher delivered the curriculum in LEAs E and J. The

existence of provision as a discrete entity or as a combination of different types depended on where the pupil lived.

5.1.5.5.4 Ad-hoc elements in the data

Pupils' experience of curriculum delivery by means of information and communications technology depended on the chance occurrence of suitable equipment and transmission cables in the hospital, or in the home. SEN provision of education otherwise than at school and the flexibility or inflexibility of schools to facilitate part-time attendance of pupils, were ad-hoc elements in the data.

5.1.5.6 Consistency of pragmatic factors

5.1.5.6.1 Type

The location of the pupil and the particular setting for education, whether in hospital or in the home, was the biggest factor in type of provision.

5.1.5.6.2 Quantity

Since many pupils received nil Home teaching, the biggest factor in quantity was the pupil gaining recognition by the LEA service. Parental pressure was a factor in the route to provision.

5.1.5.6.3 Quality indicator of arrangements

The presence or absence of a qualified teacher and pupil/teacher ratio were major factors in the quality of service. Arrangements that linked the LEA, the pupil's school and parents were a factor in the quality of service.

The next section will examine factors responsible for the diversity in provision that pupils received, residing within the professional administration in LEAs A-G, that have led to the outcomes for pupils summarised in Table 5.7.

5.1.5.6.4 Route to educational provision and outcomes for pupils

Table 5.7 Route to provision

Alias	**Route to provision** **(P) = parental pressure**	**Waiting time** **for LEA provision**	**Outcome for the pupil** **HT = Home visiting teaching (per week), p/t = part time**
Jonathan	hospital	<4	5 hrs HT
Simon	school pastoral staff & (P)	>4 then <4	5 hrs HT & schoolwork
Steven	school pastoral staff & (P)	<4	4 hrs HT & schoolwork
Debbie	complex then (P)	>4 then <4	4 hrs HT
Dan	hosp	<4	4 hrs HT or mornings in school
Miak	hosp	<4	4.5 hrs HT & schoolwork
Sally	school pastoral staff & (P)	>4 then >4	3hrs HT
Chloe	complex & (P)	<4	5 hrs & school for IT lesson
David	school pastoral staff	>4	schoolwork
Mark	school pastoral staff	>4	schoolwork
Ben	school pastoral staff	>4	nil provision
Louise	parent organised & (P)	>4	1 hr HT then FE placement
Gary	complex & (P)	<4	5 hrs HT in school or home
Jack	school pastoral	>4	schoolwork
Mary	school pastoral staff	>4	schoolwork
Karen	social W, Dr, & (P)	>4	5 hrs in school or home
John	hosp & (P)	<4	5 hrs HT & schoolwork
Sue	parent provision	>4	schoolwork & parent delivery
Richard	school pastoral staff	>4	school p/t then nil
Becky	(P)	>4	4hrs HT & 1 morning in school
Novid	hosp & (P)	<4	3 hrs HT & 3 hrs/wk in school
Paul	complex &(P)	>4	4 hrs HT & schoolwork
Alan	LEA & (P)	>4	nil provision
Lee	school pastoral staff & (P)	>4	nil provision
Nicola	school pastoral staff	>4	nil provision
Jill	LEA & (P)	<4	5 hrs HT
Liam	hosp &(P)	>4	6 hrs HT then 10 hrs in day unit
Diane	hosp	>4	8 hrs in day unit & 1day in school
Gareth	complex & (P)	>4	2 hrs HT
Michael	complex & (P)	>4	2 hrs HT & schoolwork
Nigel	hosp	<4	5 then 3 hrs HT & schoolwork
Peter	hosp	<4	6hrs HT & schoolwork
Daniel	LEA & (P)	>4	5hrs HT & ICT SEN provision
Brian	school	>4	nil provision
Max	school	>4	schoolwork & parent delivery

This section presented the results of a framework analysis of the provision received by thirty-five pupils who were out of school because of illness or injury. A consistency of pragmatic factors were related to the outcomes. The route to LEA funded provision, the process of arranging provision in the seven English LEAs and the influence of parents in the decision-making process is explored in chapter five, sections two, three and four.

5.2 Factors responsible for the type, quantity and quality of provision that pupils received

This section identifies the administrative factors responsible for the type, quantity and indicative quality of provision that pupils received in LEAs A-G.

5.2.1 The Hospital and Home teaching service in the broader context of LEA policy

At the time of the fieldwork (March 1998-1999), educational provision for children out of school because of illness was administered by LEA departments pertinent to pupil services or support (C-Unitary, E-London and F-London) or special educational needs (A-Shire, B-Shire, D-Metropolitan and G-London). Co-terminocity of 'education otherwise' was described by one LEA manager:

> We're all part of the SEN team and we now use the same headed notepaper. I say we are dealing with the same 'education otherwise' under the SEN team and the illness and disability team. (A-Shire LEA HT Manager)

LEA support services were subject to review during the course of the fieldwork, in order to meet the requirements of departmental guidance regarding 'Behaviour Support Plans' (DfEE, 1998b). Examination of the behaviour support plans published in 1998/1999, for LEAs A-G, showed that the administration of support services was in a state of flux.

Children residing in A, E and G LEAs, were codified as 'vulnerable' in the behaviour support plan which encompassed exceptional and special educational provision. Thus an umbrella framework of administration was emerging in LEAs A, E and G for the population of 'vulnerable' children:

> The document [SEN policy] has been devised in tandem with the council's plan to support and improve pupil behaviour [behaviour support plan]. The two plans are congruent. (SEN policy document Oct 1998: G-London LEA)

5.2.2 Funding the service

The LEA retained funding for the Hospital and Home teaching service in six of the seven LEAs. The service in C-LEA was managed by the PRU which, the OFSTED inspection report shows, was funded for 25 pupils with an allocation of five hours Home teaching per week. D-LEA was unusual in that funds were fully delegated through LMS to the registered Hospital special school, which had a governing body. The budget was delegated based on the age weighted pupil unit, calculated for a school roll of 492 full-time equivalent students. In practice the school OFSTED report revealed that the school provided services for 3000 part-time pupils during one year, from an income £3.6 million, with the number of full-time equivalent pupils on roll ranging between 400-600 at any one time.

Access to financial data in the broader context of LEA services was obtained in LEAs A and G, by means of LEA inspection reports and LEA documents. The budget for the education of sick children was specified in the policy or documents relevant to special educational needs in A-Shire

LEA and G-London LEA. Behaviour support planning documentation provided indicative financial data also in LEAs A-G. However, a clear basis for comparison could not be established between the different LEA systems used for budget allocation. Thus, financial data was susceptible to obfuscation and lacked transparency in all but one of the case LEAs that retained the service centrally.

A detailed breakdown of how the SEN budget was split was obtained in G-London LEA (Appendix 10.2.6). LEA OFSTED inspection data revealed that the proportion of the general school budget allocated for special educational needs was high for G-London LEA. The total budget for SEN, in 1997/98 was £19.3 million. This included some items, which were "not exclusively SEN, e.g. the Pupil Referral unit and home tuition". The Hospital and Home teaching budget was set at £86,290 and represented 0.4% of the total SEN budget.

5.2.3 Hospital and Home teaching policies

Documents specifically relevant to Hospital and Home teaching were scrutinised. Founding principles were explicated in A, C and D LEA documents only (Appendix 10.2.5). The mainstay of written policy emphasised operational procedures in LEAs A-G. The policy documents illuminated the pragmatic nature of professional decision-making.

5.2.3.1 Goal specification

A computer key word search informed by salient themes pertinent to the primary legislation and Departmental guidance was conducted on LEA Hospital and Home teaching policy documents in order to identify organisation goals (Table 5.8).

Table 5.8 Aims of LEA policy

Aim (key word search)	A -LEA	B-LEA	C-LEA	D-LEA	E-LEA	F-LEA	G-LEA
Aim [Heading]	✓	miss	✓	✓	miss	miss	miss
Aim [in text]	✓	miss	✓	✓	✓	✓	✓
Education Act 1993/1996 s. 19	✓	✓	✓	miss	miss	miss	✓
DFE 12/94	✓	✓	✓	miss	miss	miss	✓
Continuity	✓	✓	✓	✓	✓	✓	miss
Liaise	✓	miss	✓	miss	✓	✓	✓
Link [LEA/family /home school]	✓	✓	✓	miss	miss	miss	miss
Home school	✓	✓	✓	miss	✓	✓	✓
Progress	✓	miss	✓	miss	✓	miss	✓
Cost	✓	miss	miss	miss	miss	miss	miss
Effective	✓	✓	✓	✓	✓	miss	✓
Efficient	miss	✓	miss	miss	miss	miss	✓

The analysis demonstrated that specification of the 'aims' of LEA policy were evident as clear headings in the documents of LEAs A, C and D. 'Aims' were specified also within the text of the documents of LEAs A, C, D, E and G.

Policy goals were explicated by reference to the Education Act 1996 s. 19 and circular 12/94 (DfE and DoH 1994) in the documents of LEAs A, B, C and G.

The aim of continuity specified in departmental guidance (DfE and DoH, 1994) received explication in the text in all case study LEAs with the exception of G-LEA. Similarly the contribution of the home school received explication in all but one LEA, i.e. D-LEA. However the notion of a link between stakeholders was evident in LEAs A, B and C only. The academic progress of pupils received explication in the documents of LEAs A, C, E and G. This raised questions about the purpose of links between the LEA, the family and the home school, particularly in LEAs B, D and F. While all LEAs specified an implicit aim of arranging effective provision, with the exception of F-LEA, the documents of LEA A, B and G made explicit the issue of cost or the efficiency of arrangements. OFSTED inspection report of D-LEA Network Hospital School corroborated the efficient management of resources and the use of cost effective provision.

The findings suggested that organisation centred goals concerned with efficiency and cost were in conflict with child centred goals specified in the primary legislation and departmental guidance. The dilemma of child centred goals conflicting with organisation centred goals was illuminated in B-LEA policy. Simply put, open-ended entitlement to suitable education

for individual pupils on the one hand was at odds with efficiency of educational expenditure:

> Clearly there cannot be an unconditional agreement to fund any plan whatever its demands, but reasonable proposals will be met wherever possible. (B-Shire LEA HT policy document)

5.2.3.2 Role specification

Specification of roles and responsibilities pertinent to the LEA, the home school and the parent received explication in LEA policies to varying degrees. The role of an educational key worker or nominated teacher was specified in LEA A, B and G policies and a named nurse in C-LEA policy. E-LEA policy specified a named person as a parent partnership officer in relation to Statementing procedures. A computer key word search revealed that although written documentation referred to parents, only LEAs E and G explicated the notion of 'partnership' with parents, whereas the notion of building a positive 'relationship' with parents was noted by LEAs C; D; E and G.

5.2.3.3 Accountability

Systems of accountability to OFSTED, operated at LEA level in LEAs A, B, F, and G and at school level in LEAs D, C and E. During the course of the field work (March 1998-1999) LEAs A and G were inspected and the substantial lack of accountability of the service in A-Shire LEA was noted. The findings suggested that LEA professionals had substantial autonomy with low levels of accountability in LEAs A, B, F and G:

> We have a stated policy which we don't keep to really. (A-Shire LEA HT Manager)

LEAs C, D and E were subjected to school inspection during the course of the study. OFSTED inspection operating at school level promoted substantial accountability of service managers to a professional reference group or governing body.

Systems of accountability operating through client evaluation received minor explication in A-Shire and E-London LEA policy documents only. One policy document, E-London LEA policy, published in August 1999, noted the role of OFSTED school inspection in monitoring the effectiveness of provision organized by the home school.

5.2.4 Procedures

Administrative procedures were classified according to LEA eligibility criteria, accepted referral route, verification of the need for teaching, agency involvement and curriculum assessment for arrangements (Table 5.9).

Table 5.9 LEA procedures

LEA	Eligibility: Criteria for LEA funded provision	Recognition: Accepted referral route	Verification	Agency involvement	Assessment for teaching and arrangements for provision
A	Absence from school because of illness normally four weeks. Where child progresses to partial school, tuition to be reduced accordingly	Home school, Hospital teacher, or occasionally doctor.	Advice and corroboration requested from community paediatrician if necessary	Home visit by community paediatrician if requested by LEA.	Visit to home. Provision to support curriculum access appropriate to health needs and co-ordinated with home school arranged at the discretion of education manager in accordance with benefits from good practice outlined in the SEN Code of Practice. Individual education plan (IEP) recommended. Review: after four weeks.
B	Continuous absence from school because of illness, likely to be at least four weeks.	Home School, Education Welfare Officer (EWO), Hospital teacher.	Written corroboration of illness by school doctor	Home visit by school doctor if requested by LEA. Medical need reviewed if necessary.	Home school agrees education plan for curriculum access with LEA and organises provision, within quota of 5 hours/ week. (ME cases: allocation as per medical need.) Review: half term for education plan.
C	Absence from	Hospital teacher,	Written corroboration	Home visit by EWO if	Visit to home. Curriculum

LEA	Eligibility: Criteria for LEA funded provision	Recognition: Accepted referral route	Verification	Agency involvement	Assessment for teaching and arrangements for provision
	school of because of illness, normally six weeks.	Home School, EWO	from Hospital consultant who fills in pro forma estimating duration of absence.	authenticity of illness is in doubt.	access negotiated with pupil. Tuition time allocated, taking medical condition into account within quota of 5 hours. Individual education plan recommended. Review: half term.
D	Absence from school normally four weeks.	Home school, Hospital doctors, Consultant General Practitioner (G.P), Education Social Worker (ESW), Educational and clinical psychologists, Assistant Education Officer, Parents of pregnant school girls.	No evidence that written corroboration by doctor was necessary.	No evidence of planned visit to home.	School admission procedure following referral. Type and extent of provision allocated at the discretion of the referral team co-ordinator and teaching team. IEP reviewed weekly if psychiatric hospitalisation. Review: unplanned, ad-hoc.
E	Absence from school of because of illness. Successful referral triggers access to tuition unit.	EWO only, directed to LEA Curriculum Access Adviser then to Tuition Unit Manager for resource decision.	Written corroboration of illness by doctor	Home visit by education social worker to see if appropriate support is in place.	Home visit usually by tuition manager. Curriculum access negotiated with pupil. Tuition time allocated taking medical condition into account within quota of 3-5 hours. IEP

LEA	Eligibility: Criteria for LEA funded provision	Recognition: Accepted referral route	Verification	Agency involvement	Assessment for teaching and arrangements for provision
					recommended. Review: unplanned, ad hoc.
F	Absence from school of because of illness. Teacher provided as soon as possible following absence of two weeks.	Hospital teacher, ESW, Home school, Parent	Written corroboration sought only if LEA manager doubts authenticity of illness or parent refers case, or after one month teaching.	Home visit by education officer if authenticity of illness is in doubt and a medical certificate requested.	Home visit by teacher, Curriculum access "tailored to meet individual needs". Tuition time allocated within range of 1-5 hours. IEP optional. Review: not specified in policy but tuition reviewed after 6 months.
G	Absence from school of because of illness. Four week absence specified.	Home school, EWO, Hospital teacher, case referred on to panel for resource decision.	Written corroboration of illness by Consultant.	Home visit by EWO if authenticity of illness in doubt.	Home visit by teacher, narrowed curriculum needs negotiated with pupil and parent/carer and tuition time allocated within range of standard 4.5 hours. IEP. recommended. Review: half term.

5.2.4.1 Gaining recognition

The findings presented in section 5.1.2 showed that the dominant category regarding the quantity of provision that pupils received was nil hours Home

visiting teaching per week. The analysis presented in this section 5.2.4 demonstrated that pupils in need of teaching in the home reached the point of recognition by means of a referral from a designated source.

5.2.4.2 Eligibility criteria

A qualifying period of two weeks (F-LEA), four weeks LEAs A, B, D, G to six weeks (C-LEA) was specified as a threshold before provision could be accessed. E-LEA did not specify eligibility criteria on grounds of absence.

5.2.4.3 Referral

Six of the seven case LEAs accepted referrals from the home school. The role of the home school in facilitating access to the system was explicated in A and B LEA policy:

> **The School Management should have a clearly stated policy and procedure available for all parents (perhaps as part of a handbook or prospectus including the name and telephone number of a nominated teacher). (A-Shire LEA HT policy document)**

One LEA restricted referrals to the education social service only. Education social services were potentially involved in the identification and referral procedures in six LEAs. LEA managers accepted referrals from Hospital teachers without the need for additional corroboration. LEAs accepted referrals directly from parents in LEA F and D only.

5.2.4.4 Verification

Written corroboration of a medical condition was required in LEA B, C, E and G and was discretionary in A, D and F LEAs. Home visits by doctors were requested at the discretion of the LEA manager in A and B LEAs only:

> If the doctors are not willing to write and say something like this child is not able to go to school, there are degrees of illness and obviously they have to be investigated before I agree. (F-London LEA HT Manager)

Medical opinion was sought to ascertain the capability of the pupil to attend school. Medical opinion was sought for Karen, Sally and Chloe, where the medical condition was M.E. in order to establish the quantity of teaching time allocated in B-Shire LEA only.

5.2.4.5 Assessment

The assessment process was forked. The curriculum assessment for teaching was separate from the decision regarding the allocation of a quantity of visiting tuition time.

5.2.4.5.1 Curriculum assessment for teaching

Following the successful referral to the LEA service, educational professionals in all seven LEAs assessed pupils needs for teaching to inform decision-making about what areas of the curriculum would be delivered by individual tuition and how the teaching was to be organised. LEA managers and most parents in the study reported that pupils discussed

with the teacher what the pupil would be doing if she/he were at the home school and any preference for prioritising specific areas of the curriculum, to be delivered by the visiting teacher:

> Yes it was really about asking Simon what he had been doing in maths. (Mother of Simon, sixteen year old boy with significant medical condition, A-Shire LEA)

The professional and parent accounts suggested that informal assessment of the pupil's curriculum needs identified a programme of work which went beyond the curriculum that was delivered in the teaching time allocated. Parents were consulted in order to organise the home environment appropriately for Home teaching and to enlist support in the supervision of homework:

> However it must be made clear to all pupils and their parents/carers that they will be provided with a narrowed curriculum. The home tutor makes a preliminary home visit where tuition times and curriculum needs are negotiated and agreed with the pupil and parents/carers. Home tuition can only be delivered if the tutor works in partnership with parents/carers. The home tutor has expertise in this area and the skills to develop positive relationships with parents/carers in order for the pupil to work well and make progress. Ground rules are established relating to the pupil's readiness for tuition and work to be completed between home visits. (G-London LEA HT policy document)

5.2.4.5.2 Allocating provision

A quota system governed LEA resource allocation, which was quantified as time, in B, C, E, F and G LEAs. Where a quota was not explicated in the A and D LEA account, the accounts of parents residing in A-Shire LEA suggested that a quota system was in operation. The resource unit was time. The identity of the educational provision and quantity of tuition time

allocated was determined and arranged at the discretion of the tuition manager in LEAs A-G:

> Once it has been agreed that home tuition is to be provided, the pupil is allocated to the home tutor. A pupil eligible for home tuition is offered 4.5 hours a week. These hours can be varied in certain circumstances, for example if a pupil is following a public examination course. (G-London LEA HT policy document)

5.2.4.5.3 Review

LEAs A, B, C, F and G stated the intention to review provision, particularly if absence was prolonged, but managers were constrained by a lack of time:

> We have said we would review every four weeks, but we never get round to it, informally, but if it goes on for twelve weeks then, we said we would hold a formal review and we don't do that either. I think we should do it though. But we don't have time. (A-Shire HT Manager)

A minority of parents reported that the health status of the pupil was reviewed by a physician in order to corroborate with parents that a child was unfit to attend school and a continued need for exceptional provision existed. Thus, the doctor acted as a gatekeeper to the continued deployment of resources in B-Shire LEA.

5.2.4.5.4 Returning to school

The accounts of professionals and parents suggested that a return to full-time school was arranged informally, on an ad-hoc basis.

5.2.5 Section two summary: factors

5.2.5.1 Consistency of pragmatic factors

The findings illuminated the consistency of pragmatic factors within the context of LEA administration and the substantial discretion and professional autonomy of decision-makers, which, taken together, account for the diversity in the type and quantity of provision and indicative quality of LEA arrangements that pupils received.

First, local circumstances determined the relationship of the Hospital and Home teaching service within the broader context of LEA support services.

Second, a diversity of funding systems existed, depending on how the service was organised. A peripatetic service managed by the LEA with a specified budget; funding through the age weighted pupil unit and full time equivalent placement at a PRU, or a Hospital special school; and schools arranging provision and recouping costs from the LEA. Systems of resource allocation among services retained by the LEA lacked transparency. The Home teaching service was a minor element of the SEN budget in G-LEA.

Third, a diversity of specification in Hospital and Home teaching policies existed with decision-making informed more by pragmatism than guiding principles. Organisation centred goals were in conflict with child centred goals. A lack of clarity in role specification between the LEA, the school

and parents permeated most LEA policies. Partnership with parents constituted a minor factor in written policies.

Fourth, systems of accountability to a professional reference group operated at different levels within the seven case study LEAs. OFSTED inspection operating at LEA level corresponded to a low level of accountability relative to OFSTED school inspection. Formal redress procedures that were accessible to pupils and parents were a minor factor in accountability.

Fifth, consistency of professional control permeated administrative procedures from referral through to the identity of provision. Parental referrals were a minor factor in procedures.

Sixth, children were assessed for a quota of teaching time set within the parameters of existing services.

Seventh, decisions about the identity of LEA funded provision fell within the remit of the LEA manager and the teacher.

Eighth, an ad-hoc element existed: some LEAs sought the professional opinion of a doctor to substantiate the need for teaching on medical grounds.

This section described the outcomes of decision-making on the administration of educational provision in LEAs A-G. The analysis identified a consistency of pragmatic factors influencing professional decision-making in the administration of provision, which in turn

corresponded with the consistency of pragmatic factors associated with the type, quantity and indicative quality of provision that pupils received in section one. Section three explores the effects of professional decision-making in order to identify determining factors influencing professional decision-making.

5.3 Effects of professional administration on the type and quantity of provision and quality of arrangements

This section presents an analysis of professionals' perceptions in order to explore themes identified as factors responsible for the type and quantity of provision and indicative quality of the arrangements that pupils received. The results of a thematic analysis exploring the nature of professionals' working conditions and the effects of decision-making on administrative practice and resource allocation are presented:

5.3.1 The quantity of resources

> If I've have got a waiting list of ten sick children at what point do they say I'm not doing my best for the child? Therefore I must give them a teacher. Who is going to pay for it? If that is so I am very worried that my budget will be limitless. How can the LEA manage a limitless budget let alone me? (F-London LEA HT Manager)

LEA professionals were likely to be working under conditions of financial constraint. Findings presented in section 5.2.2 suggested that the demand on resources for Home teaching was set within a context of competing demands for pupil referral units and special educational provision in G-LEA:

> We will have to use someone on supply part time. Because we have not got the budget for a third tutor. (G-London LEA HT/SEN Manager)

> I have been told that definitely. It [home teaching] is a thing of the past they said. "We no longer do that" they said. Even with the doctor's note, they said, it has been abolished. (Mother of Alan, six year old boy with epilepsy, G-London LEA)

The accounts of two professionals and parents gathered in G-London LEA suggested that the Hospital and Home Teaching service was funded inadequately. The type and quantity of provision received by pupils residing in G-LEA illuminated unmet need arising from a refusal (Alan) or a delay (Paul) in arranging provision.

5.3.1.1 Summary: The quantity of resources

Inadequate resources underpinned the working conditions of LEA professionals.

5.3.2 Matching need with supply

The findings suggest that unmet need existed (section 5.1.1.3. and 5.1.2). The data collected from LEA professionals provided an explanation:

> What we are noticing is that there is quite an increasing call on the budget that we have. So we have to say, well we can't really do, much about it. But we have to be vigilant so that we're not putting money in that isn't being well used. But we have to accept that if the children need it they are gonna have to have it. (B-Shire LEA HT Manager)

> It's a local school, a primary school, they knew the child was going in for a hip operation. And so they said could I possibly pencil in this date for when the child might need home tuition. (F-London LEA HT Manager)

> We are in the process of tightening up our referral criteria. Again it's always difficult when I think. The more you build-up contacts with people, the more people will ring you up and say aghhh I've got. (E-London LEA HT Line-Manager/(PRU))

> Maybe that is something we should look into? I suppose they don't publicise it that much, they might be frightened of the demand. (C-Unitary LEA HT Manager)

LEA professionals were cognisant of the demand on the service.

The intermittent pattern of absence (Table 4.3) from school for some pupils complicated the administration of the service:

> If you accept that you have got (x) number of pounds to spend possibly and I don't know, you can't possibly forecast how many children [will] need tuition and the numbers you are going to have. It's a great worry for someone like the PRU line manager who holds the budget, because things might seem quite healthy, but if suddenly there is this great influx, then they might think oh my God I'm going to run out [of money] before the end of the year, what am I going to do? Then we just hope that we're not going to have any more oncology patients. (C-Unitary LEA HT Manager)

Unpredictability in demand increased the pressure on professionals. What were the implications for pupils?

> ... Certainly it [standard allocation] was about ten hours when you first started. Oh it was when Barry took over the budgets and it ran away with everybody. The PRU line manager over spent on home tuition. The money that was spent on home tuition was colossal. And there's no end to it, you know, so you just cut it. (C-Unitary LEA HT Manager)

> [in a previous LEA] Come November or December of the financial year, we had spending stops . We had this silly situation, where if you wanted to buy any thing, even a ream paper, you had to apply to a group of folk in the LEA, who would then take three weeks to decide and then let you know. It was just crazy. And so what you did, you planned for this spending stop. We made sure all the money was gone and they could stop as much as they wanted because there wasn't any money left. Urmm But they could also do things like tell you tomorrow, you were to cut all Home teaching, or cut hospital teaching, just like that, absolutely, because the budget had run out. (Headteacher, D-LEA Network Hospital school)

The findings suggest that demand could well increase to match the supply of resources that were available to LEA managers. LEA decision-makers were trapped in a cycle of mediocrity. The more responsive the service was to meeting the need for teaching for pupils out of school, the greater the actual demand for resources. The findings suggested that LEA

professionals were cognisant of the dilemma that if demand spiralled out of control and exceeded the LEA budget, then the larger demand forced the LEA to limit the service artificially by imposing a spending stop or cut, with the result that unmet need for teaching existed.

5.3.2.1 Summary: Matching need with supply

Matching supply with demand for services in a context of inadequate resources created pressure for professionals to conserve resources.

5.3.3 Type of provision offered

The findings presented in section 5.1.1 illuminated the diversity in the type of provision that pupils received, within the remit of LEA provision. Table 5.10 shows the range of provision offered to pupils.

Table 5.10 Type of LEA offerings

LEA offering (Triangulation Appendix 10.2.4)	**LEA**	**Triangulation**
Qualified teacher: Hospital provision	A B C D E F	All parents
Qualified teacher: Home visiting provision	A B C E FG	All parents
Education welfare/ SEN learning support assistant	A B C E	Information not available
Additional provision in school	A	A B parents
Part time attendance at home school	A B C E F G	A B E G parents
Part-time attendance FE college	A F G	B parent
Distance learning (homework)	A B C D E F G	A B C D E G parents
ICT based open learning	A D	Provider URL (A-LEA), OFSTED (D-LEA)
Transport	A E F	A E parents
Contract with non LEA provider	A B C D E FG	Provider URL
Equipment	A G	G-teacher and parent

5.3.3.1 Summary: Type of provision offered

First, professionals exercised substantial choice and flexibility in arranging the type of provision suitable to the age, ability and aptitude and any special educational needs of the pupil profiled in the study.

Second, an ad hoc element existed in the data: An education welfare or SEN learning support assistants were noted in the range of LEA offering but parents did not report this type of provision.

5.3.4 Quantity of provision offered

Section 5.2.2 illuminated that a climate of financial constraint permeated the working conditions of professionals. Professionals were under pressure to match supply with demand. This section presents an analysis of the effects of professionals' conditions of work on the quantity of Home teaching offered to pupils.

5.3.4.1 Fixing the level of service

Pupils received a quota of visiting teaching time (section 5.1.2):

> I will not give more than five hours, because I couldn't cope with the amount of time and the lack of money to pay for it. If one child got ten hours then another child would not get anything. But I have never ever lessened it without very good reason. To give less than that is unfair on the children. I know some areas only give two hours, but I mean how can you give less than that. How can you deliver a balanced curriculum in two hours? How can you do it in five? But at least you've got a chance. (F-London LEA HT Manager)

Setting a maximum quota enabled professionals to distribute resources more evenly, among the pupils recognised by the service.

5.3.4.2 Controlling referral procedures

The findings in section 5.2.4.3 suggest that professionals exerted control over demand. Referrals were accepted from a designated source and threshold criteria were applied:

> We would expect the referral to come from the educational social work service and we would always want a doctor's note. Saying how long they going to be off and what the issues are there. We do find that Rowen Hospital school will ring us. If they know the child is being discharged and they quite often ring and say well you know and say the child is now back home. But that isn't an official route that is an alert. And I would tend to ring the school. And get them to ring the educational social worker and do the official paperwork for that. (E-London LEA HT Line-Manager/(PRU))

A referral merry-go-round had the effect of causing delay as pupils were placed on a waiting list or lost in the system:

> If you go through the usual referral procedures, which by their nature are fairly time consuming. What has happened is that months have elapsed. (A-Shire LEA HT Manager)

> If the child is ready to go back into school, we pull out perhaps quicker than we would have normally. Because you know somebody else is waiting. (E-London LEA HT Line-Manager/(PRU))

> If I ever get a medical certificate saying the child cannot go to school then I will put the child on the list for home tuition. They might not get it immediately, in fact there is usually a waiting list, but they are down and they will get it as soon as I can and I write to the parents telling them that. (F-London LEA HT Manager)

The findings suggest that the service structure accommodated more pupils at one time although no more service was actually provided.

Some pupils failed to gain recognition by the service (section 5.1.3.6.).

What explanation could be found in the discourse of professionals?

> So I suppose we do rely on the hospital route for the referrals. And we can set things up for them. So if it's the GP, or the school that's saying this [pupil] has got ME and requires home tuition, we wouldn't necessarily know about them. (C-Unitary LEA HT Manager)

> It would depend I think probably on the EW0. Or the schools or somebody pushing and then they would get the referral to to.....[LEA line manager]. Because he is the holder of the budget. Again it would depend on how efficient the EW0 is. It would depend on the school ringing the alarm bells. (C-Unitary LEA HT Manager)

Professionals alluded to ambiguity in roles and responsibilities convoluting the referral process with the result that a diversity of outcomes for children existed.

5.3.4.3 Limiting access to information about the Home teaching service

> We haven't actually provided any information leaflets to parents yet. Or for anybody. Although we have written to all the schools and given them a copy of the referral form. (G-London HT/SEN Manager)

> It's not often the parents ring. (F-London LEA HT Manager)

A study of the seven case study LEA Internet web sites conducted during the month of April 1998 demonstrated that information about the LEA Home teaching service was advertised in B-Shire LEA only (Appendix 10.2.7) and referred to tuition for pregnant schoolgirls as the primary reference group rather than provision for children who were sick. LEA search engines were insensitive to the key words 'home tuition', 'Home teaching', 'illness' or 'absent'. LEAs' A; C; D; E; F and G Internet web

sites directed queries about educational provision to the school where the child was registered.

5.3.4.4 Prioritising clients

The findings presented in section 5.1.4.2 suggested that pupils at Key Stage three and four were more likely to be recognised by the service than pupils in Key Stage one and two:

> We try to ensure that we could teach every child in hospital, having said that, with a finite budget, umm we do find there are times of the year when we to have to start prioritising. (Head teacher, Headteacher, D-LEA Network Hospital school)

Prioritisation of clients was an unintended effect and led to inequalities in the administration of provision.

5.3.4.5 Summary: quantity of provision offered

First, a quota system fixed the level of service.

Second, referral procedures enabled professionals to control access to the service.

Third, limiting access to information in the public domain controlled demand.

Fourth, prioritisation of clients led to inequalities in administration.

Fifth, an ad-hoc element in the data existed: dissemination of information on local authority Internet web sites was patchy.

Sixth, professionals' perception of working practices and routines analysed in this section were consistent with the phenomenon of rationing resources (Lipsky, 1980). Thus the data suggested that the main effect of professional administration on the quantity of resources allocated was rationing.

5.3.5 Indicative quality of the arrangements

The findings presented in section 5.1.3.4. show that the type and quantity of provision changed in accordance with the circumstances of the individual pupil, for example, the relative ambulance or immobility of the pupil.

5.3.5.1 Flexibility in decision-making

> We don't say everybody gets one hour a day. We don't provide any less than that, but we might well top that up with other things. We might increase it, but we would only do that if it's a pupil in their later years who's working for GCSEs. Or for children who have such a poor scenario, we are pretty flexible as to whether its an hour a day, or an hour a day plus a bit of this. For some it might be an hour a day with a visit to school in between. (A-Shire LEA HT Manager)

> I would be giving four hours a week. But if urmm, it would be flexible and have found that the tutor may alter, alter it maybe. If the older children need a bit more and younger children may be less, it will be dependent on how many cases he has got. And how he organises the sessions during the week for older children and young children, so yes it is flexible. Within the constraints of case load really. (G-London LEA HT/SEN Manager)

> In urmm and within what we have got on offer, but but you know but but but, we are willing to try different things [pause]. We are willing to [pause] to employ different people as well. Using our budgets, if necessary. We have had urmm last year urmm an an eight year-old urmm urmm who was in a car accident, we didn't actually employ a home tutor, we employed urmm an education support assistant who worked in a special school for children who had been brain damaged. And we were able to buy more of her time, than we would have been able to if it was a teacher. And she was able to the kind of activities, that she is used doing, that the teachers didn't have expertise in. Urmm and so as long as it's you know, we are able to be flexible, we haven't got any hard and fast rules about that. (C-Unitary LEA HT Line-Manager/(PRU)

Flexibility in decision-making enabled LEA professionals to provide a timely response tailored to individual circumstances, for those pupils who were recognised by the service. The findings suggest that flexibility in decision-making enabled LEA professionals to husband resources by arranging provision to suit the changing circumstances of the pupil.

5.3.5.2 Goal displacement

The arrangements for provision encompassed the family, the school and the LEA. The findings presented in section 5.1.3.6. implied that if the arrangements included school provision, pupils received less LEA funded Home teaching:

> The home tuition budget is separate. There is a home tuition budget, but it is shrinking. It was £110,000 the first year I took over. It's now about £30 000 and we teach more children. The reason for that is not because they don't get so much tuition, but because they go to school for some of it. (A-Shire LEA HT Manager)

In the absence of LEA funded provision, pupils were dependent on outreach for provision from the home school. Paul relied on homework for a substantial period of time:

> I kept on phoning them.....and asked if they would have work ready for him. Then I pick it up. (Mother of Paul, fourteen year old boy with sickle cell anaemia, G- London LEA)

Rather than allow the pupil to miss schoolwork a minority of parents chose to arrange alternative provision independently:

> Becky was starting to go back [to school] for the odd half day, but I didn't want to jeopardise those four and half hours... She (home teacher) turned a bit of a blind eye about it. (Mother of Becky, fourteen year old girl with glandular fever, E-London LEA)

> But in the end I went to private tuition..... once a week, only once a week, for one hour. It cost about £18 a week. (Father of Novid, fourteen year old boy with orthopaedic fracture, E-London LEA)

The analysis presented in this section 5.3.5.2 suggested that the status of dual registration of pupils bound the school into the arrangements and enabled some displacement of the cost of the service in LEAs A-G to the school and to parents. Organisation centred goals, aimed at conserving resources took primacy over child centred goals and the need for segregated provision. Gratification of the pupil's need for teaching was displaced to the school.

5.3.5.3 Role ambiguity

Findings presented in section 5.1.3.3 show that schools played a part in the arrangements:

> I mean I have stressed in discussions with Ben (home tutor) at the beginning when we started that we mustn't allow schools to drop their responsibility. We must make schools accept their responsibilities. So we've got almost all the schools to accept that we have a procedure which says the home tutor must contact the school. Or want to see a scheme of work for that group, or to get the schools to send work for that group. And so we get information about subjects from schools, about what work is going to be covered that half term and we would expect to school to provide it. (G-London LEA HT/SEN Manager)

LEA professionals were cognisant of ambiguity in roles hindering the delivery of a relevant curriculum for the individual pupil. If role expectations were ill defined, then the school may be unresponsive to pupils, with the effect of causing gaps in outreach provision, or a delay in referral to the LEA, placing pupils at risk of discontinuity of educational provision.

5.3.5.4 Summary: indicative quality of the arrangements

First, the indicative quality of the arrangements were related to the efficient use of resources.

Second, flexibility in decision-making enabled arrangements to be responsive to the changing circumstances of the pupil.

Third, LEA goals of service were displaced to the school resulting in a decrease in segregated provision and the inclusion of the pupil in school provision.

Fourth, ambiguous role expectations at the interface of the LEA, school and the family left responsibility for provision unclear, with the effect of

causing gaps in provision as pupils were unrecognised by the service or delay.

Fifth, an ad-hoc element was evident in the data: the quality of provision changed if teaching assistants replaced qualified teachers in curriculum delivery.

The working conditions of LEA professionals constrained the quantity of segregated provision allocated to meet the individual need for teaching and hindered the quality of curriculum delivery. Conversely the working conditions of LEA professionals promoted a type of arrangement that linked the pupil with the school and enhanced the continuity of provision.

5.3.6 Section three summary: effects

The analysis presented in chapter five section three revealed the likelihood of inadequate resources underpinning the working conditions of professionals. Working practices and routines that were consistent with rationing the quantity of Home teaching were identified. Flexibility in decision-making enabled LEA professionals to be responsive to the relative ambulance or immobility of the pupil and the setting used for education, and enabled efficiency in the arrangements for provision. The implications of the findings are discussed in chapter six and in particular, conclusions concerning the identity of a determining factor influencing decision-making that promoted (or hindered) the administration of provision to meet the individual need for teaching. Section four moves on to consider the nature

of parental involvement in professional decision-making, and the influence parents have on the outcomes for pupils profiled in the study.

5.4 The effects of parental involvement in the process of professional decision-making

The analysis presented in chapter five section three revealed the likelihood of professional administration seeking efficiency in the type, quantity and indicative quality of the arrangements for educating pupils residing in LEAs A-G. In this section, the nature of parental involvement in professional decision-making is described. The results of a thematic analysis exploring the effects of parental involvement in professional administration is presented in order to inform a discussion regarding the implications of parental influence on the type, quantity and indicative quality of arrangements within the broader context of LEA services.

5.4.1 Parental involvement in professional decision-making

Most parents communicated with the school informally, by telephone and some parents arranged meetings (Appendix 10.2.2). Section 5.2.4.3 shows that parents were recognised in the referral procedures in LEAs F and D only, the evidence suggested that Hospital referrals were an effective route to LEA provision.

5.4.1.1 Parental inaction

Parents were passive if a child's need for teaching was satisfied; or if they were unprepared to take action; or did not recognised that needs existed:

> She (hospital teacher) basically took over and told me not to worry about anything, she would contact the schools. They contacted his school and the local education authority, to explain to them what was going on, urmm she did explain a little about, about, what would go on actually when he was in hospital. Urmm and that urmm but then I had a visit from the home tutor, once we got home. They contacted me. (Mother of Dan, seven year old boy with leukaemia, A-Shire LEA)

> The first time (pause) quite honestly it hadn't occurred to me, how long she would be in hospital, how long she would be disabled, how much work she would miss. So I was totally unprepared and didn't think it was, I didn't think it was an issue to be honest. Urmm so it was a real shock, from March, when she didn't actually get back to school until the last couple of weeks before the end of term. (Long pause). (Mother of Debbie, ten year old girl with orthopaedic reconstruction, A-Shire LEA)

Parents' self perceptions of their responsiveness to the child's need for teaching were rationalised according to circumstances.

5.4.1.2 Parental action

Perceptions of a child's boredom, or emotional withdrawal motivated some parents to act on behalf of the child:

> He didn't even want to watch television, he just lay on the sofa. So I thought well, we started going round the village and doing things in his wheelchair. And you known we would be doing jigsaws and things. (Mother of Steven, fifteen year old boy, orthopaedic fracture, A-Shire LEA)

A gap in provision prompted parents to contact the school:

> The only way we got referred was urmm after quite a lot of time, I actually contacted the head of year again, told him of Sally's condition and said 'where do we go from here?' And he said "she has now been off so long, but I will have to refer her to (pause) is it the community paediatrician? (Mother of Sally, teenage girl with M.E., B-Shire LEA)

> And so when I went back to school to see the head of lower school, or deputy head, she said she didn't want him in. And we agreed. And I said well I'm worried he's going to miss his education. She said 'let me look into home tuition'. (Mother of Steven, fifteen year old boy with orthopaedic fracture, A-Shire LEA)

Parents' perceptions of a gap between the observed state of the child and the desired state stimulated the identification and the communication of needs to professionals.

Maslow (1987) suggested that the greater the discrepancy between the observed and the desired state, the greater the motivational drive, prompting parents to act and bring about 'needs gratification'. The findings in this section suggest that parents acted according to their self-perceptions of the child's needs.

5.4.1.3 Parental influence on the type of LEA provision

The finding presented in section 5.1.3.7, suggested that parents liaised informally with professionals about the type of provision that was deemed suitable to the age, ability and aptitude of the pupil and any special educational needs a child may have.

Parents reported that informal communication channels were open if a change in the type of provision was needed:

> He had one [home tutor], his first one, who he didn't get on with. At all. A lady. And they just didn't get on, they clashed. And they were very quick to change teachers, I just contacted Becky. She's like the head, of all the home tutors and I just contacted her and spoke to her. (Mother of Dan, seven year old boy with leukaemia, A-Shire LEA)

The findings suggest that if the quality of the provision was perceived to be inadequate, the parent negotiated a change in the type of provision, to attain a satisfactory level of provision.

5.4.1.4 Parental influence on the quantity of provision

A minority of parents whose children were recognised by the service questioned the LEA professional's decision regarding the quantity of provision allocated:

> I was in contact with the LEA manager all the time. But she wouldn't budge you know. That was it, then she couldn't do any more. Again how they came to that sort of conclusion I don't know. Urmm knowing that he was in the first year, (the GCSEs) and he needed guidance. Especially science. I mean I I really pressed that, the science was the most important subject besides maths and English. (Father of Novid, fourteen year old boy recuperating from orthopaedic surgery, E-London LEA)

Parental pressure was mostly ineffective in changing the quantity of LEA provision allocated. In the broader context of the LEA policy, parents of sick children created little, if any direct pressure on the quantity of resources allocated.

5.4.1.5 Parental influence on quality of provision

The findings presented in sections 5.1.1.5 and 5.1.3.3 suggest that some parents were involved in the child's learning, while other parents were

more passive, assuming the role of supervisor. Parents described self-perceptions of their actions to support the child's learning in the home. Whereas Dan's mother acted on suggestions from the home teacher to engage her young son in cooking activities and the weighing of ingredients, to support Key Stage one mathematics, most parents of secondary age pupils wanted direction and support:

> We actually sit and watch television a lot. So whatever we are watching, we discuss. And David watches lots of quiz programmes on the television. (Pause) I wish in a way there were more, sort of informative videos. If you could go and buy a "teach yourself maths" video for children, who well, (pause) you know you can buy gardening videos. Why can't you go and buy... and we would have them all, I know we would. "Let's go for this French one", "let's go for.....". (Mother of David, fifteen year old boy with cystic fibrosis, B-Shire LEA)

> Some of the things they sent I couldn't understand, it was gobbledegook to me. (Mother of Jack, thirteen year old boy with chronic asthma, B-Shire LEA)

Parents of pupils at Key Stage three and four reported difficulty in supporting pupils in the home.

5.4.2 Section four summary: effects

First, informal communication characterised the interaction between professionals and parents.

Second, parents were active or inactive depending on their perception of the child's needs.

Third, parents influenced the type of arrangements and type of provision.

Fourth, parents had little or no influence on the quantity of provision allocated. In the broader context of LEA services parents of sick children exerted little or no direct pressure on the quantity of resources allocated.

Fifth, parents influenced the quality of the arrangements, acting as a client consumer at the boundary between different providers. Parents influenced the indicative quality of provision as a partner with professionals at the point of curriculum delivery.

Sixth, an ad-hoc element was evident in the data: in the absence of educational provision a minority of parents did not identify their child's need for teaching

Section four illuminated the nature of parental involvement in professional decision-making. The results of a thematic analysis suggested that parents influenced the type of provision and indicative quality of the arangements but had little or no influence on the quantity of LEA funded provision that pupils received. The implications of parental influence on professional administration under the Education Act 1996, s. 19, together with the evidence of a determining factor influencing professional decision-making within the broader context of LEA services is discussed in chapter six.

5.5 Professionals' and parents' perceptions of the decision-making process

The self-perceptions of participants were explored in relation to themes identified in sections 5.1 -5.4. This section presents the results of a discourse analysis, which identified the content and form of professionals' and parents' perceptions of professional administration in order to contribute to policy development in the area of parental involvement.

5.5.1 Professional control

Section 5.2.4 shows that once the pupils had reached the point of recognition of the service, LEA professionals' exerted substantial control over the decision-making process:

> They [parents] only really play the part of being consulted, being involved in the initial contact. Obviously being required to be there when the home teacher is in the home, because of health and safety, we never teach a child on our own. And being very much involved in the ongoing support, by reporting back to the case worker. (A-Shire LEA HT manger)

> Well there is a discussion, negotiation, we say 'well we are only able to offer this amount of time, so what would you say is the best way of working? I mean I could offer you two 2 hour sessions a week and maybe I could offer three, one and half or .....that kind of timing.' I mean I would say if we are going to do this, it's really important that we have a quiet space. And I will be leaving homework. So that's, what would you call that? It is discussion, it is negotiation. (G-London HT/SEN Manager)

Professionals emphasised consultation with parents, in terms of organising the home environment so that it was suitable for teaching and in agreeing the routine of home visiting:

> I want to see parents being properly involved in the education of their children. Urmm in an appropriate way. Urmm particularly when you've got young people, when you're not offering the hundred percent of education that other young people are accessing. You have to use parents, you have to involve parents, both in hospital and home, urmm and very often parents will sit in with lessons and join in, uumm and I think ensuring that the parents are kept informed about the youngsters, about the child's progress and they feel as though they have got a say in what is happening I think is vitally important. (Head teacher, D-LEA Hospital school)

Professionals encouraged parental involvement in curriculum delivery as a way of augmenting LEA provision. The findings were consistent with the substantial responsibility for family provision accepted by parents (5.1.1.5):

> In our experience it tends to be "thank goodness there is somebody else here". There is somebody else who could take some responsibility. And they [parents] are quite happy to hand that over and equally for someone to do the liasing with schools. It isn't an easy job. Trying to track down teachers, trying to get hold of work. And for mum trying to dash off to the hospital wherever... they are usually quite relieved if someone can do it for them. (E-London HT Line-Manager/(PRU)

LEA professionals perceived that parents were busy with their primary care role and welcomed the LEA manager or home teacher as someone who could lighten the load and share some responsibility for the pupil. Professionals' perceptions revealed that parents were grateful.

5.5.2 Parental influence in the route to provision

The findings presented in chapter five, section one showed that diversity existed in the type and quantity of provision and indicative quality of the arrangements for educating pupils profiled in the study. Parents communicated with school by telephone, through siblings and school friends and a minority of parents called meetings with school teachers

(Appendix 10.2.2). The findings presented in sections 5.1.4.5 and 5.1.5.6.4 suggested tentatively that parents who were persistent were successful in gaining recognition more than parents who were passive:

> You know, some people aren't as forceful as me, they might just have sat back. (Mother of Steven, a fifteen year old boy, orthopaedic fracture, A-Shire LEA referring to mainstream school)

> It was me, all the time saying I need more homework, I need for homework, I need more homework and I even wrote a letter to the headmaster, complaining. (Mother of Becky fourteen year old girl with glandular fever, E-London LEA, referring to mainstream school)

> I tried to get something sorted out for him, he was to have urmm like a bit of home help, you know one to one to help him catch up on everything, but its never been put forward. (Mother of Jack, thirteen year old boy with asthma, B-Shire LEA, referring to mainstream school)

The discourse of parents illuminated diverse self-perceptions relating to their effectiveness in gaining access to provision:

> I'm not strong enough, you know. ...Urmm I felt as though they [professionals] gave me the lovely sympathetic sounds, but never in writing, never, you know, he just stayed at home. Alan stayed at home. And then he was admitted into hospital, the last time he was at home, it was urmm (pause), it just cancelled out the problem then. Because he was in hospital then. (Mother of Alan, a six year old boy with epilepsy, G-London LEA referring to LEA professionals)

> I won't be afraid and you shouldn't be afraid to tackle these people and say what you think, don't let them dictate to you.... If they think something is wrong and you don't, say, 'I do not agree', nicely if you like. (Mother of Gary, thirteen year old boy with cancer, B-Shire LEA referring to mainstream school)

The findings suggested that self-perceptions of power to influence decisions or situations enhanced or constrained parental effectiveness in the route to provision.

5.5.2.1 Advocacy

Parents communicated with teachers, social workers, doctors, nurses or family members in negotiating the route to provision (section 5.1.3.7. and 5.1.5.6.4):

> We said we have problems to our clinical nurse. From the sickle cell clinic. And she said to me well Paul is out (of school) so long. So we have to try and see if we can urmm get Home teaching in. Perhaps write a letter also to confirm what she was saying. They write back to me and say well I have to give them a bit more explanation. Then the hospital write. The doctors, the health visitors and quite a lot of them. Even the school he used to go to, the primary school, also write to them as well. (Mother of Paul, fourteen year old boy with sickle cell anaemia, G-London LEA)

> It gets quite lonely being at home. At first I thought we would have a lot of things to do, we'd go to town, but gradually we didn't do that. (Mother of Jonathan, ten year old boy with leukaemia, A-Shire LEA)

Although pupils received LEA provision in the home, some parents disclosed self-perceptions of isolation from the wider community:

5.5.2.2 Family circumstances

> I have access to a fax machine and can fax the transport manager and the LEA manager and work it out from work and I've spent a lot of hours co-ordinating things. I shouldn't have done really. But I mean if I didn't do it nothing would happen at all. I rang school, hospital, ringing for appointments at the hospital. So I have spent a lot of time and money really. If the parents are not able to do that, very little is done. (Father of Novid, fourteen year old boy recuperating from orthopaedic surgery, E-London LEA)

> She came out of hospital urmm, I had to move house, my landlord wanted us out. So she came out [of hospital] and, probably a couple of days later, a few days later we had to move [house]. And I really wasn't in the position to chase it up. And I did try to organise, I mean I didn't try, but I did receive a notice from them about home tuition, but it went to the old house. And we were not there. Urmm and although I have told the school what our new address was, it didn't seem to crossover. One way or another, it didn't get organised. And then it was the end of term. So she missed out. (Mother of Debbie, ten year old girl with orthopaedic reconstruction, A-Shire LEA)

> So the more efficient the parent became [at medical procedures], the less the hospital was required in educational terms and the more the home tuition was required in educational terms. (Mother of John, a five year old boy with leukaemia, C-Unitary LEA)

The effectiveness of the parent was related their capacity to bear costs of time and money incurred during the referral process. The actions of parents were enhanced or constrained by the circumstances of the individual family and the demands of the care role.

5.5.2.3 Perceptions of service entitlement

Section one suggested that some children profiled in the study did not reach the point of recognition by the LEA service:

> I mean I've never asked about home tuition, but I imagine the only way we would ever get it, was if we paid for it. I don't think there is any provision county wide, is there? (Mother of Mark and Ben, teenage boys with cystic fibrosis, B-Shire LEA)

> I assumed that she would be back quite quickly. And it did take a long time. (Mother of Debbie, ten year old girl with orthopaedic reconstruction, A-Shire LEA)

Parents were constrained in seeking service by assumptions arising from a lack of knowledge about service entitlement, or uncertainness about the prospective length of absence from school.

The findings presented in section 5.1.5.6.4 show that the route to LEA provision was predominately through the pastoral system of the school. The verbal and non-verbal communication of most parents showed little or no recognition of the vocabulary of 'Statement' or 'special educational needs':

> I tended to assume that it covered specific conditions, like autism or sort of hearing loss, urmm urmm. (Mother of Debbie, ten year old girl with orthopaedic reconstruction, A-Shire LEA)

> I couldn't get through to people that he wasn't special needs. He was ill. (Mother of Simon, sixteen year old boy with significant medical condition, A-Shire LEA)

Some parents believed that a medical condition was incongruent with special educational needs. The framework of support through the identification and assessment of special educational needs was redundant for most pupils profiled in the study because parents were not informed or believed that the classification of special educational needs was inappropriate for their child.

The discourse of parents revealed in section 5.5.2 suggests that a diversity of needs existed amongst parents. The analysis suggested that personal attributes influenced the amount of pressure brought to bear on the referral route by parents. Many parents were cognisant of the demand on their own personal resources, fortitude and time. A trade off seemed to exist between the cost to the parent of seeking service and the existing demands on the parent in their primary care role. The circumstances of the family enhanced or constrained the effectiveness of the parent gaining recognition by the service on behalf of the pupil. Parent's actions were constrained by

individual beliefs relating to the prospective length of the child's absence and service entitlement.

5.5.3 Quality of professional and parent relations

Findings presented in chapter five, section one suggested that relationships between parents and professionals occurred at the level of the school, and between the individual Home tutor and the parent once LEA provision was in place.

5.5.3.1 Goodwill

> So it was more or less taken out of my hands. Which is good, because you don't want to have to think about things like that...It must have been only a maximum of two weeks. For them to find a home tutor. There was no complaints, they never let it slip, they were on top of it. (Mother of Dan, seven year old boy with leukaemia, A-Shire LEA)

> And then the lady came and it was good. She was a lovely lady, who came. (Mother of Steven, fifteen year old boy with orthopaedic fracture, A-Shire LEA)

> He's nice and you get used to him. Because when he finished teaching, he calls and I'm asking what's what. (Mother of Paul fourteen year old boy with sickle cell anaemia, G-London LEA)

> The amount of time and energy that individuals are prepared to put in (pause).....teachers, whether or not they get paid for it. I mean likewise, the school could put in little time and they actually put in more time. We were particularly lucky with the headmaster and the teacher that we had. I think we were extremely lucky with the hospital teacher and the home tutor. And so much of it, in my experience, is down to the goodwill of the individuals involved, ...against extremely difficult financial backgrounds and other difficulties. (Mother of John, five year old boy with leukaemia, C-Unitary LEA)

A dominant theme of goodwill permeated the discourse of parents. Where professionals executed a rapid response in the referral process, parents demonstrated positive attitudes. Many parents reported the development of

strong positive relationships with the home-visiting teachers. Once LEA funded provision was in place, most parents showed empathy towards the working conditions of the teacher and accepted the limitations in arranging provision. The findings suggested that a mutuality of respect existed between professionals and parents.

5.5.3.2 Give and take

> I haven't made it difficult for anybody. I've sort of looked at Gary and thought well I've got to do the right thing for him and I've got to build relationships for him with his school teachers. At the end of the day it doesn't affect me, I do whatever I have to for Gary, whether it be for a year or for ten years. At the end of the day he doesn't particularly like his home tutor but I managed to build up a rapport and get him to like her and understand what she's about, rather than "I don't want home tutoring, I don't want to sit with her" all this sort of thing. (Mother of Gary thirteen year old boy with cancer, B-Shire LEA, referring to relations with mainstream school)

> If John had a fever which nobody was expecting and the home tutor was booked up with other people, she wouldn't be able to come. Even if required. If she was freer, then she would come and do as much as she could. So we didn't always get what was necessary, when it was necessary. Because of the number of people who were able to do it and the home tutor had to work elsewhere. (Mother of John, a five year old boy with leukaemia, C-Unitary LEA)

Parents rationalised their actions in terms of building constructive relationships with professionals, or provided plausible explanations as they accepted gaps in provision.

5.5.3.3 Conflict

> It's a fight, you've got to be prepared, not just to sit back and let them tell you what to do. You have to force the issue and demand, otherwise you don't get anything. If you are just prepared to sit back and let them tell you, oh we will sort this out, we will sort that out, it doesn't work. Well it certainly hasn't worked for us. It's just been a fight, constantly, a fight all the time. (Mother of Simon, sixteen year old boy with significant medical condition, A-Shire LEA- referring to relations with mainstream school)

Perceptions of frustration and conflict were evident in the accounts of parents. If schools were perceived to be unresponsive, then the expression of need was transformed into an expression of concern and, in a minority of cases, a complaint. Following the interview, Simon's mother expressed her perceptions of fear of making a complaint to the school. She worried about the effect such action would have on the relationships between the school and Simon's siblings.

5.5.3.4 Value judgments

> Ben was with her for a little while [special needs teacher], off and on, but not for very long. I think she gets more of the ones who are just wasters you know. ..... and I think really, they are geared to that, ...than to somebody who has got really behind because he's in hospital. (Mother of Mark and Ben, teenage boys with cystic fibrosis, B-Shire LEA)

> You know if he'd been playing truant, I'd have had letters coming out of my ears, but nobody seemed concerned at all. (Mother of Michael, thirteen year old boy, with complicated orthopaedic treatment, K-LEA)

> Listen I've got it on good authority ummm if Gareth had been excluded from school, because he'd been, he'd done wrong, apparently he would get one [home tutor] within weeks. (Mother of Gareth, fourteen year old boy with congenital heart condition, K-LEA)

Value judgments concerning the relative worth of one child being more deserving than another were evident in the accounts of a minority of parents whose children, in the opinion of the researcher, were at risk of falling through net.

5.5.4 Section five summary: perceptions

First, professionals consulted parents about arranging provision. Most parents seemed content for professionals to act as experts.

Second, a diversity of parent needs existed which impinged on the identification and communication of the pupil's need for teaching to professionals.

Third, some parents were supported by professionals or family members to act as advocates for the pupil in order to resolve gaps in provision.

Fourth, parents accepted responsibility to liaise between stakeholders. Family resources, personal fortitude and persistence contributed to the self-perceptions of parents' effectiveness in influencing decisions or situations.

Fifth, the quality of professional parent relations at the provider boundary, or in partnership for curriculum delivery was related to the skills of individuals, the resources available to meet needs and the time available for liaison.

Sixth, an ad-hoc element was evident in the data: parents expressed value judgments and beliefs in rationalising inadequate resource allocation for the individual pupil.

In section five the content and form of professionals' and parents' perceptions of professional administration was identified. Decision-making power rested with professionals. The diversity of parents needs was related to the effectiveness of the parent to influence decisions or situations which impinged on the provision and arrangements for educating pupils residing in LEAs A-G. A summary of the findings presented in section 5.1-5.5 follows below.

5.6 Chapter summary

In section one the data suggested that diversity existed in the type of provision and indicative quality of the arrangements, but less diversity existed in the quantity of provision that pupils received.

In section two, consistency existed in the pragmatic nature of factors responsible for the outcomes that pupils received. Enabling legislation, inconsistent levels of accountability, inadequate resources and non-voluntary clients, allowed professionals substantial discretion in decisions about the type and quantity of provision and indicative quality of the arrangements for educating pupils profiled in the study residing in LEAs A-G. The diversity of family provision contributed to the diversity of the outcomes for pupils also.

In section three, the main effects of professional decision-making in the administration of provision were the rationing of resources and the displacement of arrangements for provision to the school and the parent.

Given the pragmatic nature of factors responsible for the diversity in the type of provision that pupils received and the indicative quality of the arrangements, together with the evidence of rationing the quantity of resources allocated, it was likely that the determining factor influencing professional decision-making was inadequate resources to fund LEA provision.

In section four, the main effects of the informal involvement of parents in professional decision making was shown to be parental influence on the type of provision and indicative quality of the arrangments, but not the quantity of LEA provision. The parent role diverged into the position of client consumer at the interface of LEA and school administrative systems and into the position of partner in curriculum delivery.

Given the limiting factor of inadequate resources and the lack of influence of parents on the quantity of resources allocated, it was likely that financial pressure within the LEA caused some displacement to schools.

In section five, the discourse of participants suggested that professionals were in control of the decision-making process and parents accepted responsibility to liaise between stakeholders. The diversity of parents needs was related to the effectiveness of the parent to influence decisions or situations that impinged on the provision that pupils received.

The implications of the findings presented in chapter five, particularly for professional practice and policy development within the broader context of LEA services are discussed in chapter six.

6 IMPLICATIONS FOR DECISION-MAKERS

By including the views of professionals and parents, together with documentary evidence presented in chapter five, the study provides a new source of information about the impact of the decision-making process on outcomes for children under the Education Act 1996, s. 19, for children who are out of school because of illness or injury. In this chapter, the implications for decision-makers are discussed. The chapter is structured in five sections, in order to maintain consistency with the presentation of the findings in chapter five, the aims and the structure of the argument outlined in section 3.1.3.2. The chapter draws conclusions in order to contribute to policy development in the area of parental involvement.

6.1 The outcomes of professional decision-making

6.1.1 Type of provision

The diversity of the arrangements included Hospital teaching, Home teaching, outreach from the school, family provision or special educational provision and delivery by means of ICT, as a discrete entity or as a combination of different types of provision. The phenomenon of diversity in the type of arrangements was consistent with the findings of previous research conducted in England by Fassam (1982) and the diversity of LEA

offerings evident in the directory of provision published by NAESC (1997a, 1999).

6.1.2 Quantity of LEA funded provision

The quantity of LEA funded provision fell within a narrow range of 0-7 hours home tuition per week, and showed substantial consistency with the range of LEA offerings reported by NAESC (1997a, 1999).

6.1.3 Quality indicator: continuity

Departmental guidance (DfE and DoH, 1994) specified continuity of provision as a fundamental tenant underpinning the provision of education for sick children. The findings suggested that continuity with home school provision was maintained to varying degrees, depending on the type and quantity of provision available to pupils as they moved from one educational setting to another.

First, the findings suggest that the presence of a qualified teacher was significant, in the eyes of parents. The findings suggest that a relatively small quantity of professional input supported and reinforced by family provision, was an acceptable arrangement to parents. This mode of provision echoes the wide-ranging drive in government policy to enlist the support of parents in their children's learning, first mooted by the labour government in the White paper 'Excellence in schools' (DfEE, 1997e); the Schools Standards and Framework Act 1998; and then in departmental

guidance pertaining to home school agreements (DfEE, 1998e) and study support (DfEE, 1998f). However, the notion of parental involvement in the education of their offspring in the home did not take into account the difficulties encountered by parents in the study in identifying a suitable starting point for a learning activity. It seemed that policy assumed an inherent level of knowledge, understanding and skills on behalf of parents and overlooked the role of a teacher in directing parental involvement in the child's learning in the home. Thus the results of the study have implications for professional practice in supporting the child's learning in the home.

Second, the narrow curriculum offered to pupils in Key Stage four who were studying for public examinations was an issue that raised concern with some parents. As the legislation stands, a gap exists between the general disapplication of a Hospital school to deliver the National Curriculum under the Education Act 1996, s.350 and the provision arranged by the school, as an institution, under the Education Act 1996 s. 19 and s. 4. If the right to cost effective education is universal (Article 2 of the First Protocol of the European Convention on Human Rights, now embodied in legislation under the Human Rights Act 1998 Schedule 1), and the aims of education apply to all children, as endorsed by the Warnock Committee (DES, 1978) then a critical review of the legislation and criteria

for disapplication of the National Curriculum for individual pupils is worthy of consideration.

Third, diversity existed in the balance of provision that was arranged between the LEA, the school and the family. It follows that continuity of provision, was largely determined by where the child lived and the resources of the family. Inequitable factors underpinning family provision compounded the disparity in opportunity for the child to study in the home, just as the socio-economic status of parents was illuminated as a key factor in the allocation of special educational provision in research conducted by Riddell et al. (1994). There was little evidence in the current study to suggest that a shortfall in family provision, for example the provision of a personal computer, was addressed by the allocation of additional equipment by the LEA or contracted provider other than for Daniel and Paul although some parents received equipment that was donated by voluntary organisations. The lack of resources and equipment in the homes of some parents, brought into focus the dilemma concerning the means by which entitlement would be operationalised in the context of practice, whereby access to the curriculum necessarily required the provision of visiting teacher time and equipment.

6.1.4 Unmet need

First, the diversity of outcomes included some unmet needs. The failure of pupils to routinely access particular types of provision was consistent with

the failure of pupils attending mainstream schools to routinely access appropriate support reported by Mukherjee et al. (2000a). Consequently, the implementation of government policy outlined in departmental guidance pertaining to the education of sick children (DfEE and DoH, 1994) was largely determined by an element of chance.

Second, the quantity of provision received by some pupils fell below the minimum standard recommended by DES and HMI (1989), or the published offerings of individual LEAs (NAESC, 1997a, 1999). Most pupils received nil LEA provision in the home, a finding which finds accord with research conducted by Fassam (1982), Bolton (1997) and Closs and Norris (1997) who noted that for many children provision lapsed following discharge from hospital. Warnock (1997) was most concerned that legislation would prohibit the token allocation for example, of two hours Home teaching a week, advocating that such a scant level of provision should be illegal and yet, the study found cases where this occurred.

Third, the findings show that linked arrangements between the LEA, the school and the family were tenuous. The work of Sieber (1981) concerning conversion mechanisms in public policy was useful here in helping to explain the phenomenon of placation. As families relied on support from the school where the child was registered, the school was thrown into a situation of placating the needs of the pupil, providing school outreach to

provide continuity of provision to varying degrees of success. However, it was likely that the goal of continuity was subverted for some pupils because the situation deteriorated as compromises in arranging provision became unstuck, or illusions of success placed the child at risk of falling through the net of arrangements for educational provision.

A gap existed between the assumptions informing parliamentary decision-making and the findings of the current research in terms of the capacity of a child to receive education when classified as 'sick' or 'ill'. If Bowe and Ball (1992) are correct in suggesting that values and beliefs permeate the processes of policy, then the implicit assumptions of local decision-makers in school or the LEA, may offer an explanation for the level of unmet need for teaching experienced by many pupils profiled in the study. If individual decision-makers believed that a child who was out of school because of illness or injury was incapacitated to the extent that education provision was not needed, or the spending on provision constituted poor value for money, then it would seem that the public campaign led by Stanley Segal (Segal, 1974), who argued that "no child was ineducable" has yet to reach the policy area of exceptional provision.

6.1.5 Opportunity

Opportunity determined the type and quantity of provision available to pupils in hospital and the home. Just as OFSTED (1999) reported that an element of chance determined the type and quantity of provision children

received, had implications for the opportunity of children with special educational needs to learn, so this element of chance permeated the provision that pupils received in the home.

6.2 The consistency of pragmatic factors responsible for diversity

Consistency existed in the pragmatic nature of factors responsible for the diversity of provision that pupils received, identified from the data of LEA professionals and parents. Professional decision-making was pragmatic at the operational level of day-to-day activity, a finding that shows consistency with the pragmatism of professionals responsible for the administration of SEN provision reported by Croll and Moses (1998). There was little evidence in the current study to suggest an overriding adherence to ideology in professional decision-making regarding resource allocation on the basis of special educational needs. Tensions were plainly evident in the policy documents and the accounts of professionals, as child centred principles were largely surrendered to accommodate the fiscal constraints on service delivery. Just as Goodinge (1998) reported that children were assessed for existing services, under the auspices of social services, the findings in the present study showed consistency with the notion of resource led administration.

The findings confirm the validity of the challenge to Parliamentary decision-making asserted by David (1998), when she suggested that entitlement to educational provision as a matter of principle was in practice

subordinate to the pragmatic concern of Ministers to constrain government expenditure on out of school provision.

6.2.1 Discretionary decision-making in professional administration

The diversity of the arrangements and the reported outcomes experienced by individual pupils suggested that education professionals in the LEA and school exercise considerable discretion in determining the type and quantity of the provision and indicative quality of the arrangements for educating pupils profiled in the study. The consistency of pragmatic factors responsible for pupil outcomes, in the aggregate, constrained or distorted decision-making at LEA level.

The power of LEA professionals was vested in three interrelated aspects of their position (Robbins, 1984). First, professionals enjoyed high levels of discretion. Secondly, professionals had relative autonomy from organisational authority. Third, no alternative to state funded provision existed, unless the family had sufficient resources to buy private tuition. These three conditions echoed the prima facia conditions for the seminal thesis explicated by Lipsky (1980) entitled 'Street- Level Bureaucracy: Dilemmas of the Individual in Public Services'. If, as Thomas and Loxley (2001) have suggested, values underpin the motivation of the individual to act, then it is likely that LEA professionals are confronted with a dilemma, when attempting to operationalise personal values within the constraints

imposed by the consistency of pragmatic factors existing within the context of decision-making.

In accordance with Lipsky (1980) the findings suggest that discretion was a relative concept. Rules and directives from above constrained the choices of LEA managers. The means of identification of the population; the level of service set as a quota; accepted norms of medical opinion defining eligibility on grounds of 'illness' or 'injury'; the nature of the four week rule recommended as a threshold to entitlement (DfE and DoH, 1994; DfEE, 2000f), were shaped by government and the medical profession. Administrative norms published by DES and HMI (1989) and DfE and DoH (1994) taken together with a national directory of provision (NAESC, 1995, 1997a, 1999) circulated information about service levels for Hospital and Home teaching to LEAs in England.

On the one hand, rule adherence was confined to the most basic and fundamental precepts of eligibility and entitlement; on the other hand, LEA managers were responsible for arranging education for individual pupils in different educational settings and negotiated with many stakeholders who had an input into the service. It follows that discretionary decision-making about the type of provision and arrangements was an essential facet of the job. LEA managers were charged with arranging education for a sick child, a task that required sensitive observation and judgment, within a context where tensions existed between personal values, compassion and flexibility

on the one hand and impartiality and rigid rule application regarding eligibility criteria on the other.

6.2.2 Accountability

The findings suggested that inconsistent levels of accountability existed.

6.2.2.1 Accountability to a professional reference group

The findings suggest that vague or ambiguous policy documents, for example omitting to specify entitlement to a quota or range of provision, as in A-Shire LEA, or delegating operational responsibility to arrange provision to schools in B-Shire LEA, but maintaining financial responsibility at the remote distance of the LEA, enhanced the opportunity for LEA professionals to exercise discretionary judgments in resource allocation. The data illuminated the notion of a 'funding fog' and the resulting lack of accountability echoes the Government's concern about LEA resource allocation (DfEE, 2000g; DoETR, 2000), with the result that substantial transparency is called for in the execution of the LEA's strategic role.

Accountability was more visible where the Hospital and Home teaching service was delegated to a Hospital school or PRU, as in C, D and E LEAs. OFSTED school inspection reports show that the accountability of the individual manager or head teacher, through school governors, to an

inspectorial professional reference group was substantial, compared with the LEA inspection reports.

The notion that accountability could be exercised through a principle of 'Best Value' that requires an appropriate outcome measure, as suggested by the DfEE (2000f) was hard to conceive, given the findings from the current study. Perhaps the emphasis on quality of life, and the beneficial effects of education on the well being of patients, very much emphasised by Peter (1990), would be a positive step to take. Further research would be needed to develop an instrument which was suitable for educational provision for sick children, for example, along the lines of the General Health Questionnaire used in the Health Survey (Prescott-Clarke and Primatesta, 1999b).

Difficulties in reconciling the responsibility of school governors under the Education Act 1996, s. 4 and the responsibility of the LEA to fund provision for children out of school because of illness was reminiscent of the difficulties expressed by Widdison (1996). He expressed dismay about the prime duty of a speech and language therapist to identify the special educational provision that a child's special educational needs called for and the ultimate responsibility of the LEA to fund that provision, if the local Health Authority was unable to meet the financial cost. Responsibility for funding speech and language therapy was a source of conflict.

OFSTED (2000) has highlighted strategies for evaluating 'inclusive' practice in mainstream schools and has flagged the support that schools offer families where children have long term illness, as an indicator of 'inclusive' practice. If school governors consider that the cost of provision was unreasonably beyond the remit of the school and the LEA was failing to arrange provision for a sick child then the accountability of LEA professionals could be brought to bear locally, on the premise of maladministration, through a complaint to the Local Authority Monitoring Officer. Under the Local Government and Housing Act 1989, s.5 the Officer has a duty to investigate such a complaint and if the outcome of the investigation substantiates a sound legal basis for the concerns raised, then a written report would be the circulated to elected members of the local authority. Thus, a mechanism exists for the school governing body and parents to generate LEA compliance with the performance of their statutory duty to arrange provision.

Further research would be worthy of consideration to illuminate the effects of control and compliance mechanisms operating between the LEA and the governors of the school where the child was registered.

6.2.2.2 Accountability to the individual pupil

A major thrust of government policy, suggested that redress procedures were gaining currency as a means of increasing the accountability of

systems to pupils and parents (The Human Rights Act 1998; The Disability Rights Task Force report, 1999; draft provisions of the SEN and Disability Rights in Education Bill, DfEE, 2000b). The impact of increased professional accountability to the individual, brought about by the duty of care imposed on professionals as a result of the Phelps judgment (Law Lords, 2000), endorsed by the legal profession (Rabinovitz, 2000) but met with reticence by the teaching profession (Hart, 2000) warrants further research.

Accountability operating through redress, however, assumes that the client consumer will use the procedures to safeguard individual rights and police the degree of professional compliance with statutory duties and discretionary powers. Research conducted by Harris (1992, 1993) suggested that redress procedures were little used. Research conducted by Davies (1993) showed that complaint action was threatening for teachers and parents, and therefore the impact of redress procedures in bringing about the compliance of decision-makers with statutory duties is an area worthy of further research.

6.2.3 Conditions of work

The findings from the current study suggested that LEA managers operated in circumstances which were characterised by four sets of conditions: inadequate resources; a level of unmet need such that demand for service outstripped the resources available to meet the supply; goal expectations

that were ambiguous or were in conflict; and performance measures that fostered a climate of competition within each domain. These conditions showed consistency with the conditions underpinning professional practice in public services explicated by Lipsky (1980).

The overall climate of the LEA funding regime suggested that the LEA was not an encouraging supplier in some cases, because of the over commitment of resources and in this respect echoed a further element of Sieber's (1981) model of conversion mechanisms relating policy intention to policy outcome. The over commitment of resources has implications for gate keeping practice and is an area worthy of further research.

However, where the service was delegated in its entirety to a Hospital school (D-LEA), according to full-time equivalent pupil places, the head teacher had control on spending, which protected the service from arbitrary spending stops on tuition imposed by the managers residing in the hierarchy of the LEA bureaucracy. The placement quota for registered pupils generated funding for pupils through the local management of schools or fair funding scheme (DfEE, 1998j) and thus pupils out of school, who were registered at the Hospital special school, were not lost to funding.

It was likely that a hierarchy of conflicting goals existed within the network of stakeholders. At the level of the Hospital and Home teaching service policy; at the broader level of level LEA policy for support services, fair funding and delegation; and then at the level of the school.

Was the increased delegation of monies to school leaving the Hospital and Home teaching services more isolated as Fletcher-Campbell and Cullen (1999) have found in their study of the impact of delegation on LEA support services? Furthermore, if school centred goals were more focussed on academic attainment and league table position, then the competitive climate fostered within schools (exemplified in research conducted by Bagley et al.,1996; Bagley and Woods, 1997; Woods et al., 1998) would suggest that the organisation centred goals of the school and the LEA may not be in unison.

Cumulative minor changes to the Education Act 1996 have potentially facilitated a fatal remedy leading to the fulfilment of Welton's (1989) prophesy of catastrophe for disabled children. In Sieber's (1981) model of conversion mechanisms operating through processes of policy, a culture clash, brought about by conflicting goals and performance measures, set the scene for the reversal of policy intentions. If the primacy of child centred goals were subverted, then individual pupils would miss education, unless parents had the resources and skills to support the child's education themselves. Thus the test of the policy was likely to rest on the strength of the compliance mechanism that parents and school governors would apply.

6.2.4 Conclusion (1)

Given that consistency existed in the pragmatic nature of factors related to the outcomes described by parents, and the data from LEA documents and

professionals perceptions, regarding professional administration the researcher concluded that LEA professionals exercised substantial discretion in decisions about the type of provision and indicative quality of the arrangements, but less discretion regarding the quantity of provision received by pupils recognised by the service. The diversity of family provision contributed to the diversity of the outcomes for pupils also. These reasons taken together lead to the conclusion that professional decision-making was constrained by pragmatic factors.

6.3 The effects of professional decision-making in the administration of provision: rationing and resourceful management

The analysis of LEA managers' perceptions illuminated a dominant theme of pressure, generated mostly by an inadequate quantity of financial resources available to match supply with demand. As such, the findings of the study were at variance with the research conducted by Vincent et al. (1996) who reported the substantial effect of parental pressure influencing resource allocation in the administration of special educational provision at LEA level.

LEA professionals were under pressure to control spending. Consequently, professionals adopted working practices and routines that rationed resources, the effects of which *hindered* access to segregated provision and *promoted* continuity with the mainstream peer group.

Working practices that *hindered* meeting a pupil's individual needs included fixing the level of service as a quota, limiting the dissemination of information about the service and controlling demand through the referral procedures. These are all practices which Lipsky (1980) suggested had the effect of artificially depressing demand and rationing resource allocation. Pupils experienced the outcome of rationing as delay in the referral process and as a queue of pupils waiting for LEA provision. Accommodating pupils in the referral procedures and a queue of pupils waiting for service was functional to the LEA, as these structures represented symbolic services when actual services were not available. The rationing of Hospital and Home teaching in England is not a new phenomenon, since it was reported in the literature as long ago as the Warnock Report (DES, 1978) and by Fassam (1982). The limited access to information by parents was consistent with the findings of multi-agency inspection reported by Goodinge (1998). Rationing of special educational provision was reported also by Weatherley and Lipsky (1997) in the USA.

The findings suggested that children at Key Stage three and four were prioritised within the Hospital and Home teaching service procedures. Lipsky (1980) used the analogy of a 'triage' system to explain inequalities in the administration of public services. All children have an entitlement to educational provision but the phenomenon of inadequate resources generated pressure for differentiating among children in need of teaching.

Second, since professionals practiced resourceful management, the findings suggested that the determining factor that influenced LEA professionals' decision-making and *promoted* continuity with mainstream provision was the pressure of inadequate LEA resources. The findings show that LEA professionals had substantial choice and flexibility in decision-making regarding the balance and type of provision arranged to meet the need for teaching children in isolation or in a group setting. Flexibility in decision-making promoted efficient use of visiting teacher time, enabling a change in the type of exceptional provision to occur as necessary, and withdrawal of provision as necessary at the discretion of the LEA manager. The timely response to individual needs released resources for other pupils, and promoted the efficiency of the service to accommodate more pupils in the service structure. Thus, flexibility in decision-making was related to efficient provision of suitable education, a desirable effect in the eyes of the Audit Commission (1992) and the government department (DfEE, 2000f). Conversely, the findings of the study suggested that special educational provision was inflexible if it was directed solely to the school placement and omitted to specify education otherwise as a part-placement in part four of a Statement.

As provision followed the pupil, it could be argued that the administration of exceptional provision was commensurate with the requirement for flexibility stated in the SEN Code of Practice (DfE, 1994, para 4.28). In the

context of inclusion, flexibility was deemed to be a necessary prerequisite specified by the government in the SEN Programme for Action (DfEE, 1998a). However the notion of flexibility in arrangements for provision was seen as a negative element in special educational provision by Weatherly and Lipsky (1977) who interpreted an increase in the pupil/teacher ratio as a means of rationing resources that were intended for individuals. Wright (2000) and Parliamentary debates during the passage of the Special Educational Needs and Disability Bill [Lords] (Parliament, 2000b) through the House of Lords and Commons emphasised the need for specificity in the wording of the Statement in order to ensure that the individual child received the type and quantity of provision that was really needed to meet the child's needs.

The status of dual registration of pupils bound the school into the arrangements, through school outreach and part-time attendance and enabled some displacement of cost to the schools and parents (Lipsky, 1980). Arguably, one benefit for children, arising from LEA goal displacement was the continuity of social contact with peers and was likely to promote the personal development and well being of the pupil, a phenomenon which was viewed positively in the health literature regarding continuity of care (Date, 1986; Johnson, 1990; Evans, 1992; Belson, 1993). However, goal displacement had implications for the quality of provision that pupils received. Although, on the surface it appeared that continuity of

provision with mainstream school was enhanced, one could argue that placation occurred as schools arranged provision of inferior quality to LEA funded provision. It could be argued that LEA funded provision was really needed if the pupil was to receive suitable education.

The findings suggested that professionals were under pressure to exploit the environment and utilise the school and parents to conserve LEA resources. The notion that pressure exerted at one point in the network had ramifications for the flow of resources within the micro-economic and political climate of the network finds accord with the work of Benson (1975). Furthermore, the effect of fiscal constraint on professional decision-making finds consistency with the notion that resources act as the determining and limiting factor in conversion mechanisms operating within processes of policy illuminated by Sieber (1981).

The tendency for LEAs to displace responsibility for provision had implications for the roles and responsibilities of school teachers and governors and parents. The findings suggested that the initial gap in provision became protracted for some pupils and the variability of school outreach provision seemed to reflect the ambiguity in the roles and responsibilities of the school governing body and the LEA towards this group of children and finds accord with the research conducted by Mukherjee et al. (2000a). Where roles and responsibilities were vague, Weatherley and Lipsky (1977) illuminated the likely slippage in meeting

the needs of children with special educational needs, if it was assumed that provision was 'somebody else's problem'. Whereas Mukherjee et al. (2000a) reported that support for pupils with medical conditions in mainstream school, was provided through the SEN and pastoral system, parents in the current study communicated with the school predominately through the pastoral system which implies that ambiguity existed in the procedures for the identification of pupils. Thus the results of the study have implications for professional decision-making regarding the identification of pupils needing additional provision and operational procedures to provide support through the pastoral route (DfEE, 1999e) or through the SEN Code of Practice following the withdrawal of the SEN register maintained by schools (DfE, 1994 and forthcoming 2001).

6.3.1 Conclusion (2)

In conclusion, the data from LEA professionals suggested that the main effects of professional decision-making in the administration of provision were rationing and displacement of responsibility for provision to the school and parents. Taking together the consistency of pragmatic factors responsible for the type of arrangements and evidence of rationing the quantity of resources allocated, the researcher concluded that the determining factor influencing professional decision-making was inadequate resources to fund LEA provision.

6.4 The effects of parental involvement in the process of professional decision-making

The findings presented in section 5.4.1. show that most parents communicated their perceptions of the child's needs to professionals informally, a finding, which shows consistency with the research conducted by Bolton (1997), Closs and Norris (1997) and Norris and Closs (1999). Parents were active or inactive, in seeking service on behalf of the child, depending on their self-assessment of the child's needs. Theories of motivation suggested by Maslow (1987) afforded an explanation for the actions or inactions of parents and the data suggested that parents sought gratification, on behalf of the child's unmet needs, at the school where the child was registered, as indeed parents are increasingly encouraged to do so within the remit of the home school agreement (DfEE, 1998e).

The diversity of the parent role finds accord with the role of 'implementer' and 'client' identified by Fylling and Sandvin (1999). The notion of teamwork at the point of curriculum delivery echoes the altruistic notion of partnership of the Warnock Committee recommendations (DES, 1978). Although parents in the study influenced the type and indicative quality of the arrangements, the fact that parents were unable to influence directly LEA decisions about the quantity of exceptional provision was inconsistent with the critical speculation of Corbett and Norwich (1997) and research conducted within the SEN paradigm under the Education Act 1996 part

four, by Riddell et al. (1994) and Vincent, et al. (1995). Since the findings in the present study show that provision was rationed, there was little evidence to support the argument of Richards (1998) that the 'hard duty' under the Education Act 1996 s. 19 was likely to drain the funds of the LEA to the detriment of discretionary applications and the statutory assessment of children with special educational needs.

6.4.1 Conclusion (3)

The data from LEA documents, professionals and parents suggested that the main effects of the informal involvement of parents in professional decision making was parental influence on the type and quality of provision, but not the quantity of LEA provision. Given the limiting factor of inadequate resources and the lack of influence of parents on the quantity of LEA resources allocated, it was likely that financial pressure within the LEA caused the displacement of responsibility for provision to schools. The implications of the findings within the broader context of the LEA are now considered.

The findings show that LEA policy was in state of flux. The LEA behaviour support plan consultation process (DfEE, 1998b) and the published plans that were submitted to the DfEE, were likely to structure the policy choices of LEA managers regarding provision for children out of school (DfEE, 2000d; Kinder, Wilkin, White and Kendall, 2000). The wider context of inclusion, suggested LEAs had a role to play in developing

inclusive policies and practices (Ainscow, Farrell, Tweddle and Malki, 1999). LEA policy was concerned to reduce segregated provision (DfEE, 1997a) and support the thrust to delegate an increasing proportion of the General Schools Budget to schools (DfEE, 1998j; Gray, 2001).

Government control on LEA spending was exercised locally through the standard spending assessment at LEA level and the capital grants available to schools and LEAs, issued centrally by the Standards fund (DfEE, 2000h), targeting specific areas of policy. In this respect the specification of an objective to "improve education for children unable to attend school because of illness and injury" as part of the Standards Fund allocation for 2001-2002, was a welcome sign that the education of sick children was to be prioritised (DfEE, 2000h).

In the broader context of LEA services parents of sick children exerted little or no direct pressure on professionals regarding the quantity of resources allocated. The analysis suggests that the position power of the parent was constrained fundamentally by the weakness of their power base, in terms of access to information and by their informal participation in professional decision-making at LEA level (Robbins, 1984).

One significant difference between the frameworks of exceptional and special educational provision was the involvement of parents in the identification of needs. The administration of exceptional provision positioned parents low in a hierarchy of citizens, who were awarded

differential rights to participate in decision-making processes, depending on whether the identification process was operationalised through the exceptional or special educational needs framework. Whereas the SEN Regulations (1994) reinforced the operational procedures to enable parents formal participation in professional decision-making and thus increased the position power of parents to influence the type and quantity of special educational provision allocated, exceptional provision was governed informally, with the result that parents had little position power.

Given the fact that most pupils profiled in the study were without a Statement of SEN, implied that the identification of pupils with medical conditions was operationalised solely under Education Act 1996, s. 19, in preference to the SEN framework under part four of the same Act. Thus, it could be argued that the primacy of the hard duty under the Education Act 1996, s. 19, accounted for the administration of individual provision for sick children.

The Green Paper 'Excellence for all Children' (DfEE, 1997a) included in its proposals, a decrease in the variation of provision across the country. If the administration of an umbrella framework under the Education Act s. 19 took precedence over the SEN framework, for all children who were classified as 'vulnerable', then arguably diversity in the quantity of resources allocated would diminish and fall within a narrow range. If the classification 'vulnerable' became a dominant descriptor in the

identification of children who required individual provision then arguably the pragmatism of resource led administration could lead to the rationing of resources for all children.

On the one hand, it could be argued that policy processes had enabled a 'fatal remedy' (Sieber, 1981) to concerns expressed by Marks (2000) about the cost of SEN provision. The possibility existed that reverse effects would subvert policy goals intended to support the inclusion of disabled children in mainstream provision. Since the principle of needs led provision was subverted, provision specified and quantified on a Statement would be illusive. On the other hand, it could be argued that the legislation necessarily enabled professionals to ration resources in order to distribute the quantity of provision more evenly among the population of children.

Marks (2000) reconciled the tension between needs led funding for SEN provision specified on a Statement and the escalating costs borne by the LEA, by suggesting that the principle of needs should be abandoned, in favour of special provision determined simply by a category of disability. If that were so then the model of administration of exceptional provision for children out of school because of illness, explicated in the current study would have substantial relevance to the administration of individual provision for all children who have a disability. Moreover, the notion that entitlement would be divorced from the identification of special educational

needs and the identity of special educational provision would raise a moral dilemma for professional decision-makers.

In reality, since unmet need existed because pupils failed to reach the point of recognition by the LEA service, equality of entitlement to LEA funded exceptional provision for children profiled in the study was a myth. In contrast to the aspiration expressed by Warnock (1991) when she criticised the link between needs and the identity of provision, the evidence from the study suggests that professional discretion underpinning entitlement without the identity of provision enabled rationing of resources to the extent that unmet need existed.

Just as Goacher et al. (1988, p. 163) suggested that the Education Act 1981, set in train a paradigm change as professionals were required to 'take account' of the views of parents, so the findings from the study suggest that a further paradigm change has taken place. The findings of the study suggest that a consolidation of the consumerist role for parents has occurred. The paradigm is modelled on self advocacy and redress on the one hand, along with responsibilities for the development of a partnership at the point of service delivery on the other.

Lipsky's thesis (1980) suggested that ambiguity in policy goals and the autonomy of the decision-makers enabled professionals to exercise control over policy to the extent that it provided a mechanism of legislative conflict resolution, where intractable conflicts were settled (or not) in the context of

practice. The intractable tensions between the rationalisation of public expenditure in terms of the efficient use of resources and the magnitude of a child's individual need for teaching, or special educational provision, when absent from school, was irresolvable, unless the Government supported financially, the intentions of Parliament. In reality, the findings suggest that the balance of responsibility for the educational provision of sick children was shifting from the LEA towards the school and ultimately to the parent. State control was extending, through the home-school contract, to regulate the role of parents in supporting the child's learning in the home, emphasising the responsibility of parents (Blair and Waddington, 1997; Brown, 1990). In practice, the findings suggest that parents of sick children accepted substantial responsibility for education and health care provision.

The government has invested considerable currency in the potential effect of information and communications technology (ICT) on the education of children out of school because of illness as a means of creating opportunities for learning (DfEE, 2000f). However, the findings suggest that a gap existed between the context of practice and the government intentions represented in the context of policy text production. At the time of the field work (March 1998-1999) Internet access had made little penetration into the homes of parents in the study. Only a minority of parents in the study were alert to the potential of ICT enabling electronic

access to the community of the home school. Thus the notion of meeting the curriculum needs of children who were out of school, under the auspices of ICT and distance or open learning, is an area that warrants further research. Further research is needed to understand the impact of the culture of the school on professional decision-making and resource allocation for this group of pupils. Further research is needed to ascertain the role of the private sector in the arrangements for educating sick children as part of a co-ordinated national strategy.

6.5 Professionals' and parents' perceptions

Most parents were content for LEA professionals to act as experts in arranging provision and assumed responsibility for family provision. A multiplicity of power relations existed between LEA managers, hospital and home tutors and parents and between schools and parents. It was likely that the individual's source of power and the strength of their power base within the different cultures of the LEA, the school and the family, produced a resultant effect, indicated by the diversity of provision that pupils received (Robbins, 1984).

However the diversity of parent needs that existed, impinged first on the parental perceptions of the child's needs and second, on the capacity of the parent to communicate the child's needs to professionals, the fortitude and persistence of parents and the amount of parent pressure exerted to gain school outreach provision or a referral to LEA provision. It was likely that

the diversity of parents needs impinged directly on the opportunity for pupils to study school work in the home, just as research has linked scholastic performance with parents' socio-economic status and extra familial resources (Hoffeth, Boisjoy and Duncan, 1998).

Parents wanted to support the child's learning in the home, but most parents lacked knowledge, skills and resources and thus their power to affect the child's situation was weakened. Would Fielding's (1996) interpretation of empowerment suggest that responsibility to cause their children to receive education rested with parents, with the result that State responsibility for provision was abandoned? Would Fielding (1996) interpret parental involvement in curriculum delivery and family provision the result of state manipulation and therefore render parents enervated by the state, or view parents as empowered individuals because they influenced situations in order to enhance opportunities for learning in the home?

Clearly the source of power and the strength of the parent's power base constituted a vital element of the policy process in the context of practice, in directing resources to pupils in need. Those parents of sick children who had the necessary resources, enabling them to support learning in the home, were powerful in the sense that their degree of emancipation was reflected in the type and quality of provision pupils received. For some parents, their power base extended beyond the family, mobilising support networks and involving various professionals and members of the community to redress

the imbalance in power between professionals, pupils and parents so clearly described by Malcolm, Peake and Walker (1996). For other parents, support networks were lacking, with the resultant effect that individual pupils fell through the net. Since parents were isolated and were unable to influence LEA professional decision-making regarding the quantity of resources allocated and consequently passively assumed responsibility to liaise between stakeholders it could be argued from the position asserted by Vincent (1996), that parents were not empowered as agents in a democratic learning society.

The quality of professional parent relations at the provider boundary, or in partnership for curriculum delivery was related to the skills of individuals, resources available to meet needs and the time available for liaison. A pervasive theme of goodwill permeated the relations between LEA professionals and most parents, which was at odds with the image of conflict evident in studies of parental involvement in professional decision–making regarding the identity of special educational provision reported by Cornwell (1987), Galloway et al. (1994) and Weatherly and Lipsky (1977). Whereas contemporary commentators (Simmons, 1998; Wright, 1999; Gravell, 1998, 2000) allude to the provocation of parents in response to government proposals perceived to weaken the SEN legislative framework, there was little overt expression of anger emanating from parents interviewed in the current study. Nevertheless, in situations where pupils

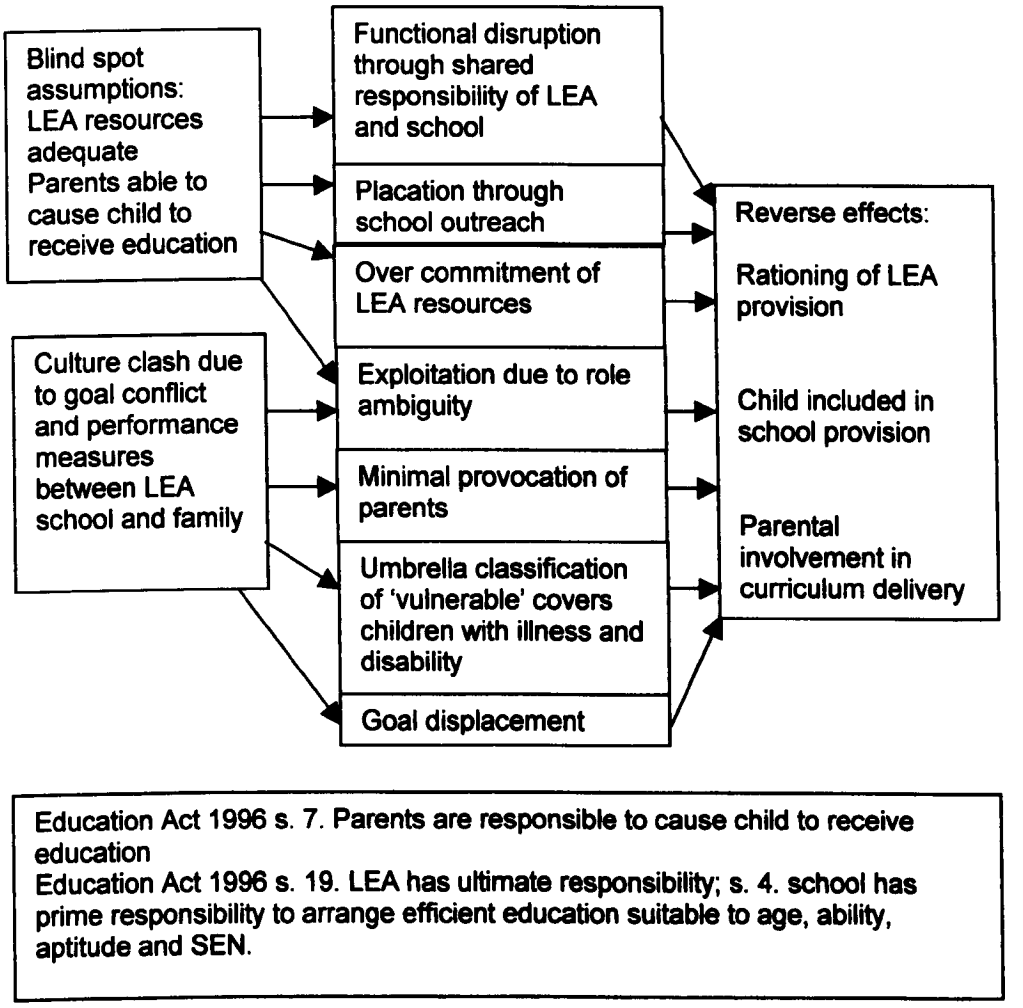
received two hours teaching per week, for an extended length of time, parents rationalised the lack of provision in different ways, but anger was expressed ultimately as a value judgment in terms of justifying the worthiness of one child to receive provision above another. In the eyes of these parents of sick children profiled in the study, legislative rights were a minor issue, if not an issue that remained unrecognised.

6.5.1 Conclusion (4)

The discourse of participants suggested that professionals were in control of the decision-making process and parents accepted responsibility to liaise between stakeholders. The diversity of parents needs was related to the effectiveness of the parent to influence decisions or situations that impinged on the type and quality of provision that pupils received. Parents require information about services, which are available to sick children and advocacy in order to negotiate the processes of policy and secure the child's entitlement to suitable education when absent from school. Parents need support to acquire knowledge, skills and understanding in order to support the child's learning in the home, and the provision of equipment if necessary where family provision is lacking.

6.6 From policy intention to outcomes and effects

Figure 6.1 From policy intention to outcomes and effects



The model presented in Fig 6.1, modelled on Sieber (1981) explains a mechanism by which invisible processes are likely to reverse the intentions

of Parliament. The strengthening of the legislation regarding exceptional provision and the commonality of education otherwise to the Education Act 1996 s. 19 and part four of the same Act enabled local policy making processes to be operationalised through the discretion of professionals. The result was diversity in the type of provision that pupils received, less diversity in the quantity arranged due to rationing and substantial parental involvement in family provision.

It would seem that the findings of the study represented in Figure 6.1 reflect the ironies of social intervention codified by Sieber (1981). In order to avoid 'fatal remedies', he called for the development of a 'moral consensus' based on shared values, but recognised the danger of ideological naïveté denying that forces of retrogression are inherent in the forces of progress. This would be an area worthy of further research.

This chapter has discussed the implications of the findings for decision-makers. The chapter noted the consistency or inconsistency of the findings with existing research and allowed a series of conclusions to be drawn. The reliability of the conclusions and implications for further research will be discussed in chapter seven.

7 SUMMARY AND IMPLICATIONS FOR FURTHER RESEARCH

This thesis reports on a study which investigated LEA policy for educating children out of school by reason of illness under the Education Act 1996 s. 19 and the effects of decision-making on outcomes for children in order to contribute to policy development in the area of parental involvement. The research was carried out in LEAs covering both urban and rural areas of England. In depth, qualitative data were collected from parents of 35 children residing in 18 LEAs, and LEA professionals responsible for Hospital and Home tuition services working in seven LEAs.

The reliability of the empirical evidence presented in chapter five together with the link between the research design to the structure of the argument supporting the conclusion is evaluated. The implications of the findings for further research are discussed.

7.1 Limitations of the study

7.1.1 Sample

A replication strategy for data collection added strength to the study. However the response of parents varied by LEA, with response being lowest in F-LEA, and highest in B-LEA. A more consistent distribution of parents within the sample of the case LEAs would strengthen the capacity

of the study to compare administrative processes between LEAs in order to identify effective practice. For this reason, themes illuminating the type, quantity and quality indicators of provision received by pupils were derived from the data collected within and without the case study LEAs.

The opportunity sample of parents was inherently biased as response to the interview was higher among women than among men. Consequently, the findings relating to the effect of parental involvement in professional decision-making was biased towards the involvement of mothers.

Further corroboration of a medical diagnosis was not sought for ethical reasons. The criteria for the selection of parents were determined by the generic classification of illness based on self-reported information about their children. The terminology would not necessarily correspond to the medical diagnosis.

Bias in the purposeful LEA sample was checked by comparing the consistency of outcomes in terms of the hours of provision pupils received, between the volunteer and case study LEAs A-G, with evidence of outcomes for pupils gathered from non-case LEAs, for pupils recognised by the service and the balance of provision arranged by the LEA, the family and the school (section 5.1.3.6). The allocation of provision was skewed slightly, towards an increase in the hours of visiting tuition allocated to pupils residing in non-case LEAs, but an increase in the proportion of pupils that fell through the net, in non-case LEAs. The implication of

sampling bias, in terms of reliability of the data, was that stronger links existed between the LEA and schools in the case LEAs A-G, than for LEAs H-R. It was likely that sufficient consistency existed between outcomes for children in the LEAs A-G and LEAs H-R to allow some generalisation of the findings about processes of professional administration in the light of data collected nationally by NAESC (1997a, 1999). However, given the tentative nature of generalising claims to knowledge based on a small sample, the study would be strengthened by further research in order to gather data about the type and quantity of provision that pupils received on a larger scale in order to map the outcomes and effects of policy in this area.

7.1.2 Collecting and analysing qualitative data

Firstly, data collection took place following the pilot study. The revised methodology added strength to the data collection procedures. Interviews conducted by telephone yielded data of comparable quality to face-to-face interviews, but tended to be shorter.

Second, Foster et al. (1996) have argued that interview transcripts contain second hand information and for this reason, the validity of a conclusion must be weighed against the accuracy of the data. Since a gap in time existed between the actual experience of the phenomenon and the parent or professional recalling the experience, inaccuracy of recall was a potential threat to the reliability of the findings and so parents and professionals were

encouraged to check information with documentary sources and some parents provided copies of letters and school reports. Following transcription, accuracy of the draft was checked by participants. In the present study, verification of the information can be obtained by returning to the original source and documentation of facts. Thus, corroboration was an important strategy used to strengthen confidence in the findings.

Third, for most parents the immediate experience of acute emotion stress, associated with an emergency admission to hospital, or the news of a medical diagnosis had passed. Most parents were calm, often demonstrating a sense of humour during the interview with the exception of two mothers who showed signs of distress. Since most pupils that were profiled in the study were attending school when the parent was interviewed, parents were not distracted and were able to concentrate on the interview guide. Overall, the impression of parents coping in a positive manner when caring for a sick child finds accord with research conducted by Douglas et al. (1998) and Foster, Bryon, and Eiser (1998) on levels of self- reported stress, and Webster-Stratton (1990) on stress as a potential disruptor of parent perceptions and family interactions. The health literature suggested that parents responded to their circumstances in a matter of fact way.

Fourth, there was little reason to question the authenticity of the accounts of professionals and parents since participants had first hand experience of professional administration, either as a provider or as client consumer.

Participants did not achieve any material gain from participating in the study and there was no evidence to suggest that vested interests motivated individuals to mislead or lie to the researcher. Furthermore, professionals in different LEAs were unknown to each other, as were most parents.

Fifth, the researcher has written elsewhere about the reliability of the human instrument when the researcher was positioned as one and the same as the researched, and recommended the use of systematic procedures in order to enhance analytical rigor and to separate the effects of the researched on the researcher (Davies, 1997). The use of the Access® database and systematic data retrieval procedures using a word processing program strengthened the consistency of the researcher's judgment exercised in the conduct of the analysis. Compiling a database was time consuming but the researcher was impressed with how well it supported the identification of themes from patterns in the data, and would recommend the use of 'Framework analysis' (Ritchie and Spencer, 1994) in applied policy research using qualitative data.

It would be worth exploring participant observation as an alternative methodology as suggested by Gitlin et al. (1993). Although the researcher has conducted participant observation, reporting the findings arising from this method of research is problematic for ethical reasons (Davies, 1997). Nonetheless, the insights gained from pre-existing and unreported participant observation provided a launch pad for the present study.

As Sparkes (1995) might describe, this research report constitutes a 'scientific tale' using a textual strategy consistent with a 'style of no style', which objectifies the position of the researcher through depersonalisation. The technique implies that participants were subjects of the study but the researcher did not view participants as subjects during the process of data collection, in order to respect the dignity and integrity of the individuals who kindly participated in the research.

However, during the process of writing the report the researcher found the textual strategy useful in maintaining a distance from underlying issues, which were value laden and politically volatile. Having said that, although the author vanished from the text after a brief introduction in reality she dominated the text as the 'absent author' and scientific narrator.

Ultimately the use of reported information raises questions about the reliability of the findings, even though a process of corroboration was used. The empirical evidence alone is insufficient to support a firm conclusion. This is not to debase the quality of the present study, but simply recognises the difficulty of conducting evidence based research in this substantive field. In the same way that Larcombe (1995) suggested that the research she conducted, based on reported data was inconclusive, so the empirical findings of the present study would be considered inconclusive. For these reasons, the validity of the conclusion rests on the strength of the argument

and the link between the evidence and the conclusion illustrated in Appendix 9.9.

7.2 Reasoning to support the main conclusion

Appendix 9.9 illustrates the relationship between the findings and the structure of the argument.

7.2.1 The diversity of arrangements made for provision (aim1).

Overall, the data from parents suggested that diversity existed in the type of provision and quality of the arrangements, but less diversity existed in the quantity of LEA funded provision that pupils received once they gained recognition by the service.

7.2.2 Factors responsible for that diversity (aim 2)

Consistency existed in the pragmatic nature of factors related to the outcomes described by parents, and the data from LEA documents and professionals' perceptions. Enabling legislation and inconsistent levels of accountability allowed LEA professionals substantial discretion in decisions about the type of provision that pupils received, and indicative quality of the arrangements. The diversity of family provision contributed to the diversity of the outcomes for pupils also.

7.2.3 *The effects of professional decision-making in the administration of provision (aim 3)*

The data from LEA professionals suggested that the main effects of professional decision-making in the administration of provision were rationing and displacement of responsibility to the school and parents.

Given the pragmatic nature of factors responsible for the diversity in the type and indicative quality of LEA provision that pupils received, together with evidence of rationing the quantity of resources allocated, the study concluded that the determining factor influencing professional decision-making was inadequate resources to fund LEA provision.

7.2.4 *The effect of parental involvement in process of professional decision-making (aim 4)*

The data from LEA documents, professionals and parents suggested that the main effects of the informal involvement of parents in LEA professionals' decision-making was parental influence on the type and quality of provision, but not the quantity of LEA provision.

Given the limiting factor of inadequate resources and the lack of direct influence of parents on the quantity of LEA resources allocated, it was likely that financial pressure within the LEA caused the displacement of responsibility for provision to schools.

In the broader context of the LEA as provider, the argument at this point extends in principle to parents of children who are identified as 'vulnerable' under the remit of the Education Act 1996, s. 19. The evidence of inadequate LEA resources and the lack of parental influence on the quantity of LEA resources allocated as exceptional provision, allows the researcher to conclude that these findings had implications for the distribution of resources allocated for individual provision within the LEA. The argument at this point finds a parallel to parental involvement in the decision-making process concerning the identification of need within the administration of special educational provision. The fact that the majority of pupils profiled in the study did not have Statements of special education needs justifies the belief that a new paradigm of administration of individual provision, that is different to special educational provision, has emerged.

7.2.5 Professional and parent perceptions of the decision-making process (aim 5)

The discourse of participants suggested that professionals were in control of the decision-making process and parents accepted responsibility to liaise between stakeholders. The diversity of parents' needs was related to the effectiveness of the parent to influence decisions or situations that impinged on the type and quality of provision that pupils received.

7.2.6 The feasibility of alternative conclusions

It could be argued that parental involvement in professional decision-making under the Education Act 1996 s. 19 speeds up decision-making as professionals play the role of expert, including the child in decision making about the curriculum directly. It follows that rationing of services under the Education Act 1996 s.19 is a fair way of distributing limited resources to the entire population of disabled children narrowing the gap between winners and losers, if and only if sufficient resources are available for all children. Here lies the flaw in the argument leading to an alternative conclusion, since the research suggests strongly that resources were the determining factor in professional decision-making. If, and only if adequate resources were available then the evidence of a gap between LEA and school provision would imply that ambiguity in role expectations and responsibilities relating to the identification of pupils was ultimately responsible for the diversity in provision that pupils received.

7.3 Possible areas for policy development

The main implications of the study for policy development in the area of parental involvement are that parents require professional support in four different ways. First, in the role of client consumer, parents need information about the pupil's entitlement to provision under the Education Act s. 19. Information about the child's entitlement to services could be provided by publication in the school brochure, information leaflets

disseminated by doctors and nurses, or access through the local authority Internet website. Second, most parents in the study were bewildered in relation to identifying a starting point for the pupil's learning in the home, and needed professional support in order to support the pupil's learning activities. Third, because of the diversity in parents' needs, parents may require access to equipment and curriculum materials to be used in the home. Fourth, parents require advocacy to be operationalised on behalf of the pupil, perhaps through the co-ordination of different agencies in order to secure the child's entitlement to suitable education when absent from school.

Decision-making of Hospital and Home Teaching service managers about resource allocation was constrained in the face of limited resources. However there were signs that LEA visiting teacher provision was augmented by the use of interactive computer software and electronic communication by e-mail or fax for a small number of pupils profiled in the study. There were signs that policy in LEAs A and D was moving in this direction. In the fullness of time, a national strategy, which capitalises on providing access to computer based interactive software and the Internet could augment opportunities for learning for this group of children.

7.4 Implications for further research

The findings of the study have implications for further research regarding policy development in the area of parental involvement. The principle of

access to goods and services for disabled citizens underpinning the Disability Discrimination Act 1995, now applied to education with the enactment of the Special Educational Needs and Disability Bill/ [Lords] /Act (Parliament, 2000b) brings with it significant implications for policy development regarding opportunities to access the curriculum for this group of children. There is much to be learned about the impact of the new legislation on the type and quantity of provision received by pupils and the indicative quality of arrangements for educating vulnerable children.

The relationship between the principle guiding resource allocation on the basis of curriculum entitlement under the Education Act 1996 s. 19, and the identification of needs under part four of the same Act, on the type, quantity and quality of provision that vulnerable pupils receive is an area worthy of further research.

7.5 Dissemination activities

The author disseminated the outcomes of analyses regarding the conceptual field of the research, the empirical findings and implications of the study for decision-makers during her period of registration for the professional doctorate in Education. A brief account of the opportunities that arose for dissemination and published work is to be found in the Appendix 13.

7.6 Contribution to knowledge

The study has provided new information about the impact of the decision-making process on outcomes for children under the Education Act 1996 s.19. The study has made a contribution to knowledge regarding policy in action.

7.7 Chapter summary

This chapter has evaluated the reliability of the empirical evidence presented as reasons supporting intermediate and a main conclusion. It identified recommendations for policy development in the area of parental involvement and professional practice. The chapter has noted areas worthy of research to be taken forward by others in relation to the contribution of knowledge arising from the present study.

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9 APPENDIX A: RESEARCH PROCESS

9.1 Background information

Sample from NAESC (National Association for the Education of Sick Children) (1997a) *Education for Sick Children. Directory of Current Provision in England and Wales 1997*, October, London: NAESC.

DESCRIPTION OF PROVISION: Registered hospital school also providing home teaching

HOSPITAL SCHOOL

The School has detailed Admissions and SEN Policies. These emphasise, amongst other things: access to high quality education and training, including the National Curriculum; provision for all special needs pupils with or without Statements; fast and effective liaison with the child's own school. Policy is to admit from day 1 pupils of statutory school age who are: in hospital for 3 days or more, recurrent admissions, sibling of seriously ill child, children with SEN, examination candidates, short stay admissions with likely need for subsequent out of school provision, children for whom a special request has been made by a consultant. Liaison between teaching and medical staff to ensure pupils on school roll are able to access that education.

Criteria for Receiving Hospital Teaching: Other criteria, e.g. condition/ treatment pattern (details above).

Hours Offered: see above

HOME TEACHING

Entitlement based on length of convalescence/ length of period of absence from school/ case made by medical professionals. Immediate provision for on-going long term medical problems. If the child has a predicted absence of 3 weeks and following illness/ injury, tuition is set up as quickly as possible. Cases of prolonged absence picked up as and when School notified.

Criteria for Receiving Home Teaching: See Details.

Hours Offered: 5 hours per week

When does teaching start? Immediately discharged from hospital or after 3 weeks absence from school.

Mechanism For Activating Home Teaching: All referrals received from EWO, medical professionals, schools etc., must be backed up by the recommendation of a consultant/ GP (either by letter or an appropriate referral form).

Designated Contact For Notification: Hospital School staff.

Where is Teaching Based? A combination of home, tuition centre and hospital bases; home school.

POST 16 PROVISION

Each referral is looked at on an individual basis.

Additional tuition for exam pupils? Yes

Exam pupils in hospital admitted from day one. Exam pupils out of school on tuition for medical reasons: each request for extra hours would be looked at on an individual basis.

9.2 Pilot study

9.2.1 Developing the interview protocol

Six key questions and probes were tested.

Could you describe the types of arrangements made for provision?

Probe: Who is responsible?

Could you describe the referral routes?

Probe: Does it matter which route is taken?

Probe: Are there any exceptions?

Could you describe the sort of factors that influence the decisions about the provision?

Probe: Provision / no provision

Probe: Hours allocated

Are decisions about provision flexible? Are there any exceptions?

Probe: Age ability aptitude

Probe: Parents asking for provision?

Does it make a difference if a child has a Statement for SEN provision?

Probe: Placement

Could you describe any broader influences that make a difference to the arrangements?

Probe: Doctor perceptions

Probe: LEA policy priority

What part do parents play?

Probe: In decision-making

Probe: Choice

9.2.2 Revised interview protocol (LEA professionals)

Question "what part do parents play?" added; prompts and probes removed.

9.2.3 Revised protocol

Could you describe the types of arrangements made for provision?

Could you describe the referral routes?

Could you describe the sort of factors that influence the decisions about the provision?

Are decisions about provision flexible? Are there any exceptions?

Does it make a difference if a child has a Statement for SEN provision?

Could you describe any broader influences that make a difference to the arrangements?

What part do parents play?

9.2.4 Revised interview protocol (parents)

Question "Could you describe any broader influences that make a difference to the arrangements?" removed.

9.2.4.1 Revised protocol

Could you describe the types of arrangements made for education in hospital or in the home?

How did you obtain information about arrangements for hospital and home teaching? Could you describe the referral routes?

Could you describe what influences the decisions about arranging teaching in the home?

Are decisions about providing teaching in the home flexible? Do the number of hours vary?

Does it make a difference if a child has a Statement for Special Educational need?

What part do parents play in arranging teaching in the home?

9.3 Negotiating access: LEA manager

9.3.1 Letter to named LEA manager sent by post

Dear

An investigation of the arrangements for the provision of education for pupils who are out of school by reason of illness.

I am writing to a number of local education authorities (LEAs) to invite them to participate in this personal research study and wish to extend this invitation to X LEA. I would be most grateful if you could spare half an hour of your time to share your views and add an additional perspective to this project.

Background to the study

The study will investigate local education authority policy regarding the statutory duty to arrange provision of education otherwise than at school for sick children, under current guidance of DFE circular 12 /94, 'The Education of Sick Children'. It aims to examine the diversity of arrangements made for provision around the country and will examine factors responsible for that diversity. LEA policy on individual, group tuition otherwise than at school will provide a focus for the research.

A collation of policy documents and plans pertaining to education otherwise is being gathered. In the very near future individual interviews will be sought with LEA officers responsible for home tuition and officers responsible for special educational provision, about policy in their local authority. The study will include parents' perceptions also. I enclose a copy of the standardised interview protocol for your perusal. As the study moves along and results become available, I will provide a digest of the main findings to each participating LEA. Anonymity of participants is assured and personal information will not be passed to any other body or published in any way unless it is in aggregated form, which would make it impossible to identify an individual.

Right now, it would be helpful if you could indicate your interest in the study by completing the pro forma and return it to me in the pre-paid envelope enclosed for your convenience.

Thank you for your time spent reading this letter.

Sincerely,

Susan Davies

Standardised Interview Protocol

Could you describe the types of arrangements made for provision?

Could you describe the referral routes?

Could you describe the sort of factors that influence the decisions about the provision?

Are decisions about provision flexible? Are there any exceptions?

Does it make a difference if a child has a Statement for SEN provision?

Could you describe any broader influences that make a difference to the arrangements?

What part do parents play?

✂.....

Please reply to

Susan Davies

I am available for interview ☐

A policy document for home/individual tuition (or draft) is available ☐

A policy document for special educational provision is available ☐

Information leaflets are available ☐

Other written documents are available ☐

From

LEA address

9.4 Negotiating access: parents

9.4.1 Letter to named parent distributed via third party gatekeeper

Dear Parent,

RESEARCH REQUEST: HOSPTIAL AND HOME TEACHING FOR SICK CHILDREN

I am seeking to contact parents of children who need teaching in hospital or in the home. The research investigates local arrangements for education in hospital and in the home in different parts of the country and includes interviews with a small number of parents. I would particularly welcome a call from parents living in X LEA.

All information is strictly confidential and the research will be reported in such a way that it is impossible to identify an individual. Please complete the reply slip or leave a message with the answering service on XXXX, giving details of where I may contact you.

Yours sincerely,

Susan Davies

Reply slip.....

Name of parent Telephone number where I may contact you Name of child..... Age Typical length of absence from school Number of half-day absences noted on the annual school report. My child has a Statement of SEN.....□	Home Address Postcode Occupation: Parent (1)..... Parent (2).....

Please reply to Susan Davies Oxford Brookes University, School of Education, Wheatley Campus, Oxford OX3 OBP.

9.5 Responding to enquires: parents

9.5.1 Responding by post

RESEARCH REQUEST: HOSPTIAL AND HOME TEACHING FOR SICK CHILDREN

Thank you for responding to the notice in the XXXX Journal Magazine. The research investigates local arrangements for education in hospital and in the home in different parts of the country and includes interviews with a small number of parents based on the six questions enclosed. Please give a brief written reply and return it to me in the pre-paid envelope, or if you prefer to talk on the telephone, or in person, please give details of a convenient time. All information is strictly confidential and the research will be reported in such a way that it is impossible to identify an individual.

Yours sincerely,

Susan Davies

Reply
slip.....

Parent Name of child..... Age Typical length of absence from school Number of half-day absences noted on the annual school report. My child has a Statement of SEN.....□	Telephone number where I may contact you Morning □ Afternoon □ Evening.....□ Occupation: Parent (1)..... Parent (2).....

Please reply to Susan Davies Oxford Brookes University, School of Education, Wheatley Campus, Oxford OX3 OBP.

HOSPITAL AND HOME TEACHING: Parent research questions.

1. Could you describe the types of arrangements made for education in hospital or in the home?

2. Did you obtain any information about arrangements for hospital and home teaching? Could you describe the referral routes?

3. Could you describe what influences the decisions about arranging teaching in the home?

4. Are decisions about providing teaching in the home flexible? Do the number of hours vary?

5. Does it make a difference if a child has a Statement for special educational needs?

6. What part do parents play in arranging teaching in the home?

9.6 Qualitative data: sample

9.6.1 LEA document text - scanned and processed with OCR text recognition

HOME TUITION FOR SICK CHILDREN IN G-LEA.

There is a duty placed on the Local Education Authority to provide education for children who are unable to attend school because of sickness. The 1993 Education Act introduced the provision of the education of sick children as a statutory duty and this is set out in DFEE circular 12\94.

If children are in hospital their education is provided by a hospital tutor or within a hospital school. G-London-LEA LEA provides the Hospital Tuition Service at the local Hospital and this is managed by the Headteacher of A-Special School.

If children are sick at home their education is provided by the Home Tuition Service. The service is also managed by the Headteacher of A-School. The pupil's school retains responsibility for them and the task of the home tutor is to liaise with the school in order to plan the curriculum while the pupil is sick and to facilitate their return to school. The Home Tuition Service works within the framework of equality and the tutor is expected to deliver a high quality service to all pupils regardless of family circumstances, cultural background, religion, disability or special educational need. G-London-LEA's child protection procedures are followed and any concern or disclosure by a pupil must be passed on to the home tuition manager immediately.

The Home Tuition Service seeks to deliver an efficient and effective educational programme for children within the London Borough of G-London-LEA who cannot attend school because of sickness. It aims to minimise the disruption to children's education during periods of absence from school and to offer suitable, balanced programmes of study based on the National Curriculum. The service takes as its starting point the needs of the individual child, which may be varied and complex.

2.Criteria for Home Tuition

A pupil will be eligible for home tuition once they have been absent from school for 4 weeks because of sickness. During this time the school will be responsible for providing work for the pupil. If it is known that the pupil, will be absent for more than four weeks, then tuition may commence earlier. If a child has an illness which results in regular absences from school, tuition may commence from the beginning of their absence. There

needs to be a medical opinion that the pupil cannot attend school because of sickness.

3.Referral for the Service

Referrals for the service primarily come from schools, the Education Welfare Service and hospitals, but may also come from other agencies. The referral form gives all relevant information including details of other professionals and agencies working with the child. Before a child can be considered for home tuition there must be a medical diagnosis and opinion that the child has an illness which prevents them attending school. This opinion must be provided

9.6.2 Interview transcript

9.6.2.1 Professional

LEA case B-Shire.

Interview transcript

Officer responsible for home tuition/ B-Shire LEA. Recorded 30th March 1998.

Checked for accuracy 12th June 1999.

B-Shire HT Officer: On the first one then the types of arrangements. The children who are hospital, there are 2 hospitals in the county. And each of those has teachers based in the hospital. Kettly has 2 teachers and Greenton has 1. Reason for that is historical I think more than the size of the hospital. Those teachers are each members are staff of a special school. So in Kettly they are both members of staff of Bingsley special school. And in Greenton its Shields special school, they are there to get professional support from the staff. They are members of staff and it helps with their professional development and that kind of structure. In Kettly one of them works on the hospital ward. And the other one works on the children's ward which is a sort assessment Ward that they have. And in Greenton it slightly different there is just one teacher and she works on the children's ward. So that's how that's arranged.

B-Shire HT Officer: Umm when the children come out of hospital or if they don't go into hospital, or if they don't need hospital, we would normally say if they are likely to be off for four weeks or more. That's basically because if they have got chicken pox for two weeks and are probably not well enough to do anything anyway. But if they are coming out of hospital and we know in advance that they are going to be off school for a while because

they have got complicated Plasters or whatever, then there wouldn't be 4 a week gap, then it would be pre-arranged.

B-Shire HT Officer: Umm The tuition at home is always organised through the child's home-school.

Researcher: oh right

Respondent: so we would expect, but it doesn't always work as well as you want, but we'd expect that the home-school would keep track of the child while they were in hospital and while they were ill, so they would know with the help of the welfare officer umm what was happening, and they would make a plan for that child's education, to secure it over time. Now that needs, will probably involve additional resources. In terms of teaching time, (pause) but usually teaching time, when they submit their plan, they should have contacted the school doctor. Who will also have written just a little letter confirming that this child is really ill and cannot go to school. They submit that to the assistant education officer working with the area. We will agree with the school okay this is likely to be about half a term or whatever, and would agree five hours a week tuition for a set amount of time which varies according to the prognosis. Umm And in line with the plan the school has done. We then transfer the equivalent amount of money to the school budget. And the school will then organise it and we reimburse them for the time.

B-Shire HT Officer: The philosophy behind that is uum that the child is on the school' s role. School has responsibility for that child and knows the child, and the family. Umm Knows exactly where they are in their work and knows what levels they are working at. And that's probably the best way to maintain continuity for the child. Because also then the home tutor can often be someone the child may know. It may be a part-time teacher in the school or someone who does supply. So as far as possible its organised to make liaison better, and continuity for the child is better. We feel that it is better but also it is more cost-effective, and it's better than having a team of peripatetic teachers because they are going in to work with children they don't know, with schools they don't know. They have to make up all that time trying to get to know everybody before they can start teaching. Whereas probably the school has a teacher that knows the child, can probably start straight in, and then that maintains the continuity. That's where it starts from, but also it is a more cost-effective [laughs] way of doing it.

B-Shire HT Officer: We've been doing this for about three or four years now. And although it's taken a little while for the schools to get used to it, because there was a tradition of "well this is somebody else's problem", and we wanted to get over that by saying its not a problem. This is your child,

you're responsible and you're the people best placed to put things in place for this child. And it does work quite reasonably well (pause) now.

9.6.2.2 Parent

Interview: recorded in NTown (A-Shire LEA), 1998 11th November. 3.30 p.m.

Access provided by LEA Home tuition manager.

Checked for accuracy and anonymity 22nd June 1999.

Respondent Background. He was diagnosed in March 97, with Leukaemia. And then he attended, he did part-time school up until October 1997.

Interviewer: what was part-time school? Had he started school part-time like the other children?

Respondent: no he was going full-time until he was diagnosed, in March he did mornings [pause] urmm till [pause] 9 till of 12 , and then urmm that was until, till October 97, and then he went full-time. Until December urmm and we found out on Dec 16 that he had relapsed, so then he went straight back on his treatment. And then as from January 19th, he had home tutoring urmm and then he went back after Christmas, he had home tutoring until two weeks before the end of term, he had home tutoring until July. He urmm actually went back full-time for the last two weeks of the summer term.

Interviewer: that is a lot time isn't it?

Respondent: and then he has been back full-time since September. In year two. So his absences were, [referring to school report] in reception, absences were 62 days, and in year one it was 209.

Interviewer: and is everything all right now?

Respondent: yes it is. We got the all clear a couple of weeks ago. He went for his assessment and it is still clear so. He's all right (laughs). He's as fit as a fiddle he is (laughs).

Interviewer: if we could just go through these questions.

Respondent: shall I just read through these questions?

Interviewer: yes please.

Respondent: [question 1] shall I describe the arrangements? when he was diagnosed, a senior teacher at the children's hospital, Jenny , She basically

took over and told me not worry about anything, she would contact the schools. They contacted his school and the local education authority, to explain to them what was going on, urmm she did explain a little about, about, what would go on actually when he was in hospital. Urmm and that urmm but then I had a visit from the home tutor, once we got home. They contacted me. So it was more or less taken out of my hands. Which is good. Because you don't want to have to think about things like that. At first, urmm and it was urmm they basically said like when the child is first admitted to the (hospital) school, the (home) school is notified. In the actual hospital school then, work, work was brought to the ward. According to his age. They had obviously contacted the school, and had the reports from school. To see what level Dan was at urmm. There was urmm a school in the hospital, where if the children were well enough, they could attend the [hospital] school. Although Dan wasn't actually in hospital a lot, so he'd never really got to attend the [hospital] school. Urmm so he'd never actually attended the school. He had the tutor to come, when he was in [clinic], and they usually did work on the computer and stuff like that. That was at the CITY Hospital.

9.6.3 Field notes

Field notes re. Interview recorded with Mrs B in rural A-Shire on the 11th of November 9.30 a.m.

Standard introduction letter sent out by LEA. Parent reply posted to the University. I telephoned to make first contact. Chatted and answered her question as to why I was doing the research I worked on building trust.

Weather mild, good visibility, reasonably sunny.

Interview dress blue trousers and jumper, sleeveless Barbour jacket, no make up

Procedural reactivity: She had just undergone an operation on her wrist and said I was lucky this week to catch her at home. Both of her children were now at school.

Personal reactivity: Atmosphere very relaxed, easy communication. Having just driven for an hour, I always feel a little tense, on arrival. I didn't want to be late as she had specifically agreed an early appointment to leave her the flexibility to go out for the day. When I arrived Mrs B. saw the car and came out to the fence to greet me. Mrs B. made a cup of coffee. We chatted informally. My aim was to illustrate that I was human, not a powerful outsider, but someone who shared a common interest.

She was a cheerful plump lady of about five foot 1 in height. She came over as being very relaxed, and assertive. Great sense of humour. She had a very positive attitude, bright eyes, cheerful, direct but not aggressive.

Biscuit crumbs on the coffee table. Supportive husband and daughter, who were running around for her during the post operative recovery phase.

Powerful MATERNAL instinct, wall of the living room covered with photos of the children, lots of birthday cards on display.

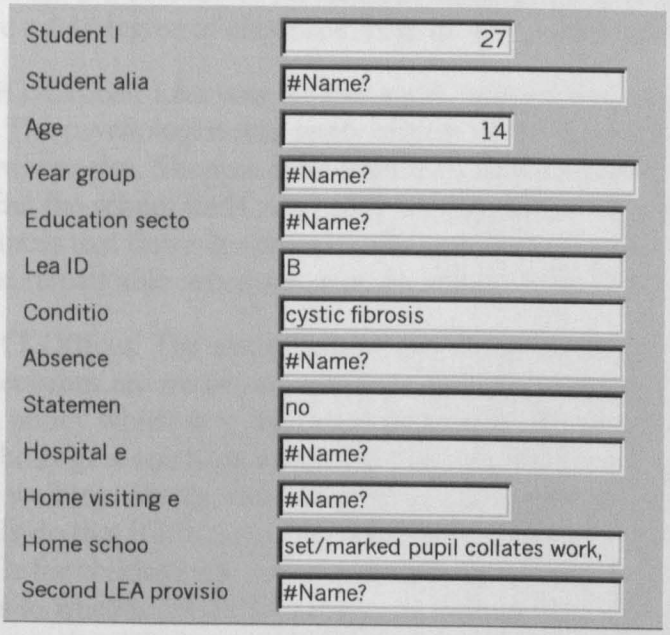
Domicile

Very small rural village.

Mrs B. lived in a very old small country cottage, made of brick and had concrete on the outside building brick. The exterior concrete had been removed partly because of repairs needed to the house. It was a very small cottage, tiny little garden which is very overgrown. Scraps or pieces of carpet on the bare floor, wallpaper peeling off the wall in the corner. No car in the drive, husband at work.

9.7 Access® data entry form

Figure A. 9.1 Access® data entry form



9.8 Identified theme: sample analysis

LEA professional: flexibility in decision-making.

Theme: flexibility in decision-making

A-Shire HT Officer: Sometimes it might be in a separate room, it depends on the nature of the child and the nature of the illness. We don't think in terms of set policies. It works well with the primary schools, most of the primary schools are accessible. Most of them are flexible and that is not implying ant criticism of the secondarys'. With most of the secondarys' its more difficult, it's because of the national curriculum. In primary, most of them have a fair degree of classroom help as well, which we use flexibly.

A-Shire HT Officer: Last year we had a girl, who couldn't go near the building. The psychologist was pretty critical of the school. So we had to use somewhere else. She was quite keen then and she moved on to an FE college. But the school itself was pretty unsympathetic. There are unusual circumstances that throw up occasionally and we have to be flexible. We have some remarkable success stories, by approaching it in that way.

A-Shire HT Officer: The sort of factors that influence decisions, really are that the decisions are made very much on an individual basis. We don't work to a policy which says if you've got something you get this. We don't say everybody gets one hour a day. We don't provide any less than that, but we might well top that up with other things. We might increase it, but we would only do that if it's a pupil in their later years who's working for GCSEs. Or for children who have such a poor scenario, we are pretty flexible as to whether its an hour a day, or with an hour a day plus a bit of this. For some it might be an hour a day with a visit to school in between. Its very much geared to the individual case.

A-Shire HT Officer: Our budget. You have to be pretty flexible with schools, school are pretty good at providing funding for children if it's a long term absence. If it's a year 10 / 11 pupil, who has been out of school for six months and inhabits that peculiar area of emotional difficulty and phobia, or because of factors associated with it and it was difficult for him to go back to school and so we negotiated a college place for the pupil last year.

B-Shire HT Officer: So we recently had a meeting with various people focused on ME but it would equally work for any other difficulties of that kind. With health and educational psychology and with some schools who had experience of this. But we brought out some specific guidelines about that kind of illness that keeps coming back. And could upset the education

over the period of time , over a long period time. That's where we've actually got got some quite flexible plans or suggestions, of what might be useful in these situations, depending on the child's age and ability and whatever. I have given them, in terms of making the plans, 'you might want to use some of these', some suggestions, they might want to consider, distance learning for example. Tuition, tuition at home, tuition at home followed by support in school. Special travel arrangements, because sometimes with ME, what's best is that they come into school when they can. When they can get there. We usually say with ME that home tuition is a very blunt instrument. The home tutor can arrive at the house and the youngsters is not able to do it then. But the tutor can't come back.

B-Shire HT Officer: yes they do[find it more difficult]. But on the other hand, the liaison with secondary schools is even more difficult because of the range of subject areas, which is even worse for a peripatetic teacher to latch on to the subject teachers. So again although we feel that it may not be ideal, it's probably the best chance of keeping the continuity and liaison going. For somebody going in and out of the school anyway because they're doing a part-time job, they have access to the science teacher or whatever already. And it could be more than one teacher, yes may be, so it could leave schools flexible to do the best they can for the child and then using distance learning materials as well if that is appropriate.

C-Unitary HT manager(M): the only flexibility that we have, are again.....I mean the ones you deal with are the ones usually off school for a block of time. Whereas the oncology ones are in an out all the time. Sometimes in the run-up to exams, or what ever we do say twenty hours a month. So that's where we are flexible . So if the child is off [in hospital] for a week and is not going to be seen again for three weeks and then maybe you can put in more than five hours that week if it is appropriate if it is necessary, but nothing is written down anywhere . We've got to be very careful, you understand.

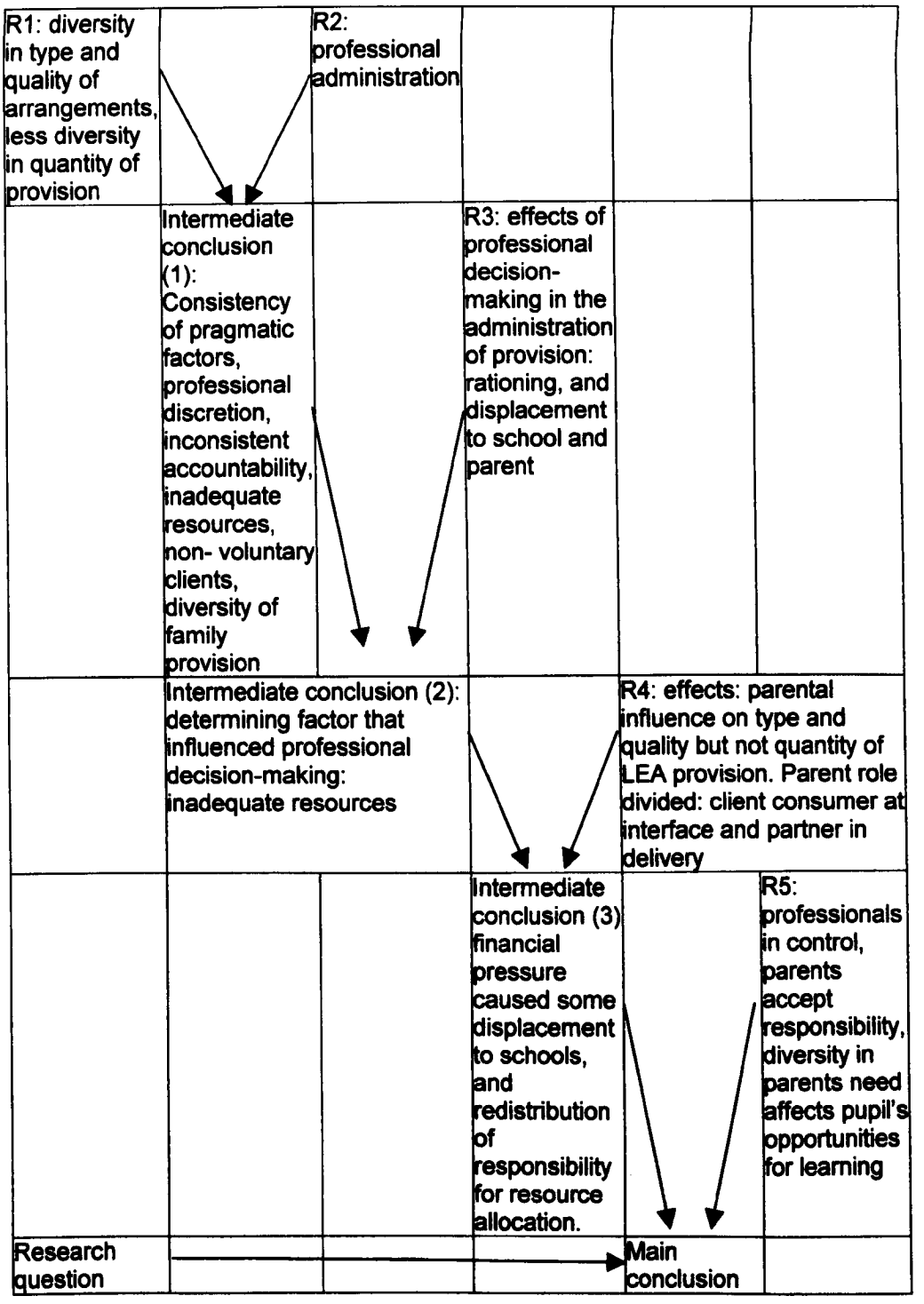
C-Unitary HT manager (a): I think the home tuition budget could be more flexible.

C-Unitary HT manager (a): So I can appreciate that globally, it must be a nightmare and very difficult. But for sick children I think that, you could be flexible without it necessarily costing any more. Now there's no point in putting in five hours home tuition when the child is not well enough and can't appreciate it. You've got one pot and

C-Unitary HT manager (b): because they don't come under the six weeks out of school rule . And there isn't the system yet in place.

9.9 Linking evidence, reasons and conclusion

Table A. 9.1 Evidence, reasons and conclusion



10 APPENDIX B: RAW DATA

10.1 Data: sample characteristics

10.1.1 Length and pattern of pupil absence

Table B. 10.1 Length and pattern of pupil absence

Alias	Lea ID	Substantial absence Key Continuous (C) absence more than 4 weeks Intermittent (I) absence less than 4 weeks	Pattern
Jonathan	A	18 months, (hospitalised 3 months), intermittent	C & I
Simon	A	intermittent and continuous Y7-11, all Y9	C & I
Steven	A	3 months, one off absence	C
Debbie	A	3x two months	C & I
Dan	A	4-6 months duration for two years	C & I
Miak	B	12 weeks continuous	C
Sally	B	Y9 absence 124 half days, Y10 11 months	C
Chloe	B	1 year	C
David	B	2 weeks duration every 8-12 weeks	I
Mark	B	10-14 days duration, frequent	I
Ben	B	10-14 days duration, frequent, now hospitalised	I & C
Louise	B	1992-1995 three years	C
Gary	B	2 days up to several weeks duration	I & C
Jack	B	odd days- or 4 -13 weeks duration	I & C
Mary	B	intermittent short duration	I
Karen	B	8 months continuous and intermittent 3 years	C & I
John	C	substantial continuous, intermittent	C & I
Sue	D	long term	C
Richard	D	continuous from Y10 onwards	C
Becky	E	3 months, one off absence	C
Novid	E	six months (hospitalised 2.5 months)	C
Paul	G	1 year	C
Alan	G	frequent, intermittent	I
Lee	G	1 year intermittent continuous	I & C
Nicola	H	frequent intermittent 2-3 days/week, up to 7 weeks	C & I
Jill	I	2 years continuous	C
Liam	J	intermittent Y7-9, then continuous since Y10	I & C
Diane	J	Y7- Y11, intermittent, then continuous from Y9	C & I
Gareth	K	continuous 1 year, (hospitalised 4 months)	C
Michael	K	8 months	C
Nigel	L/M	9 months	C
Peter	N	1 year	C
Daniel	O/P	3 years	C
Brian	Q	odd days - week, frequent	I
Max	R	substantial continuous	C

10.1.2 Parent occupation

Table B. 10.2 Parent occupation

Alias	Lea ID	Mother working outside home (f/t: full-time) (p/t: part-time)	Occupation main wage earner Key father (F) mother (M)
Jonathan	A	no	F semi-skilled worker
Simon	A	no	F police constable
Steven	A	p/t evening	F vehicle mechanic, M kitchen assistant
Debbie	A	no, then p/t	M single, charity co-ordinator
Dan	A	no	M single
Miak	B	no	M single
Sally	B	p/t then no	F engineer
Chloe/ Louise	B	f/t	M single, adult learning support assistant
David	B	no	F company director - own business
Mark/ Ben	B	no	Information not available re. partner
Gary	B	no	F warehouse supervisor
Jack	B	no	M single
Mary	B	f/t	M single, secretary
Karen	B	f/t then p/t	F engineer, M midwife
John	C	no	F company director, self employed
Sue	D	p/t	M&F school teacher
Richard	D	no	F unemployed
Becky	E	f/t	M single, book-keeper
Novid	E	no	F civil engineer
Paul	G	no	F unemployed
Alan	G	no then p/t	M single, secretary
Lee	G	no	F p/t photographer, self employed
Nicola	H	p/t	F sales representative, M cosmetics
Jill	I	no	F skilled office worker
Liam	J	p/t	F manual worker, M secretary
Diane	J	no	Information not available re. partner
Gareth	K	no	F office manager
Michael	K	no	Information not available re. partner
Nigel	L/M	no	F semi-skilled worker
Peter	N	no	F office worker
Daniel	O/P	no	F financial investigator
Brian	Q	f/t	M accountant, F company director
Max	R	no	F post office worker

10.1.3 Parent interviewed

Table B. 10.3 Parent interviewed

Alias	Lea ID	Parent interviewed (n= 34 of 35)
Jonathan	A	mother -at home
Simon	A	mother -at home
Steven	A	mother -at home
Debbie	A	mother -at home
Dan	A	mother -at home
Miak	B	mother -at home
Sally	B	mother -at home
Chloe/ Louise	B	mother -at home
David	B	mother -at home
Mark/ Ben	B	mother -at home
Gary	B	mother -home visit and telephone
Jack	B	mother -telephone
Mary	B	mother -telephone
Karen	B	mother -at home
John	C	mother -at home
Sue	D	mother -telephone
Richard	D	mother -telephone
Becky	E	mother -telephone
Novid	E	father -telephone
Paul	G	mother -at home
Alan	G	mother -telephone
Lee	G	Mother and father -at home
Nicola	H	mother -telephone
Jill	I	mother -at home
Liam	J	mother -telephone
Diane	J	mother declined interview, written account only
Gareth	K	mother -telephone
Michael	K	mother -telephone
Nigel	L/M	father -telephone
Peter	N	mother -telephone
Daniel	O/P	mother -telephone
Brian	Q	mother and father at workplace
Max	R	father -telephone

10.2 Data: findings

10.2.1 Key professional contact for parental liaison

Table B. 10.4 Key professional contact for parents

Alias	Key professional contact for parent. (T: teacher)
Jonathan	Hospital T
Simon	Year Head, LEA tutor
Steven	Deputy Head
Debbie	Hospital T, pastoral T
Dan	Hospital T, pastoral T
Miak	Hospital Dr., social worker
Sally	Year Head
Chloe	Year Head
David	Pastoral T
Mark	Year Head
Ben	Pastoral T, Hospital T
Louise	Principle FE
Gary	Head teacher, hospital T, school senco
Jack	Year Head, asthma specialist nurse, senco
Mary	Pastoral T
Karen	Social worker, G.P. school Dr. pastoral T
John	Hospital T
Sue	Hospital T
Richard	Pastoral T
Becky	Year Head, pastoral T
Novid	Year Head
Paul	Year Head, clinic nurse
Alan	LEA officer, nurse
Lee	Year Head
Nicola	Hospital T, Head teacher
Jill	School. Dr.
Liam	Hospital T/ LEA manager
Diane	Hospital T/ LEA manager, school senco
Gareth	Pastoral T
Michael	Pastoral T
Nigel	Hospital T
Peter	Hospital T, pastoral T
Daniel	GP, Cons. Paediatrician.
Brian	Year Head
Max	Pastoral T

10.2.2 Parent action in route to provision

Table B. 10.5 Referral: parent action

Alias	Parent action in route to provision (P=Persistent)
Jonathan	passive then arranged meeting at school
Simon	asks & visit school, Y11/'phone LEA, (P)
Steven	asks & visit school, (P)
Debbie	passive, then (P) 3rd abs/asks at hosp & visit to school
Dan	passive
Miak	asks G.P. then passive
Sally	asks at school (P)
Chloe	asks & meetings at school (P)
David	asks & letter to school then passive
Mark	asks & visit school, meetings at school then passive
Ben	asks & visit school, meetings at school then passive
Louise	meetings, organised FE placement for Y11 (P)
Gary	asks & visit & meeting at school, (P)
Jack	asks & visit school & meeting at school, then passive
Mary	asks at school then passive
Karen	'phone anyone and everyone', (P)
John	asks & visit & meetings at school, (P)
Sue	parent active as main provider
Richard	father asks school, mother has substantial illness, passive
Becky	asks/letter/complaint at/to school, phone/LEA, (P)
Novid	asks/visit school, phone/LEA, (P)
Paul	asks/visit school/ asks clinic nurse, (P)
Alan	'phone LEA, (P)
Lee	asks school, LEA, (P)
Nicola	asks school then passive
Jill	phone/letter/complaint to LEA, (P)
Liam	(P) solicitor then passive
Diane	passive then insisted on EOTAS only '96
Gareth	asks school, phone LEA, & county councillor (P)
Michael	asks school, phone LEA, (P)
Nigel	phone LEA then passive
Peter	passive
Daniel	phone/letter to LEA, (P)
Brian	asks school then passive
Max	asks school, parent active as main provider

Sixteen parents gave the impression of a passive personality, nineteen parents were persistent.

10.2.3 LEA service context: triangulation matrix

Table B. 10.6 LEA service organisation

	Service organisation	**Evidence of service positioning within LEA policy.**	**Resources: LEA resource allocation/ School based resource allocation**	**Triangulation** **Data Source: LEA interviews [^]** **LEA document [#] Secondary sources [*].**
A	Home teaching and /or support staff [^ # *] Regional tuition centre (ICT) development. [^ #*]	Provision specified in LEA SEN policy. Education otherwise managed centrally as part of SEN countywide service. Provision for sick children, as 'vulnerable children specified in BSP. [^ # *]	LEA retains budget to fund service [^ #]. SEN Code of Practice, stage three status for child recommended for resource allocation in schools. Also specified in BSP.	Parent interviews SEN policy BSP (LEA behaviour support plan) LEA inspection report.
B	Separate hospital teaching units, teachers affiliated to special schools No peripatetic service. Home schools organise education plan and home teaching. [^ # *]	Provision specified in Hospital/home tuition policy. Education otherwise managed centrally as part of Special provision service. [^ #]. Education otherwise as non-LEA funded provision specified as choice option in SEN policy and as support service in BSP for children whose attendance pattern prevents	LEA retains budget, authorises funding for teaching time up to a maximum of 5 h /week. Home schools reimbursed for [supply] costs. [^ #*] (BSP specifies Code of Practice stage 3 status for child needing additional provision in school).	Parent interviews Hospital teacher interview (field notes) Hospital/home teaching policy. SEN policy BSP.

	Service organisation	**Evidence of service positioning within LEA policy.**	**Resources: LEA resource allocation/ School based resource allocation**	**Triangulation** **Data Source: LEA interviews [^]** **LEA document [#] Secondary sources [*].**
		full access to the curriculum.		
C	Combined hospital and home teaching service [^ # *] Education otherwise managed from LEA tuition centre (PRU).	Provision specified in Hospital/ home teaching policy and also as part of support service for 'vulnerable' pupils, in BSP. Provision for all 'vulnerable' children noted in SEN policy.[^ # *]	Funding for tuition centre provided on place basis. Budget set for 25 'ill' pupils at 5 hours /week [^ # *] (BSP specifies Code of Practice stage 3 status for child needing additional provision in school).	Parent interview. Hospital/home teaching policy. PRU inspection report. SEN policy BSP (LEA behaviour support plan)
D	Registered hospital (special) school with teaching units, home teaching, ICT.[^#*] Education otherwise devolved to Hospital special school as unified service.	Provision specified in school development plan & as a service under development for 'vulnerable' pupils, specified child in BSP and CSP. [^ # *].	Budgeted for 492 full time equivalent pupils on roll (age weighted pupil unit) or as dual placement and as placement for pupils with Statements [^]. (BSP specifies Code of Practice stage 3 status for child needing additional provision in school).	One parent interview. School development plan. CSP (Children's services plan) BSP (LEA behaviour support plan) Hospital school OFSTED inspection report
E	Hospital and home teaching service. [^ *] Education otherwise managed from LEA tuition service (PRU)	Education otherwise provision for the seriously ill specified in BSP. [^ # *] Learning support and SEN policy.	LEA retains budget to fund service in hospital and tuition centre.[^ #] (BSP specifies Code of Practice stage 3 status	Parent interviews LEA. BSP (LEA behaviour support plan). OFSTED inspection report

	Service organisation	**Evidence of service positioning within LEA policy.**	**Resources: LEA resource allocation/ School based resource allocation**	**Triangulation** **Data Source: LEA interviews [^]** **LEA document [#] Secondary sources [*].**
			for child needing additional provision in school).	
F	Teachers sent into hospital or the home from tuition centre. [^ # *] Education otherwise managed centrally under behaviour/pupil support service	Provision specified in Hospital/home teaching policy. [^ #]. BSP and SEN policy.	LEA retains budget to fund service in hospital and tuition centre [^ #]. (BSP specifies Code of Practice stage 3 status for child needing additional provision in school).	No parent interviews obtained for corroboration. Hospital/home teaching policy. SEN policy.
G	Tuition service based in special school, including outreach and part-time placement. To be amalgamated with mainstream secondary and developed as resources base for children with special health and educational needs. PRU arranges provision also. [^ # *]	Provision specified in Hospital/home teaching policy. Education otherwise specified as arrangements under SEN and BSP "which are congruent". [^ # *]	LEA retains budget to resource full time service teacher. [#] (BSP specifies Code of Practice stage 3 status for child needing additional provision in school).	Parent interviews Hospital/home teaching policy. SEN policy. BSP (LEA behaviour support plan). LEA inspection report.

10.2.4 LEA type of provision: triangulation matrix

Table B. 10.7 LEA type of provision

LEA provision.	**Case LEA** **Interview ^** **Document #** **Secondary source ***	**Triangulation**
Qualified teacher	Hospital provision A,B,C, D, E, F Home visiting provision: A, B, C, E, F, G.	LEA interview Teacher interviews Parent interviews F-LEA parent / student written evaluation
Education/ learning support assistant at home	A ^ B ^ C ^ E ^	LEA interviews
Welfare support at school	A ^	A-LEA parent interview LEA interview
Part time attendance at school	A and B ^# C,E,F,G ^	A,B,G LEA parent interviews LEA interview
Part-time attendance FE college	A ^ F # G #	LEA interviews and documents
Distance learning (as set homework)	LEAs A-G	Parent interviews LEA interviews
ICT based open learning, Hospital/school Telephone link up	A ^# D ^# B ^	Internet web page LEA documents B-LEA interview and parent interview Hospital teacher
Transport	A ^ E,F ^#	A,E,-LEA parent interview LEA interview
Equipment e.g. Tape recorder Computer, e-mate Disability stair climber	A ^ A ^ G ^ A ^	G-LEA parent interview, LEA interviews. G-LEA Home teacher interview.
Curriculum		

resources		
Public Library resources	Teacher A/B LEA	A/B-LEA parent interviews
Using Statemented resource e.g. learning/care support	A #, B ^, C ^ E ^ F ^#	LEA interviews LEA documents
Education otherwise for 'vulnerable' children contracted with voluntary organisation or other non LEA provider	G # D # A& B # A& D # E #	Parent interview G-LEA SEN document LEA BSP. A,B,C,D,E,-LEA BSP

10.2.5 Policy documents: principles

D-LEA

Guiding Principles

•to respect, value and understand the individual needs of pupils

•to strive to ensure equality of opportunity for all our pupils,

within the framework of the National Curriculum as appropriate

•to hold high expectations of young people,

within realistic challenges for academic achievement

•to foster a secure, safe, stimulating educational environment

•to co-operate and communicate effectively with other involved agencies

•to foster strong working relationships with pupils, parents and mainstream schools

•to enable each young person to return to mainstream education,

training, or work as soon as practicable

A-LEA

Principles.

Children within the age range 5-16 who are out of school long term through illness are entitled to an education which as far as possible:

•is broad, balanced and appropriate to their needs

•is co-ordinated by the appropriate providers which will normally

be any two from school, hospital and tutor service

•is provided by teachers, home tutors or specialised service

with access to relevant information and appropriate training

•benefits from the good practice outlined in the DFE's 'Code of Practice'

on the Identification and Assessment of Pupils' with Special Educational Needs Section 2.38 to 2.52.

10.2.6 Data: SEN spending in G-LEA 1997/98

Table B. 10.8 SEN spending in G-LEA

Description	Budget (£)
A) FUNDS DELEGATED TO SCHOOLS	
Special schools:	
A	559 200
B	697 660
C	627 320
D	1 027 000
Sub total	3 812 190
Special units/ resource bases:	
A	119 137
B	119 137
C	81 230
Sub total	319 504
Mainstream schools:	
a) non Statemented SEN	
Primary	3 573 632
Secondary	1 520937
b) Statemented SEN	
Primary	0
Secondary	587 179
Sub total	5 681 748
TOTAL DELEGATED SEN BUDGET	9 813 442
B) CENTRALLY HELD BUDGETS	
Out-borough placements	
Independent – residential	701 000
Independent – day	565 000
Recoupment exp - special school	2380 000
Recoupment exp – mainstream school	438 000
Sub-total	4084 000
Other external SEN support	
Cenmac	12 500
Dyslexia institute	19 00
Speech therapy	61 000
SEN support for Orth. Jewish independent sch	40 000
Deaf/ blind consortium	0
Sub- total	32 500

Transport	
Within LEA – coach (inc escorts)	1 901 420
Taxis	543 000
Inter authority charges	65 100
Sub- total	2 509 520
Primary support	
Primary and specialist team	1 223 830
Sub-total	1 223 830
Pupil Referral Unit (PRU)	
PRU	659 000
Contingencies	
SEN	146 180
Resource base	46 180
Sub-total	1920 180
Recoupment income	
Special schools	(626 000)
Mainstream support	(60 000)
Sub-total	686 000
Hospital tuition/ recoupment	
Tuition unit/ Home teaching for sick children	101 590
Recoupment exp- hospital schools	15 300
Recoupment inc- hospital schools	(30 600)
Sub-total	86 290
Administration	
SEN management	72 290
SEN administration	219 790
Parent partnership scheme	0
Educational Psychology Service	540 620
Portage Service	41 830
School X	435 140
Sub-total	1 309 670
TOTAL CENTRALLY HELD BUDGETS	9 510 990
GRAND TOTAL	19 324 432

10.2.7 Data: LEA Internet web sites

10.2.7.1 B-LEA Web page

April 1998
</images/BULGAZ-1.GIF>

A-Z GUIDE TO CONTACTS AND SERVICES

A
Select a category from the list below to search the service entries:
Abandoned Vehicles
Abnormal Loads, authority for the movement of (Police service)
Abnormal Loads, routes for the movement of
Absent Pupils (Home Tuition)
Access to council buildings for people with disabilities
Accident Information Line
Accommodation, Council houses
Accommodation, private rented
Adapting homes for people with disabilities (Home Adaptation Advice)
Admissions, Schools (School Admissions/Transfer)
Adoption of Roads
Adoption (Children's Services)
Adult Education
Adult Literacy Basic Skills
Adult Offenders
Advertisements and Signs, Misleading
Advertising Applications
Advertising Drums
Aerial Photographs
Agenda 21
AIDS/HIV (HIV/AIDS)
Air Quality
Alarms for Elderly People
Allotments
Alterations to Council Homes
Ancient Monuments (Listed and Historic Buildings, Conservation)
Animal Health Inspections
Animal Pests/Nuisances (Pest Control)
Animal Welfare
Animals, Movement of, Licensing
Archaeology, Contract Services
Archaeology, Historic Environment
Architecture, Council Buildings
Archives
Area Managers, Planning and Transportation Department, County Council, Customer Support Branch
Art Galleries
Arthritis Care Project
Arts
Athletics Tracks
Audio Visual Materials, Loan of (Libraries and Information Service)
Menu last updated: April 1998

</images/BULGDN-1.GIF>
Hyper-link to contact details.

HOME TUITION

EXCLUDED AND PREGNANT PUPILS

County Council:
Education and Libraries Department,
Service for Teaching
Out of School Pupils
Named officer (n) ,
Head of Service
Tel: xxxx
Fax: xxxx
Pupils absent due to illness -
B-Shire County Council:
Named officer ,
Assistant Education Officer
Tel: xxx
Fax: xxx

Named officer (n)
Last updated: March 1998.

11 APPENDIX C: GLOSSARY AND ABBREVIATIONS

Table C. 11.1 Glossary and abbreviations

Advocacy	Used in the every day sense of the word: support, encouragement, sponsorship
Agency	Power of individual in broader citizen-state relations (Ranson, 1986)
Bottom up [policy process]	Process of policy implementation enabled from bottom in hierarchy (Hill, 1997a, 1997b)
DES	Department of Education and Science
DfE	Department for Education
DfEE	Department for Education and Employment
DoETR	Department of the Environment, Transport and Regions
DoH	Department of Health
Empower[ment]	Fielding (1996) and Vincent (1996)
Enabling legislation	"The Act is enabling rather than coercive. Inherent in such a system is the assumption of 'good practice' as well as that of goodwill" (Goacher et al., 1988, p. 2)
ESW	Education social worker
EWO	Education welfare officer
G.P.	General Practitioner
HMI	Her Majesty's Inspectorate
Home school	School where child is registered (DfE and DoH, 1994)
ICT	Information and communications technology
Ideology	Used in the every day sense of the word (Croll and Moses, 1998) philosophy, belief, principle, idea
IEP	Individual education plan
Illness	A condition marked by pronounced deviation from the normal healthy state (Dorland's Medical Dictionary, 1977)
Inclusion	UNESCO (1994) gives the thinking underpinning inclusion Definition used in the thesis: Re-organisation of schools and innovation in teaching and curriculum to offer provision to all pupils, and respond to all pupils as individuals (Sebba and Ainscow, 1996)
Integration	Pupil on roll of mainstream school (Sebba and Ainscow, 1996)
LEA	Local education authority
ME	Myalgic encephalomyelitis (ME)
OFSTED	Office for standards in education
Power	The capacity to affect people, things, situations and decisions (Lee and Laurence, 1985, p. 129)
PRU	Pupil Referral Unit
Pragmatism in decision-making	Used in the everyday sense of the word (Croll and Moses 1998): practical, common sense, uncomplicated, convenient
SENT	Special Educational Needs Tribunal

Top down [policy process]	Process of policy implementation from top position in hierarchy (Hill, 1997a, 1997b)
>	Greater than
<	Less than

12 APPENDIX D: USEFUL ADDRESSES

Central Office for Government Information: http://www.nds.coi.gov.uk.

Cabinet Office, 10, Downing Street, London. http://www.cabinet-office.gov.uk.

Department for Education and Employment, Sanctuary Buildings, Great Smith Street, London. open.gov.uk/dfee.

Education-line (BERA) http://www.leeds.ac.uk/educol/

Independent Panel for Special Educational Advice, 6 Carlow Mews, Woodbridge, Suffolk IP12 1DH. http://www.ipsea.org.uk

Journals online: http://www.journalsonline.bids.ac.uk

National Association for the Education of Sick Children/Present: 18, Victoria Park Square, Bethnal Green, London E2-9PF. http://www.ednsick.demon.co.uk

OFSTED, Alexandra House,33 Kingsway, London, WC2B 6SE, http://www.Ofsted.gov.uk.

UK Parliament publications database: http://www.parliament.the-stationary-office.co.uk.

UK Acts of Parliament: http://www. hmso.gov.uk/acts.htm

UNESCO education information service: http://www.education.unesco.org

13 APPENDIX E: DISSEMINATION

13.1 Published work

Davies, S. (1994) The education of sick children: a parent's view of DfE circular 12/94, National Association for the Education of Sick Children Newsletter, issue 3, October, pp. 3.

Davies, S. (1996) Post graduate diploma in educational studies (sick children) – a new course proposal, National Association for the Education of Sick Children Newsletter, issue 7, March. pp. 8.

Davies, S. (1998) Speaking up for the excluded, *Cascade, issue 29*, December, pp. 12.

Davies S. (1998) Speaking up for the excluded. Cascade, December, issue 29.

Browsing through the Sunday newspapers the other day, I was struck by a sense of irony! What sparked this off?

First, there was the Government pledge to provide a full time education to pupils excluded from school. Quite rightly, the plight of a future poverty-stricken 'underclass' arising from the ranks of pupils rejected by the system is now a top priority. Secondly, debates in Parliament and reports emanating from the Cabinet Office regarding social exclusion would suggest that children dropping out of society because of ill health, are to be abandoned.

In March 1997, Lord Henley argued against an amendment intended to secure full-time education for children not in school, suggesting that "full time education may not be appropriate" for children in hospital (1). Baroness Blackstone echoed the same argument in June 1998 (2) when referring to reports from the Social Exclusion Unit (3). The attitude seems to be nothing can be done to maintain education provision for sick children in hospital or at home. What a shame!

But something can be done. Given half a chance, it is possible for a sick child to succeed and fulfil their academic potential. I know this because my son is a living example of a success story. Putting many years of dislocated schooling behind him, he has achieved above average scores in Standard Assessment Tasks (SATs) at Key Stage Three and is now studying for ten GCSEs. He did not achieve this alone however. He needed access to a relevant curriculum, in hospital and in the home, together with support and encouragement to keep his education going. As a teacher myself, I knew the system and was able to apply my professional skills to my own son's education. But what of those parents less familiar with the system and less able to work it for their individual child's benefit. Many parents are not informed about the possibilities for educational support once their child has left hospital and is recovering at home.

If teachers working in hospital and in the home follow a relevant scheme of work, drawn up by the home school, then there is no reason for a child to fall behind his classmates. Computers and interactive learning can play an enormous part in education and in helping a child keep in touch with their friends. But without encouragement and cajoling, a sick child is unlikely to sustain independent learning on their own. Teachers are a vital part of the process. Clearly sick children are in need of special attention in many ways. Wherever they are, they still need teaching and teachers are needed to do the job. In many cases, parents are having to take on the responsibility of

liasing with their child's school and providing their child with the correct books.

Any complacency about the need for hospital and Home teaching needs turning around. The legality of a local authority decision to reduce home tuition from five to three hours per week, across the board, because of financial difficulties has been challenged. In the Tandy case (4), the Lords of Appeal said that a suitable education, is determined on an individual basis, according to age ability and aptitude and any special educational needs a child may have. The duty to arrange education for sick children should not be compromised by an LEA pleading poverty. Money has to be found. If excluded pupils are to have access to full time education, then why not sick children? It seems that children occupying the limelight get a better deal and currently, excluded pupils are centre stage.

Whilst child actors are working they must, under the Children (Performances) Regulations of 1968, be given a minimum of three hours private tuition every school day. Presumably, if the curtain falls on their acting career, they always have an education to fall back on. But what of the children? Has the dream of limelight faded for them? They are lucky to receive three hours tuition a week, let alone each day.

Sadly, sick children and their parents would seem to have very little voice. Rather they enjoy Hobson's choice, unless parents have the skills and resources to do the job themselves.

References

(1) Lords Hansard Column 1511- 1514, March 1997.

(20 Lords Hansard Column 747, June 1998

(3) Social Exclusion Unit, (1998) *Truancy and School Exclusion.* London. Cabinet Office

(4) Opinions of the Lords of Appeal (20 May1997), Judgments– In re T (A Minor) 1997, UK Parliament publications on the Internet.

Davies, S. (1999) Sick children need teachers, Cheers Extra (Newsheet for parents and carers, Association of Youth with M.E.) issue 6, March/April, pp. 7.

Browsing through the Sunday newspapers the other day, I was struck by a sense of irony! What sparked this off?

First, there was the Government pledge to provide a full time education to pupils excluded from school. Quite rightly, the plight of a future poverty-stricken 'underclass' arising from the ranks of pupils rejected by the system is now a top priority. Second, debates in Parliament and reports emanating from the Cabinet Office regarding social exclusion would suggest that children dropping out of society because of ill health, is to be accepted. It seems that for sick children, it can't be helped, nothing can be done. What a shame!

The argument pursued by Lord Henley in March 1997, against an amendment intended to secure full-time education for children not in school, (Lords Hansard Column 1511-1514), suggested that for children in hospital "full time education may not be appropriate". Even so, the noble Lords debated the meaning of the expression 'full-time education'. Baroness Blackstone echoed the same argument in June 1998 (Lords Hansard Column 747). In following the report Truancy and School Exclusion from the Social Exclusion Unit, she advised that departmental "statutory guidance will explain in detail the kind of provision that might not easily be defined as 'education'" (Lords Hansard Column 748). Enhancing opportunities for the chronically sick and disabled receives scant reference. Instead, the Minister without Portfolio reminds us in a speech at the Fabian Society, that individuals who are little able to help themselves "should be stakeholders in Britain's economic success and share its rewards". In the next breath, emphasising that the government "must concentrate effort on helping individuals who can escape their situation to do so..."

But opportunities can be created! Given half a chance, it is possible for a sick child to succeed and fulfil their academic potential. I know this because my son is a living example of a success story. Putting many years of dislocated schooling behind him, he has achieved above average scores in Standard Assessment Tasks at Key Stage Three and is now studying for ten GCSEs. But he did not achieve this alone. He needed access to a relevant curriculum, in hospital and in the home, together with support and encouragement to keep his education going.

If teachers working in hospital and in the home follow a relevant scheme of work, drawn up by the home school, then there is no reason for a child to fall behind his classmates. Computers and interactive learning can play an

enormous part in education and in helping a child keep in touch with their friends. But without encouragement and a little cajoling, a sick child is unlikely to sustain independent learning on their own. Teachers are a vital part of the process. Clearly sick children are in need of special attention in many ways. Wherever they are, they still need teaching and teachers are needed to do the job.

Any complacency about the need for hospital and home teaching needs turning around. The legality of a local authority decision to reduce home tuition from five to three hours per week, across the board, because of financial difficulties has been challenged. In the judgment in re T (A Minor) 1997, the Lords of Appeal said that a suitable education, is determined on an individual basis, according to age ability and aptitude and any special educational needs a child may have. The duty to arrange education for sick children should not be compromised by an LEA pleading poverty, money has to be found. The outcome of the Tandy case implies that education services in hospital or in the home must be a priority for local education authorities. If excluded pupils are to have access to full time education, then why not sick children? It seems that children occupying the limelight get a better deal and currently, excluded pupils are centre stage.

Whilst child actors have the privilege of working, the Children (Performances) Regulations of 1968 ensure they receive a minimum of three hours private tuition every school day. Presumably, if the curtain falls on their acting career, they always have an education to fall back on. But what of the children ill in hospital or at home? Has the dream of limelight faded for them? They are lucky to receive three hours home tuition a week, let alone each day.

Sadly, sick children and their parents would seem to have very little voice. Rather they enjoy Hobson's choice, unless parents have the skills and resources to do the job themselves.

References are located on Government Internet web sites, http:www.open.gov.uk

Opinions of the Lords of Appeal (20 May1997), Judgments– In re T (A Minor) 1997, UK Parliament publications on the Internet

Minister without Portfolio, Extract from a speech on the 14 August at the Fabian Society, Internet publication Social Exclusion Unit

Truancy and School Exclusion Report (1998) by the Social Exclusion Unit Reports from the Social Exclusion Unit, Cabinet Office.

13.2 Conference and seminar papers

Davies, S. (1995) Factors worthy of investigation in the education of sick children, *paper prepared for the NAESC, Bethnal Green, London, March 10th 1995.*

Davies, S. (1995) Ed.D research/ action research proposal, *paper prepared for the NAESC council meeting, House of Lords, London, October 1995.*

Bolton, A. (1997) *Pupils and Parents' Voices about Education for Sick Children*, London: National Association of the Education of Sick Children.

Advice provided by the researcher during the initial proposal development for the NAESC Pupils' and Parent's Voice project and supervision has received formal acknowledgement in the publication.

Davies, S. (1998) Arrangements for the provision of education for pupils who are out of school by reason of illness: a conceptual framework for research, *paper prepared for the Postgraduate Research Forum, School of Education Research Centre, Oxford Brookes University, November 4th 1998.*

Davies, S. (2000b) Arranging education for sick children: some evidence from research, *paper prepared for a seminar at the Department for Education and Employment, SEN division, London, February 2000.*

13.3 Continuing professional development

Davies, S. (1996) New course proposal: Stage one validation document for postgraduate study re: Postgraduate Diploma in Educational Studies (Medical Needs), *paper presented to the School of Education and Quality and Standards Unit, Oxford Brookes University, January 1996.*

Davies, S. (1997) Professional development for serving teachers: module specifications, *paper presented at the Stage Two Validation Event, Postgraduate Diploma in Educational Studies (Medical Needs), School of Education and Quality and Standards Unit, Oxford Brookes University, October 16th 1997.*

Davies, S. (1997) Professional development for teachers: some evidence from research, *paper prepared for European courses in special educational needs for hospital teachers, Seminar, Atelier 14, Hospital Pedagogues in Europe (H.O.P.E), Birmingham. October 23th –24th.*

Davies, S. (1997) Professional development for Hospital and Home Teachers, *paper prepared for the National Association of Hospital and Home Teachers- study day, University of London, 5th July 1997.*

Davies, S. (1998) Amendments to Stage Two Validation document for Stage Three Validation re: Postgraduate Diploma in Educational Studies (Medical Needs), *paper presented to the School of Education and Quality and Standards Unit, Oxford Brookes University, Oxford, March 1998.*

Davies, S. (2000a) Teaching children with medical needs: continuing professional development, *paper presented to the Department for Education and Employment, SEN division, London, February, 2000.*

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