Different and unequal: The experiences of families with children with learning disabilities.

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How to cite:

Roberts, Susan (2004) *Different and unequal: The experiences of families with children with learning disabilities..* thesis, Swansea University.
http://cronfa.swan.ac.uk/Record/cronfa43134

‘DIFFERENT AND UNEQUAL’: THE EXPERIENCES OF FAMILIES WITH CHILDREN WITH LEARNING DISABILITIES

A THESIS SUBMITTED FOR
THE DEGREE OF MPHIL

Susan Roberts

SUMMARY

This dissertation focuses upon the sense of 'difference' which characterises the lives of children with learning disabilities and their families, setting them apart from others; and the subsequent inequality which they experience. Central to the thesis is consideration of the manner in which difference and inequality pervade the lives of these families on a daily basis, whether that be in terms of their interaction with professionals; with their own family members; with their extended social networks; or with wider society.

A qualitative approach was adopted in this small-scale, exploratory study. The extent to which multi-disciplinary team working, and the establishment of a Family Support Team (FST) in West Wales could provide a solution to the problems so often encountered by families caring for children with learning disabilities was examined. This task was undertaken as part of the process of evaluating the development of the FST during the first 12 months of its life.

The views of FST members on issues germane to their development are reported. Moreover, the views of 22 families for whom the FST provided a service are highlighted. Families' previous experiences of services are charted, together with their views on the newly established FST. The resulting data are drawn upon in an illustrative capacity, and comparisons are made between research participants' experiences at the time the study was undertaken, and other families' experiences of learning disability services today, in

an attempt to establish change or improvement. The extent to which these families are marginalized, excluded and isolated are considered. The implications of the findings for social welfare policy and practice are explored.

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signec ....(candidate)

Date.......31.12.04.......................

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged, giving explicit references. A bibliography is appended.

Signed. ....(candidate)

Date....31.12.04.......................

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed. ....(candidate)

Date.......31.12.04.....................

CONTENTS

ACKNOWLEDGEMENTS

I should like to thank Professor Matthew Colton for his advice and support during the course of this dissertation. I should also like to express thanks to Professor Peter Raynor for his help, and to Professor Michael Sullivan. In addition, I should like to acknowledge the contribution of the late Dr Sue Sullivan. Thanks are also due to Mrs Carol Cook for her assistance with the submission process. Finally, I should like to thank all those who participated in the research reported here. Above all, thanks are due to the families with children with learning disabilities who so readily shared their experiences with me.

CHAPTER ONE - INTRODUCTION

Setting the research in context

This dissertation focuses on the extent to which multi-disciplinary team working, and the establishment of a Family Support Team (FST) in West Wales provided a solution to the problems experienced by families caring for children with learning disabilities. For some years now, the problems commonly encountered by these families have included: a lack of information, in terms of their child's disability, and also the services available to them; an unco-ordinated approach to service delivery, and parents' subsequent involvement with numerous professionals; and the need to fight for services (Beresford 1985; Case 2000; Swain and Walker 2003). All these issues feature in this dissertation which comprises two central themes: namely, the sense of 'difference' which characterises the lives of children with learning disabilities and their families, and sets them apart from others; and the subsequent inequality which they experience. Indeed, as the title of the dissertation – '"Different and Unequal": The Experiences of Families with Children with Learning Disabilities' – suggests, the work focuses upon the manner in which difference and inequality pervade the lives of these families on a daily basis.

In essence, the emphasis is upon the differing forms of marginalisation, exclusion and isolation experienced by families, in part as a result of the problems identified above. The attitudes of 'significant others' play an influential role in the lives of families with children with learning disabilities in two senses: namely, in an internal sense vis a vis their extended family and social network, and also in an external sense, in terms of their relationships with professionals. The differing dimensions of the forms of exclusion such families experience will be explored using the research findings reported here as base-line data.

The research study which provides the back-drop for this dissertation was small-scale, and qualitative in nature. It was commissioned as part of the evaluation of services within the All Wales Strategy (AWS), and was funded by the former Welsh Office. The author was employed by a health authority as a researcher with the brief of charting the development of a FST during the first twelve months of its life. Data were collated as part of the process of evaluating that development. During the course of this dissertation the research findings are drawn upon, and used in an illustrative capacity to make comparisons with the contemporary experiences of families in an attempt to establish change or improvement in their situation with regard to service provision.

The multi-disciplinary team at the heart of the research was set up to provide additional support to families with children with learning disabilities. The team comprised a social worker; health visitor; teacher; and community nurse. It was led by a co-ordinator, who was also a health visitor, and was supported by an administrator. One of the key questions to be posed within this dissertation, is the extent to which the team provided the intended level of support to families.

The aims of the research were twofold:

- to evaluate the development of the FST, and test whether it was meeting the objectives set at its inception

- to evaluate the extent to which the needs of service users were being met by the team

There is a dearth of research on the effectiveness of services provided to children with disabilities and their families (Beresford *et al.* 1996). The intended outcome of the research reported here was the collation of detailed information which could be disseminated to other health authorities which might be looking to develop similar services. The views of both service users and providers in relation to the development of the FST, are highlighted within the dissertation. However, due to the problems encountered in setting up the new service, which are discussed in detail in Chapter Four, families had had minimal contact with the team at the time the research was undertaken. Thus, it was not possible to evaluate the extent to which need was being met. Rather, the focus shifted to families' previous experience of services, and their views on their initial contact with the FST.

As already mentioned, the research findings which emerged from the study are utilised here in an illustrative capacity in an attempt to highlight current issues within the field of learning disability. In the true spirit of qualitative enquiry an attempt is made to make sense of those findings, and their meaning for families. Central to the thesis is consideration of the extent to which multi-disciplinary team working, and the establishment of the FST provided a solution to the numerous problems experienced by families with children with learning disabilities in West Wales. The nature of these problems are explored in Chapter Two as part of the review of the relevant literature. In Chapter Three consideration is given to the research methods employed in undertaking the study. The research findings are presented in Chapters Four and Five. In the former, the views of those families who participated in the research are presented; the latter contains the views of FST members. In Chapter Six, the implications of the findings for policy and practice are considered. There is a particular focus on an assessment of progress in relation to service provision since the fieldwork was undertaken, and upon whether the experiences of families with children with learning disabilities are now more positive in nature.

In this opening Chapter issues of relevance to the field of learning disability are introduced, in particular the social exclusion, stigma, and sense of isolation so often experienced by those with learning disabilities, and their families. A historical perspective is adopted; definitions and labels, and the manner in which these have changed over time are considered; and the policy context within which the research is located is explored.

Beresford (2002, p.149) asserts that:

> 'Social exclusion is an experience that permeates the lives of disabled children ... the consequences of social exclusion are long-term and hard to reverse.'

Implicit in the above is the adverse effect of such exclusion on the quality of life for children with disabilities, and the resulting consequences as they move towards adulthood. Clearly, in recent years, attempts to tackle the problem of social exclusion have been amongst the key features of the United Kingdom policy agenda. There has been a concerted effort to introduce initiatives at a local, regional and national level to address the exclusion experienced by particular groups in society. However, in his Foreword to the Government White Paper 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (2001), Tony Blair notes the challenges which remain:

> 'People with learning disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all

> encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives. Such prejudice and discrimination – no less hurtful for often being unintentional – has a very damaging impact. It leads to your world becoming smaller, opportunities more limited, a withdrawal from wider society so time is spent only with family, carers or other people with learning disabilities. What's also a real cause for concern and anxiety is that many parents of learning disabled children face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best, they can feel obstacles are constantly put in their way by society. At worst, they feel abandoned by the rest of us.'
>
> Foreword to Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)

The history of learning disability has been characterised by the fear of those perceived as 'different', and of their subsequent labelling, segregation and exclusion from wider society. Indeed, the stigma attached to mental handicap has played a central role in the development of services which have further stigmatised adults and children with disabilities, as articulated by Kendall and Moss (1972, p.7):

> 'A cause and consequence (of segregated services) has been the stigma attached to the mentally handicapped and the separate institutions for them … Isolation and stigma help the non-handicapped to lose sight of the essentially common features that they share with the handicapped – common needs, feelings, reactions, behaviours, worth and humanity; instead, differences are searched for and stressed.

Ryan and Thomas (1980, p.13) taking a historical perspective, argue that:

> 'The changing definitions of difference constitute the history of mentally handicapped people. These definitions have always been conceived of by others, never are they the expression of a group of people finding their own identity, their own history. The assertion of difference between people is seldom neutral; it almost always implies some kind of social distance or distinction. The differences between mentally handicapped people and others have mostly been seen negatively, making them a problem to themselves and to others. Only in a few instances has the 'otherness' of mentally handicapped people been valued positively or respected.'

The following quotation serves to illustrate the sense of isolation experienced by those with a learning disability in contemporary society:

> 'For people like me, and a lot more, you know, people were frightened of us. So in them days they said OK, there's nowhere for you, you get shut away in the big institutions. If people are different then other people get frightened. I still see it. People are frightened of people like me, and a lot more, because we're different.'
>
> (Mabel Cooper, in Atkinson *et al.* 1997, p.11)

It has already been acknowledged that the structural element of exclusion features in today's policy arena. The concept of the social exclusion of those with disabilities in the attitudinal sense has received less attention, however. What form does the social exclusion of parents with children with disabilities take? Clearly, there is a financial element to consider, as these families bear the brunt of the additional and often prohibitive costs of caring, but what also of social relationships, of relationships with 'significant others'? The latter are considered here, while particular reference is made to the difficulties faced by parents following the birth of their child with a disability; the subsequent caring process; and its impact on families. Moreover, the professional rivalries and power struggles inherent in multi-disciplinary team-working, and integral to the establishment of the new service also feature.

Definitions, labels and changes over time

Disability is defined by the World Health Organisation as a restriction or inability to perform normal activities, as a result of an impaired structure of body or mind (NCH Action for Children 1996). It is estimated that there are approximately 210,000 people with severe learning disabilities in England; 65,000 of this number are children and young people. Around 1.2 million people have a mild or moderate disability (Valuing People 2001). Approximately

£3billion is spent on health and social services for adults with learning disabilities. Considerable progress has been made in the last 30 years with regard to closing the large institutions which cared for people with disabilities, and which are often now associated - as is the case with Ely hospital - with abuse scandals, and in moving services into the community. Yet significant problems remain. These include:

- poorly co-ordinated services for families with disabled children especially for those with severely disabled children
- poor planning for young disabled people at the point of transition into adulthood
- insufficient support for carers, particularly for those caring for people with complex needs

('Valuing People: A New Strategy for Learning Disability for the 21st Century', 2001)

Under the Children Act (1989), children with disabilities are included within the category 'children in need', and local authorities have an obligation to provide resources for them. Although this indicates that some progress has been made during the latter part of the twentieth century, a considerable divide remains between the disabled and the non-disabled, and there is evidence that exclusionary practices persist today. Indeed, it is clear that service provision is patchy, and that families continue to fight for services (Department of Health 1994). Moreover, in spite of policy shifts in relation to the education of children with disabilities, many are denied the services they need (NCH Action for Children 1996).

Definitions of learning disability abound. A recent definition refers to the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

(Valuing People 2001, p.14)

The labels attached to people with learning disability have changed over the years as have public attitudes and governmental policy. Indeed, during the last 50 years use has been made of terms such as mentally defective; mentally subnormal; and mentally handicapped. At the beginning of the twentieth century, imbecile; idiot; and feeble-minded were in common usage. From 1920 through to 1950, mental defective, and mental deficiency were the favoured descriptors. A plethora of labels, then, but what do all these descriptors have in common? What is apparent is that each has negative connotations, implying that the individuals in question are somehow lacking in ability, and have little to contribute to modern industrial society. Throughout this dissertation, use will be made of the term learning disability, however, terms such as mental handicap will also be used when reference is made to a particular historical period.

The label mental handicap encompasses a broad range of conditions, with the stereotypical image of mental handicap having its roots in the Eugenics Movement. Indeed, arguments put forward by the Eugenics Movement to justify the segregation of people with mental handicap continue to have resonance today. For, according to Shearer (1972, p. 51):

> '...it is still widely believed that mentally handicapped people are uncontrolled and perverted in their sexual appetites. In the past this belief has been one of the main incentives for shutting them away in segregated institutions.'

The labelling process, while used on a daily basis as a means of ordering our social world is integral to the act of identifying deviance or difference, and is subject to social context, and public reaction. Those who are mentally handicapped have over time been perceived as dangerous, and in need of segregation in the interest of public safety. They have also been perceived as different or abnormal. The labelling process with regard to learning disability is clearly discriminatory, functioning to promote segregation, and to deny access to specific services, employment etc. The process has undoubtedly proved oppressive and has functioned to exclude, as highlighted by Booth (1997, p.158):

> 'Labels are part of the language of oppression. People with learning difficulties know at first hand the power of language to imprison and exclude. Big words (and big meetings) shut them out.'

It was not until the eighteenth century that mentally handicapped people were identified as a social problem. Medieval writing contains little reference to what is now termed mild mental handicap. English law first distinguished between those who were *non compos mentis* and 'natural fools' during the reign of Edward II. Those who are today labelled mentally handicapped were not labelled as deviant in the early Middle Ages. Those who would now be perceived to have a mild or moderate handicap would, with their family's assistance, have worked on the land. If that were not possible, then like other dependent people, they would have been cared for by their families or within the monasteries. In other cases, however, they might live as beggars, dependent on charity.

The fourteenth century brought changes to the feudal system, and an increase in the number of beggars and vagrants. There was a shift in attitude towards those who were dependent. Legislation decreed that the able-bodied should not be given assistance; those who were sick, handicapped or old, however, were entitled to aid.

Abbott and Sapsford (1988) note the emergence during the sixteenth century of Calvinist and Lutheran denouncements of the mentally subnormal as possessed by Satan, lacking souls, and fit for destruction only. Moreover, according to Ryan and Thomas (1980, p.88):

> 'The idea of handicapped children being a punishment for the sins of individual parents...'

is clearly evident in Lutheran writing. Here, an abnormal child results from parental failings; perhaps they were not sufficiently God-fearing, or had illegitimate children. At the same time, the belief existed that an abnormal child resulted from sexual intercourse between a woman and the devil, with the child's birth being seen as evidence of witchcraft.

This was the era of the 'witch hunt', a time when the handicapped and mentally ill were victimised. Thomas Willis (1672) in his attempt to define mental subnormality, made the distinction between mental handicap, and mental illness. The former were seen to be 'stupid', and the latter, 'foolish'. These characteristics were perceived to have been inherited.

With the sixteenth century came the dissolution of the monasteries, and an increase in the number of unemployed labourers, with the continuation of the enclosure movement. The subsequent increase in the number of vagrants was perceived as a real threat to law and order and attempts were made to suppress vagrancy and begging.

The English Poor Law Act (1601) was directed at the poor and unemployed, but failed to address the mentally ill or handicapped. They were left to their own devices provided they were not considered dangerous. The end of the seventeenth century, however, saw a change in attitudes in relation to those perceived as marginal to society. The 'Great Confinement' resulted in the incarceration of vagrants, the unemployed, criminals, idiots, and lunatics in an attempt to alleviate the threat they posed. The sin of idleness was subject to the strongest condemnation. The workhouse contained the sick and the aged along with those who were idle.

The first residential schools for people with learning difficulties were established in Bath in 1842, and Highgate in 1847. Stainton (1991) points out that these establishments aimed to provide an education '...They were pedagogical rather than medical or custodial...' (p.15). In the late nineteenth century, however, there was a significant shift in opinion; the mentally handicapped were perceived to belong to the 'dangerous classes', and to be a real threat to the fabric of society. Connections were made between moral degeneracy, poverty and criminality; the poor were perceived as deviants in need of control. Britain was moving from a country with a rural, agricultural base to an urban, industrial society. Reformers believed that the idle should be disciplined, and mass schooling was introduced as a means of social control.

Indeed Ayer and Aleszewski (1986, p. 4) argue that:

> 'The identification of the mentally handicapped as a distinctive group at the end of the 19th Century is associated with the development of a system of universal and

> compulsory education.'

As a result, one sees the identification by means of a Royal Commission (1889), of 'feeble minded' children who were often in poverty and came from large families. The Commission recommended that such children should be separated from their peers so that they might receive 'special instruction'.

Stainton (1991, p.14) notes that the Idiots Act of 1886:

> '...marks a watershed between rather benign Victorian paternalism and the coming storm of the Eugenics Movement which would break over the lives of people deemed to be mentally, which also meant morally, deficient. This would eventually lead to the incarceration of some 65,000 at the height of the institutional dominance.'

Those labelled mentally defective were not only perceived to be a problem for the education system, but were seen to threaten society itself by means of their degenerative behaviour and high levels of fertility. Abbott and Sapsford (1988, p.16) point out that:

> 'By the early twentieth century it was generally accepted that this group needed to be shut away and prevented from breeding for the protection of society.'

Moreover:

> 'A firm conviction developed that the retarded could not be trained to be productive members of society and that as well as being a burden on society they were also a social menace, posing a constant threat to civilisation.'
>
> (Abbott and Sapsford 1988, p.22)

Thus:

> '... marriage regulation, birth control, sterilisation and segregation ... were seen as the way forward in the USA and Britain.' (*ibid.*)

Mental handicap is a social construction, the nature of which changes according to time and place, and according to the prevailing societal norms and values. Abbott and Sapsford (*ibid.*, p.2) argue that:

> '…the process by which mental handicap came to be defined as a distinct condition and as a social problem can be seen as an outcome of the concurrent development of industrial capitalism.'

Those who were unable to participate in the labour market were subject to the fear and distrust of the general population, and labelled a 'problem'. Subsequently, institutions which could contain, and treat the problem developed. Segregation of the retarded was perceived as a solution, and steps were taken to prevent them from breeding, more for society's protection than their own.

Brigham (2000, p.31) notes that industrialisation had major implications for people with physical or mental impairments. An emphasis on the means of production led to the exclusion of those who failed to keep pace with developments. For, the contribution they could make to a society in which employment was becoming increasingly factory-based was perceived as limited:

> 'The nineteenth century can be summed up as a period of economic, political and social change that had an impact upon all groups in society. Whereas women were increasingly segregated in the private institution of the family, people who were physically or mentally impaired were increasingly segregated in the public institutions of the workhouse or asylum. The nineteenth century can therefore be seen as a time for the re-drawing of boundaries between classes, between masculinity and femininity, between public and private, and between normality and abnormality.'

In 1904, the Royal Commission on the Care and Control of the Feeble Minded found that mental defectives were a distinctive group of people who presented a social threat. Parents were deemed responsible for such defects. It therefore followed that defectives should be immediately removed from their families to prevent further harm. The Commissioners in Lunacy accepted the Commission's recommendations, and in 1913 the Mental Deficiency Act became law.

According to Race (1995, p.15), the Act:

> '...provided the first supposedly exact definition of the various grades of mental deficiency... and its categories were to remain the legal terminology for nearly half a century'.

Defectives were classified under 4 headings, namely: idiots, imbeciles, feeble-minded persons, and moral defectives. Idiots were deemed unable to protect themselves against physical danger; imbeciles, as incapable of managing their own affairs; the feeble minded as in need of care and control both for their own protection and the protection of others; finally moral defectives were deemed to display a permanent mental defect from an early age, along with criminal tendencies. Those who fitted into one of the above categories were to be placed in an institution which provided for defectives, or under guardianship at the request of a parent or guardian.

The Act '...was built around the principle of life-long segregation within mental deficiency colonies' (Ayer and Alaszewski 1986, p.10). Certification was the overriding principle; all those admitted to institutions were to be certified as mentally defective. Moreover, the Act:

> '... gave the mentally deficient a distinctive legal identity and established the framework for their care and control.' (*ibid.*, p.18)

Stainton (1991) highlights the plight faced by 'feeble minded women'. The over riding obsession with their control was illustrated in the belief that the birth of an illegitimate child was proof of their moral weakness and feeble-mindedness. The author writes that:

> 'Many women paid for a single illegitimate sexual encounter with their freedom, many languishing until the Act was changed in the 1950s.'(p.14)

A centralised administrative body - the Board of Control - was created to act in a supervisory capacity. County and County Borough Councils were to establish the number of mental defectives in their areas, and set up institutions to care for them. As already noted, the mentally deficient were perceived to be a threat to society. The prevailing attitude was that they should be supervised, controlled or even segregated in institutional settings. However, many local authorities were slow in implementing the Act, and by 1927, only 5,301 beds for the mentally handicapped were provided, whereas the number of 'defectives' was estimated at over 60,000.

Stainton (1991, p.15) argues that the most significant aspect of the Bill:

> '...is that it set the stage for the rapid expansion of large institutional facilities and the dominance of the state over the lives of people with a learning difficulty. With this Bill, for all intents and purposes it became a crime to have a learning difficulty.'

The 1913 Mental Deficiency Bill epitomised an era of classification and segregation. Moreover, under the Education Act 1914, local education authorities were required to provide separate schools for the 'educable mental defective'. The invention of IQ testing by the French psychologists Binet and Simon in 1908 had heralded a shift in thinking about 'mental defectives', (Ryan and Thomas 1980). They were perceived as ineducable with little potential for improvement. Thus, they were more in need of medical than educational provision.

Categories of mental deficiency emerged, ranging from low grade through to medium and high grade. An IQ score of 50-70 was labelled high grade, but perceived to be feeble minded, mentally handicapped and educationally subnormal; at 25-49, the term medium grade was applied, together with retarded and trainable. A score of 0-24 implied low grade, severely mentally handicapped and untrainable (Bone *et al.* 1972).

In 1924, the Wood Committee, incorporating the Board of Education and Board of Control, was established. Its remit was to undertake a survey of the numbers of adults and children with mental handicap and the educational provision available. It was estimated that there were '72,000 unascertained defectives' in schools and that provision was inadequate (Sutherland 1984). The emphasis was on the care and control of the 'defective', and the Committee made recommendations as to the size of colonies and also the design of institutions. Further, it recommended that the guardianship and license system, whereby those deemed defective needed a licence to gain access to the general community, be expanded (Jones 1972). Clearly, the Eugenics Movement continued to exert influence as illustrated in the following quote from the Wood Report (1929):

> 'If we are to prevent the racial disaster of mental deficiency we must deal not merely with the mentally defective persons but with the whole sub-normal group from which the majority come...The relative fertility of this group is greater than that of normal persons...'

The sterilisation campaign proposed by the Eugenics Society was fuelled by the finding that the number of mental defectives was significantly greater than had been previously estimated. The belief, as put forward by the Wood Committee, that defectives were part of a larger problem group also played a part in this. In the US, sterilisation had been imposed on criminals, rapists, idiots and imbeciles on the recommendation of experts (Searle 1976). In Britain, Winston Churchill, who was Home Secretary from 1910 to 1911, warned the Prime Minister (Asquith) of a '...very terrible danger to the race...' proposing that until there was public acceptance for sterilisation, segregation between the sexes, and from the community was essential (Searle 1976).

In 1930, the Eugenics Education Society formed the Committee for Legalising Eugenics Sterilisation. The intention was that the Committee would lobby the Government to move towards legislation on the matter. Due to this pressure, a Departmental Committee led by Sir Lawrence Brock was set up by the Ministry of Health in 1932. The resulting report recommended that mentally handicapped females should be sterilised. However, in spite of considerable support, the Eugenicists' campaign failed. According to Macnicol (1989) there were a number of reasons for this. First, there was a belief that this was an anti-working class measure. Second, there had been strong opposition from the Catholic Church. Third, concerns had been expressed as to the legality of sterilisation, and finally there were fears that compulsory sterilisation would follow. The Eugenicists had failed to prove that mental defectiveness was hereditary.

A shift in policy – a period of reform

In the early twentieth century there was a policy commitment towards institutionalisation, however, slowly, came the realisation that perhaps the mentally handicapped were not such a threat after all. Professionals began to articulate the view that they could be cared for in the community. The fact that institutional care was costly was undoubtedly one of the factors which played a part in the policy shift at this time. Four policy-making cycles can be identified since the Second World War according to Ayer and Alaszewski (1986). Of course, a fifth may be recognised in the form of 'Care in the Community', and this will be considered later in this Chapter.

The first of these cycles relates to the establishment of the National Health Service (NHS), in 1948; the second to the Royal Commission on law in terms of mental deficiency and mental illness during the 1950s and early 1960s; the third began with the scandals surrounding mental handicap hospitals, and the subsequent inquiries during the late 1960s; finally the 1970s characterised '...a period of consolidation both nationally and within local agencies...' (*ibid.*, p.28).

Prior to the creation of the NHS, there had been little consideration about services for the mentally deficient, the Board of Control being the sole representative body. However, Aneurin Bevan, Minister of Health, was determined that services for both the mentally and physically ill should be integrated in the NHS. This determination is illustrated by the following quotation:

> 'Mental illness is no longer regarded as belonging to a world of its own. I consider this to be one of the outstanding features of the British Health Service. The segregation of mental from physical treatment is a survival from primitive conceptions and is a source of endless cruelty and neglect.' (Bevan, 1952, p.182, cited in Ayer and Alaszewski *ibid.*)

In an administrative sense, the NHS clearly focused upon services for those who were physically ill. Services were divided between those in the community, which were the responsibility of local health authorities; primary care services, the responsibility of executive councils; and hospital services which were administered by hospital management committees.

The majority of services for the mentally deficient were provided in institutional settings; residents were not seen to be suffering from any form of physical illness, but were perceived to be in need of supervision.

Stainton (1992) argues that this period of reform did not impact on the lives of people with a mental handicap in a significant way. For, mental subnormality hospitals were not afforded priority in the NHS. Indeed, the mentally deficient did not feature as a priority on either the national policy agenda or that of local health authorities. Acute and primary care services clearly remained the focus of attention. Limited resources were allocated to institutions and scant attention was paid to those housed in them. A pamphlet entitled '50,000 Outside the Law' published by the National Council for Civil Liberties (NCCL) in 1951 condemned the practice of segregated care for the mentally deficient. The fact that the families of certified defectives were denied rights was highlighted, and the philosophy of permanent segregation was no longer deemed acceptable.

In 1954, a Royal Commission undertook the task of reviewing current legislation in relation to the mentally deficient. Revisions were made both to classification and terminology regarding the mentally disordered. The 1913 Mental Deficiency Act had promoted the perception of the mentally disordered as a threat, linking low levels of intelligence, moral defects and social incompetence. The Commission recommended the re-classification of mental disorder as the mentally ill; the severely subnormal; and psychopaths. Further recommendations were made that the mentally disordered should be allowed access to the same services as all other members of society. Such changes in legal classification were encapsulated in the 1959 Mental Health Act. In 1961, Enoch Powell, Minister for Health, reported plans for investment in hospital services, alongside an intention to review the development of community services. This resulted in a period of investment and expansion in terms of services for the mentally handicapped, within the auspices of the NHS framework.

During the late 1960s, the public was alerted to the first in a line of scandals involving institutions which were responsible for the care of mentally subnormal patients. The mistreatment and level of exploitation uncovered at Ely Hospital, Cardiff, paved the way for reform in learning disability services. Ely had once been a Poor Law institution, and at the time of the scandal housed 600 people with mental handicap. The Committee of Inquiry established by the Minister of Health, Kenneth Robinson examined allegations made in the 'News of the World', during the summer of 1967, and uncovered '…serious shortcomings in services and policies for the mentally handicapped.' (Ayer and Alaszewski 1986, p.25). These shortcomings were wide ranging, relating to organisational and administrative functions; low funding, and staffing levels; and a lack of clarity in terms of policy and objectives.

The Committee, chaired by Sir Geoffrey Howe, reported to the newly formed Department of Health and Social Security, which had replaced the Ministry of Health. Richard Crossman, the Minister of Health, took the opportunity to publish the inquiry report in full, and this was followed by range of policy initiatives. Read (2000, p.6) writes that the 1970 Chronically Sick and Disabled Person's Act:

> '…has often been regarded as an early example of ground-breaking legislation in relation to service provision for disabled children and adults.'

The creation of social services departments played a significant part in the development of community care for the mentally handicapped. The Seebohm Committee made the recommendation that the new social services departments were to be responsible for community care of the mentally handicapped. Further, they were to be an important part of the network of services in the community. In spite of opposition from the medical profession, Richard Crossman accepted the recommendations, and local authority social services departments were required to provide a comprehensive range of community services for the mentally handicapped under Section 2 of the Chronically Sick and Disabled Act 1970.

In 1971, the White Paper, 'Better Services for the Mentally Handicapped', resulted from the working party set up to review policies in relation to the mentally handicapped. It marked a shift in responsibility in terms of the care of the mentally handicapped. The health service was no longer to be the principal support agency. Rather, local authority social services and their social workers were to undertake the main supportive role in relation to families and residential services. The NHS was to assess and care only for those who needed medical care. Moreover, local education authorities and the Department of Education and Science took over responsibility for the education of severely handicapped children from health authorities and the Department of Health and Social Security.

The publication of the White Paper led to the use of the term mental handicap within policy-making procedures, as a means of highlighting similarities between those who were mentally handicapped, and other handicapped groups. Prior to the Second World War, mental deficiency was believed to have been hereditary, and was associated with certain groups in society.

The White Paper placed emphasis on the fact that the cause of most mental handicap was unknown:

> 'It is often the result of unpredictable and unavoidable factors – hereditary or environmental or both – including the lower end of the normal range of variation of intelligence.' (DHSS Better Services for the Mentally Handicapped, para. 9)

Moreover, the White Paper recognised the key contribution made by those families caring for the mentally handicapped, and the inadequate support they received while doing so.

Ayer and Alaszewski (1986, p.26) argue that:

> '...The policy initiatives of the 1968 to 1971 period marked a major transformation of services for the mentally handicapped...'

Until 1969, the medical profession had principal responsibility for the development of services for the mentally handicapped. In the years after 1971, with local government and NHS reorganisation, 3 main agencies, the NHS, local social services, and local education authorities became key players. As a result of the scandals in mental handicap institutions, it was social workers and teachers rather than medics who now played a central part in service development. In order to aid the process of developing a comprehensive package of services for people with mental handicap, a number of working groups were established. Mental handicap nursing and care became the responsibility of the Jay Committee, which was set up by the DHSS. Here, the emphasis was clearly upon the fact that:

> '...the family played a key role in the life of the mentally handicapped and that the family must form the starting point and focus of any service for the mentally handicapped...one of the major rights of a mentally handicapped child should be to live with a family' (Ayer and Alaszewski 1986, p.28).

Under the Education (Handicapped Children) Act 1970, local education authorities were deemed responsible for the education of children with severe learning disabilities. Moreover, the Warnock Committee which was established in 1974, explored the educational needs of handicapped children. The Committee's recommendations were published in the report 'Special Educational Needs' in 1978.

In terms of context, until 1971 most severely mentally handicapped children were excluded from the education system, and classed as ineducable. Indeed, '…their permanently hopeless state was held to warrant their complete segregation…' Ryan and Thomas (1980, p.110). Junior Training Centres provided by the local health authority undertook a training role in relation to such children. On April 1st 1971, however, local education authorities became responsible for the education of all children, resulting in a major construction programme to provide places for the education of the severely mentally handicapped.

The Warnock Report proposed major changes to the education of children with special needs. Such children were not to be treated any differently to other children, unless they required additional educational provision. Dale (1996, p.249) writes that:

> 'The Report was heralded as a major step forward in the thrust towards integration of children with special needs into the mainstream education system.'

The issue of partnership with parents was a central feature of the Report's recommendations. The need for improvements in the relationship between parents and professionals was emphasised; parents were to be equal partners in the process of educating their child. It was proposed that a named worker would support parents and enable their participation. The government responded to the Warnock Report by passing the 1981 Education Act. The introduction of the concept of special educational need, and the 'statementing' process was accompanied by parental rights with regard to participation in decisions about their child's education.

Much attention has been paid in recent years to the key role played by parents in their children's education, both in terms of policy, and legislation (Moses and Croll 1987). Prior to the 1981 Act, professionals had made decisions as to where a child with a physical or learning disability should be educated. Post 1981, parents were to be an integral part of the decision-making process. They could request an assessment: this, the local authority were bound to comply with if the request was deemed 'reasonable'. Parents could put forward their views; could be present at the assessment; and could comment on the draft statement of special educational needs. Parents also had access to an appeal process if they were dissatisfied with the final 'statement' when produced.

It would appear that significant progress had been made in terms of the integration of children with special needs into the mainstream education system. However, Dale (1996, p.250) argues that:

> 'Although the spirit of the Act was for 'parents as partners' and the expectations of parents and professionals were initially high, parental rights were weakly articulated in the Act and many problems ensued once the Act was in operation.'

Moreover, Read (2000, p.6) points to the fact that additional funding was not made available to aid implementation of the Act, and also that:

> '... the statementing process was to prove complex, protracted and costly for all concerned ... Despite the hopes held out for it by some, the Education Act (1981) did not pave the way unequivocally for the inclusion of disabled children in mainstream schools.'

In 1970, the King's Fund had chosen to focus upon the improvement of standards and raising professional awareness with regard to learning disability. Consequently, the initiative entitled An Ordinary Life (AOL) was operationalised during the 1980s:

> '...as a focus for rethinking the opportunities and support which should be available to people with learning disabilities, producing evidence-based design guidance for the necessary supports to community living, mobilising and assisting local change strategies and learning from experience.' (Felce 1998, p. xi)

This move towards community living led to a 37% decrease in the hospital population, between 1980 and 1990; in terms of numbers, a reduction from 51,500 to 32,700 (Booth 1997).

Having reflected on the shifts in policy with regard to learning disability during the latter part of the twentieth century in particular, in the final section of this introductory chapter, the focus is on more recent policy initiatives. These include amongst others, the All Wales Strategy (1983), the Children Act (1989), and the NHS & Community Care Act (1990). Each of these, in their own way, has played a significant part in the lives of those with learning disability and their families, and hence, they are considered here in some detail.

The All Wales Strategy (AWS)

In Wales, improvements in services for people with learning disabilities were driven by the All Wales Strategy (AWS). The Strategy was launched by the Secretary of State for Wales in 1983, with implementation being aided by a 10 year package of additional funding. It was envisaged that the Strategy '...should be the touchstone for future developments in services...' for people with a mental handicap (Welsh Office, 1983). The AWS was committed to the 3 AOL principles, that people with a mental handicap:

- have a right to ordinary patterns of life within the community;
- have a right to be treated as individuals; and
- have a right to additional help from the communities in which they live and from professional services in order to enable them to develop their maximum potential as individuals.

McGrath (1991, p.65) argues that:

> 'The vision set out in the Strategy guidelines was of a service tailored to the individual needs of each mentally handicapped person and his/her family. It embraced the concept of a needs-led service; the interweaving with support from informal carers and voluntary organisations; and participation of users in planning their own services (as well as broader service plans). Individual programme plans (IPPs) were advocated as the main foundation on which these aims would be achieved.'

The AWS resulted in a complete restructuring of services, and placed a clear emphasis upon the right of people with learning disability to participate in community life, regardless of the severity of their disability. A substantial level of financial investment was to result in locally provided support services. Further, people with learning disabilities were '…to receive the respect and equal opportunities that are their due…' (Welsh Office, 1983, pii).

For McGrath (1991, p.16) the AWS:

> '…was a bold initiative reflecting contemporary thinking on services for mentally handicapped people.'

Hunter and Wistow (1987) refer to the unique nature of the AWS, which is explicit in its rejection of the medical model of mental handicap; and its emphasis on the integration, development, and provision of opportunities to mentally handicapped people, alongside support for their carers.

According to McGrath (1991) the AWS aided inter-agency collaboration due to strong central government support; a clear philosophy, goals and guidelines; additional financing; financing of plans only where there was evidence of collaboration and carer participation; and a clear focus on a single client group.

Within the Strategy document, the need for improved co-ordination of comprehensive, accessible, quality services was highlighted. Community Mental Handicap Teams (CMHTs) were perceived as a mechanism for ensuring that people with learning disabilities were treated as individuals, and allowed normal patterns of life within their own communities. However, CMHT's focused largely on the needs of adults and consequently, specialist services for children diagnosed as having learning disabilities or developmental delay were inadequate and fragmented. This was the case in spite of the establishment of Child Development Teams (CDT's) to co-ordinate assessment and support for children with special needs.

The Children Act (1989)

According to Read (2000, p.7):

> 'The 1980s and 1990s saw unprecedented and wide-ranging changes in the organization and delivery of health, education and social care services across the public, voluntary and private sectors.'

Numbered amongst such changes was the Children Act (1989), a key development in terms of children with disabilities and their families, emerging as it did during a period characterised by a series of tragic child abuse deaths: namely, those of Kimberley Carlisle, Jasmine Beckford and Tyra Henry; and also the Cleveland Inquiry (1987).

Dale (1996, p.261) notes that:

> 'The Children Act strives to reform the law relating to children and to achieve a better balance between the duty to protect children and ensure that their needs and safety take priority and a recognition of parents as key agents in the upbringing of children. The main principles espoused in the Act include:

- the welfare of the child is the paramount consideration in court proceedings,
- wherever possible, children should be brought up and cared for within their own families,
- parents continue to have parental responsibility for their children, even when their children are no longer living with them. They should be kept informed about their children and participate when decisions are made about their child's future,
- parents with children in need should be helped to bring up their children themselves,
- this help should be provided as a service to the child and family.'

Through the Children Act, one sees the introduction of the notion of parental responsibility as opposed to parental rights; implicit in the former are the concepts of obligation, and duty towards children. There is, for the first time in law, an emphasis on support mechanisms as a means of preventing family breakdown. According to Dale (1996, p.262):

> 'The Act establishes the basic principle of the value of *supporting families*, so that family breakdown should be minimised through the detection of need and early intervention.'

Local authorities are duty-bound by the Act to identify children in need in their area; to provide services which enable the promotion of the health and development of those children; and further, to enable their upbringing within their own families. The focus is very much upon the provision of support services in a non-stigmatising manner. Moreover, one sees for the first time that cultural differences are to be taken into account in the assessment process. The Act places a firm emphasis on the need to work in partnership with parents, and calls for increased levels of co-operation between education, health and social services.

Children with disabilities are included within the category 'children in need' under section 17 of the Act. Subsequently:

> 'Every local authority shall provide services designed: i) to minimise the effect on children within their area of their disabilities; and ii) to give such children the opportunity to lead lives which are as normal as possible.' (Schedule 2, paragraph 6)

Local authorities are bound to work towards the systematic provision of information and needs assessment by means of a register of children with disabilities; the publication of information regarding the availability of services; and a policy of ensuring that service users know what is available to them. Notwithstanding such improvements, however, service delivery for children with disabilities is patchy, and families continue to face difficulties in obtaining help (Department of Health 1994).

This finding is borne out by Read (2000, p.8) who argues that although there have clearly been significant policy and legislative changes in relation to children with disabilities and their families in the 1980s and 1990s:

> '...it would be extremely unwise to assume that the positive impact of such policy developments has been felt universally by the children and their families. It is clear that services remain patchy and under-funded and as a consequence, children and their families are often predominantly reliant on their own personal coping resources and strategies for much of what they need.'

Community Care

The concept of community care has been a policy feature for some years now and has been the subject of much debate. Ayer and Alaszewski (1986) highlight the ambiguous nature of community care which may be perceived to be an alternative to institutional or hospital care; an alternative to specialised, segregated services; or to mean care by the community. As noted earlier, during the 1950s and 1960s there was increasing criticism of the large-scale institutions for the mentally ill and mentally handicapped. The American sociologist Goffman was only one of a number of critics. His seminal study 'Asylums' was published in 1961, and focused on the 'total institution', one which was isolated from the rest of society. Within the institution, two differing cultures existed, the dominant staff culture, and the patient culture. The institution was characterised by the subordination and control of inmates who became incapacitated and dependent, and thus allowed the institution to operate. For Goffman, all institutions regardless of nature share problems such as the depersonalisation of inmates.

Two major studies of hospitals for the mentally handicapped highlight issues raised by Goffman. Morris (1969) published her report in the same year as the Ely Hospital Inquiry Report. She noted that many of the issues resulting from the Ely Inquiry were true of other hospitals:

> 'There are many things wrong with our subnormal hospitals, conditions in some places are Dickensian and grotesque.' (p.315)

King, Raynes and Tizard (1971) also identified major problems inherent in the large mental hospital. Together with Morris (*op.cit.*) they emphasised the need for small community based residential units of the type called for in the Report of the Royal Commission (1957):

> 'Whatever form of accommodation is favoured in any particular locality, we are convinced that the aim should be a deliberate re-orientation, away from institutional care in its present form and towards residential homes in the community.' (Cmnd. 169, para. 618)

The Hospital Advisory Service was set up as a result of the Ely Report to explore conditions in long-stay hospitals. The White Paper, 'Better Services for the Mentally Handicapped' (1971) roundly acknowledged the failings of large scale institutional care:

> 'Patients become apathetic and institutionalised, and sink into a state of complete physical and social dependence...' (Cmnd 463, para. 114)

The White Paper recommended a ban on the construction of hospitals with over 500 beds, and the establishment of local authority residential homes. The Mental Health Act 1959 had required local authorities to make provision for a full range of community services, but progress in achieving this had been slow. The focus of the White Paper was on the reduction in mental handicap hospital beds from 60,000 to around 30,000, and at the same time, the expansion in local authority residential homes from 6,000 to 35,000 places. It was intended that hospitals would provide care for the severely disabled, while local authorities would care for those who were more able. The establishment of training centres was also a feature of this restructuring of services.

Whereas the Royal Commission and White Paper had focused on the services provided, and made recommendations to address failings, Ayer and Alaszewski (1986) write that the Jay

Committee was more radical in its approach. Here, the focus was on the rights and needs of people with mental handicap, and the development of a service framework to meet those rights and needs. Moreover, the implementation of changes in order to create such a service were explored.

The Committee acknowledged the criticisms of large-scale institutional care, but highlighted the fact that problems could also develop in community based residential accommodation. It recommended that residential care should be small-scale, and located in houses similar to ordinary homes. The Committee saw no role for the mental handicap hospital, stressing that mentally handicapped people, however severe their disability, had the right to live in houses in the community. Thus, one sees a shift from segregating those perceived as outside the norm, to their reintegration into the local community.

The move to integrate people with mental handicap into the community is well established in Wolfensberger's principle of 'normalisation'. The concept of 'normalisation' originated in Denmark in the late 1950s (Sharkey 1995). Then, in the USA during the 1970s and 1980s, Wolf Wolfensberger further developed the concept, later describing it as 'social role valorisation'.

Normalisation:

> '...attempts to change the fact that some groups of people have often been regarded as of lesser value in society.' (Sharkey *op.cit.* p.33)

It played an influential part in the care of people with learning disability during the 1980s, with its emphasis upon the value of each individual; and their right to choice, opportunity, and any additional support needed to fulfil their potential. Institutions were recognised as significant obstacles to inclusion, and this recognition impacted upon service planning and delivery. Moreover, the principle of normalisation made a contribution to the 'ordinary life' movement in the UK, and 5 major 'service accomplishments' may be identified as a result of the application of 'ordinary life' values in practice:

- 'Community presence – the right to live and spend time in the community rather than in residential day or leisure facilities which segregate them from other members of society.
- Competence – in order for a full and rewarding life to be lived in the local community, many will require help to learn more skills and have access to a wider range of activities.
- Choice – a high quality service will give priority to enhancing the choices available to people and generally protecting their human rights.
- Respect – services can have an important role in helping people enjoy the same status as other valued members of society.
- Relationships – help and encouragement is needed to mix with other non-disabled people in their daily lives.'

(King's Fund Centre, 1991, p.45, cited in Sharkey *op.cit.* p.35)

Ayer and Alaszewski (1986, p.43) write that:

> '…the intellectual roots of moves to reintegrate the mentally handicapped can be found within sociological theories about the nature and cause of deviance.'

Indeed, Wolfensberger (1972, p.49) took the concept of deviance as his starting point. He noted that deviance could be managed by:

> '...the destruction of deviant individuals, their segregation, reversal of their condition or prevention thereof.'

Wolfensberger argued that the reversal or prevention of deviance would provide a basis for the normalisation of people with a mental handicap; the process of altering the deviant individual, and their social environment would result in the person no longer being perceived as deviant. However, while the concept of normalisation has proved influential in the field of learning disability, it is neither without its weaknesses, nor its critics. For, it emphasises the need for devalued groups to assimilate with the dominant group. This proves totally unacceptable for those who believe in the need to celebrate difference, and not have it subsumed within the larger majority group.

As already noted, the post-war period was characterised by attempts to move people out of long stay hospitals, and into the community; and by efforts to enable people to live at home rather than in hospitals or residential homes. Notwithstanding this however, Sharkey (1995, p.2) argues that:

> 'The efforts were not pursued with great energy or determination and by the mid 1980s most commentators and politicians of all political parties agreed that community care was not being well-managed.'

Several key problems were identified: namely, social care and health organisations were not working effectively together; health and social care authorities often worked to different geographical boundaries; discharge into the community was not accompanied by adequate provision of services; the financial costs of care in nursing and residential homes were increasing rapidly; and finally little support was available to carers (Sharkey *ibid.*).

The 1986 Audit Commission Report, 'Making a Reality of Community Care', focused on 4 priority groups: namely, the elderly; those who were mentally ill; mentally handicapped; and those who were physically or sensorily handicapped. The Report drew attention to the problems inherent in community care, concluding that if financial, organisational and staffing issues were not addressed then there would be:

> '...a continued waste of scarce resources and, worse still, care and support that is either lacking entirely, or inappropriate to the needs of some of the most disadvantaged members of society and the relatives who seek to care for them.'

The Griffiths Report (1988), 'Community Care: Agenda for Action' was published as the Government's response to the problems identified above. Roy Griffiths recommended that one organisation should take the lead in terms of community care, and that this should be the local authority social services department. In 1989, the White Paper, 'Caring for People', was published; it contained most of Griffiths' recommendations.

The White Paper defines community care as follows:

> 'Community care means providing the services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in homely settings in the community.' (DoH 1989, p.3)

Six key objectives were laid out:

- to provide services to enable people to live in their own homes wherever feasible and sensible
- to ensure that service providers make practical support for carers a high priority
- to provide proper assessment of needs and good care management (individual care plans)
- to promote the development of a flourishing independent sector alongside good quality public services
- to make providers of services more accountable
- to secure better value for money by introducing a new funding structure (p.5)

Shortly after the publication of the White Paper, came the 1990 National Health Service and Community Care Act. In 1993, social services departments took on the lead role with regard to community care. A number of key themes are evident in community care legislation: namely, the thorough assessment of need; the effective provision of services through care management; an emphasis on quality assurance; better planning and co-ordination; a greater choice of services for service users; and a mixed economy of care, resulting in a more competitive 'market' situation, and the purchaser/provider split (Sharkey 1995).

Central to any discussion of community care is the nature and extent of the informal as opposed to the formal network of care. The 1981 White Paper 'Growing Older' highlighted the contribution made by unpaid carers, and placed emphasis on the fact that care in the community was increasingly to mean care by the community (DHSS 1981). In spite of Government recognition of the significant contribution made by carers, as evidenced in 'Caring for People' (1989), they are paid little attention in the NHS & CC Act (Sharkey 1995). The implications of a caring role for families with children with disabilities are considered later in this dissertation.

Each of the 3 policy initiatives referred to above – the AWS; the Children Act (1989), and the NHS & Community Care Act (1990) – were implemented during the decade prior to the establishment of the FST. Each represented a significant shift in thinking around learning disability. However, other initiatives of importance to families with children with learning disability have emerged in the years since the FST came into existence. These are listed below because they too, are representative of that policy shift:

- the 1993 and 1996 Education Acts, both of which are key pieces of legislation in terms of the education of children with learning disabilities. Here, the emphasis is upon the need for schools to have explicit policies on special educational needs; on the assessment process; identification of need; a regular process of review; and parental involvement. Moreover, one sees the establishment of SEN Tribunals and the subsequent increase in parental rights with regard to decisions taken about their child's assessment and placement.

- the Disability Discrimination Act (1995) which gives people with physical and learning disabilities new rights in terms of transport, employment, information about education, property, goods and services. The Disability Rights Commission was established in 1999, and plays a key part in monitoring implementation of the Act. The schools section of the Act was amended by the Special Educational Needs and Disability Act 2001. The new duties, which came into effect in September 2002 extend the 1995 Act to cover all aspects of education. Part 4 of the Act – the code of practice for schools - focuses on the prevention of discrimination against people with disabilities in terms of access to education.

- the Community Care (Direct Payments) Act (1996) allows local authorities to make discretionary cash payments to those assessed as in need of community care services, thus allowing individuals to purchase services appropriate to the level of support needed. Implicit in this is the potential for those with disabilities to take control in an area of their life where previously there had been little opportunity to do so.

- the Human Rights Act (1998) came into force in October 2000. Under the Act, it is possible for individuals to challenge human rights violations through the court system. Articles of particular relevance to people with learning disability include the right to life; prohibition of inhumane or degrading treatment; the right to marry; prohibition of discrimination; and the right to education.

- the Health Act (2000) in which one sees new arrangements whereby one agency may fund another to provide services, for example, a health authority may fund social services to provide a service to children with disabilities and their families.

- the Carers and Disabled Children Act (2000) enables local authorities to make Direct Payments to parents who have children with disabilities, and to 16 and 17 year olds, instead of providing services for them. Under the Act, carers who are not parents may for the first time, receive services in their own right. The child's developmental needs are a priority, while emphasis is also placed on eliminating those barriers which may prevent a family's social integration.

- the White Paper, 'Valuing People' (2001), was the first White Paper on learning disability for 30 years. Four key principles are embedded in the White Paper – civil rights; independence; choice; and inclusion. The focus is upon an integrated approach to service delivery for children, together with the provision of opportunities to live a full adult life. It was intended that the White Paper would lead to improvements in social services, health, education, housing, employment, and support for people with learning disabilities, their families and carers;

- the Learning and Skills Bill was implemented in 2001. It aims to tackle social exclusion, and provide equality of opportunity for people with learning disabilities. Amongst its key duties include improving the design, delivery, funding and support available in terms of education and post-16 training. Moreover, it also aims to make improvements in the transition phase. A new national Learning and Skills Council with 50 branches, has been established in place of the Further Education Funding Councils and Training and Enterprise Councils;

- the Commission for Care Standards (2002) and the resulting 8 regional Commissions which have the task of regulating domiciliary care services; small children's homes, and local authority homes according to Government standards.

(Foundation for People with Learning Disabilities Website 2004)

Of course, also of significance in terms of child and family services have been the Quality Protects Programme (DoH 1998) in England, which aimed to effectively protect children, provide them with better quality care, and thus improve their life chances; and its equivalent in Wales, the Children First Programme (Welsh Office 1999).

The Children First Programme has been perceived as a …'major landmark…' (Colton *et al.* 2004, p.9), aiming as it does to reduce gaps in outcome between children in need and other children. Moreover, the Social Services White Paper for Wales, 'Building for the Future' Implementation Plan (NAW 2000) identifies key principles in the establishment of a 'Children's Strategy' to improve the quality of services for children through clear expectations in terms of outcomes driven practice; effective management; and performance indicators.

The NAW Planning Guidance on the Children and Young People's Framework (WAG 2002) is informed by the UN Convention on the Rights of the Child, and focuses on planning for children on a national and local level.

The aim here is:

> '…to ensure that all children and young people in Wales enjoy the best possible physical, mental, social and emotional wellbeing within a framework of service provision that is informed by their best interests and which respects their wishes…'
>
> (Colton *et al.* 2004, p.9)

The above list is by no means exhaustive, however, it does provide some indication of the extent of activity in the policy arena with regard to services for children with disabilities in recent years. It is, of course, beyond the scope of this dissertation to focus in detail on each of these initiatives. However, where appropriate they will feature in discussion.

Conclusion

In this opening chapter of the dissertation the research undertaken has been placed in context, and issues of relevance in the field of learning disability have been introduced. Definitions of, and labels associated with learning disability, and the means by which these have changed over time have been considered. The segregation and containment of people with learning disabilities in large-scale institutional settings has also been charted. Moreover, attention has been paid to the policy framework, to the changes evident during the latter part of the twentieth century, and to the more recent initiatives of significance to children with learning disabilities and their families.

On the face of it, there is evidence of a real policy shift in terms of learning disability, with a particular emphasis on inclusion and integration. Yet, Mencap (2004) places this shift firmly in context, and reminds us how much more needs to be achieved in an attitudinal sense:

> 'The day-to-day lives of people with a learning disability and their families have always been much affected by the way they are perceived and treated by the communities they live in. The history of public and private attitudes over the last three centuries is one of intolerance and lack of understanding. The right to freedom from discrimination for people with disabilities, including those with a learning disability, has been enshrined in the Disability Discrimination Act 1995. But there is still much to be done to change public attitudes.'

The above quote encompasses much of what this dissertation is concerned with. For, the work is in every sense a journey in which the history of learning disability, so often characterised by an intolerance of difference, is charted. The crucial part played by the attitudes of others during the course of that journey is also highlighted. The thesis focuses on the extent to which a new support service provides a solution to the problems experienced by families with children with learning disabilities, and in some way redresses the balance in their favour. What is clear is that there has been no shortage of policy initiatives in recent years. Notwithstanding this, however, of importance is the extent to which implementation of those policies has occurred in practice. A more detailed consideration of these issues is contained within the final chapter of this dissertation, while a review of the relevant literature follows.

CHAPTER TWO – A REVIEW OF THE LITERATURE

Introduction

In the preceding Chapter of this dissertation, the research reported here was placed in context, and the concept of learning disability was explored from a historical perspective. Definitions and labels, and the manner in which these have changed over time were considered, alongside the segregation and containment of people with a learning disability. Moreover, attention was paid to the policy framework: namely, to the changes evident during the latter part of the twentieth century; and to the more recent policy initiatives of relevance to children with learning disabilities and their families.

The emphasis in Chapter One was on the historical and policy context. In this Chapter, the emphasis is firmly placed on the experience of having a child with a learning disability, and in the spirit of qualitative enquiry, establishing what that actually means for families. The detailed review of the literature which follows was undertaken in the hope that an understanding of families' situations would result. Here then, with that in mind, attention is paid to the nature and extent of disability. Further, models of disability are considered; together with issues around disclosure of disability. Also explored, are families' experiences of having a child with a learning disability; the concept of professional power; and finally multi-disciplinary teamworking, and the establishment of the FST as a potential solution to the problems experienced by families with children with learning disabilities in a particular geographical area in Wales.

The nature and extent of learning disability

It was in the wake of a speech to MENCAP in 1996 by Stephen Dorrell, Secretary for Health, that the term 'learning disability' came into common usage (BILD website 2004). However, many people now prefer to use the term adopted by the international advocacy organisation *People First*, that is, people with learning difficulties. Approximately 3% of children in the UK have a disability. Over 100,000 children have a severe disability, and '...at least two different sorts of significant impairment' (NCH Factfile 2001). Estimates suggest that between 0.45% and 0.6% of children in England - between 55,000 and 75,000 children - will have a moderate to severe learning disability (DoH website 2002). There are just over 12,000 people with a learning disability in Wales (WAG Data Unit 2001). Most of these are able, with appropriate support, to live independently in the community. At 31 March 2001, there were 2,433 children under the age of 16 with a learning disability in Wales; 185 of these children live in the county where the research reported here was undertaken (SSDA 901, 2001).

The majority of children with learning disabilities live with their parents or other carers. Multiple impairment is commonplace (Rowntree Foundation 1999), and in a significant number of cases, families will have more than one disabled child. In a health authority area which includes 500,000 people, there are likely to be approximately 250 families with 2 or more children with significant levels of impairment. Moreover, the numbers of children with increasingly complex support needs, including nursing care, are increasing (*ibid.*).

According to figures produced by the Royal National Institution for the Blind (RNIB), in 1996, there were 24,200 children under 16 years with significantly impaired vision. Sixty per cent of those children also had physical disabilities, learning difficulties, or were deaf. It is estimated that there are around 73,000 children in the UK who are autistic. Autism is a developmental disorder resulting from a physical dysfunction of the brain. Its cause is unknown and four times as many boys as girls are affected by it. The condition ranges from the manifestation of extreme behavioural and communication problems, to cases where children have above average IQs and no learning disability, but nevertheless experience severe forms of social impairment. The diverse nature of the condition makes diagnosis and therapy problematic (BILD website 2004).

The causes of learning disability are many and varied. Events may occur before, during, or after birth which lead to the development of a disability. Prior to birth, for example, congenital causes may be identified, as is the case with Down's Syndrome or Fragile X syndrome. During birth, a baby might be deprived of oxygen, thus giving rise to cerebral palsy. In the post natal period an illness, injury, physical abuse or neglect may result in either accidental or non-accidental brain injury (*ibid.*).

Each year in the UK approximately 1,000 babies are born with Down's Syndrome. For every 1,000 babies born, one will have Down's Syndrome. These children will share distinctive physical characteristics with others who have Down's Syndrome. However, they will also have a learning disability which will vary in severity from individual to individual, and some may experience health problems, such as heart conditions. Estimates suggest that currently, there are approximately 60,000 people with Down's Syndrome in the UK (Down's Syndrome Association website 2004).

Down's Syndrome was first identified in 1866, by the Englishman Dr John Langdon Down. Proof that the condition resulted from a chromosomal irregularity became evident in 1959 when Professor Jerome Lejeune discovered that people with Down's Syndrome had 47 chromosomes in each cell, while 46 were usually present. This additional chromosome gives rise to the physical characteristics associated with Down's Syndrome. There is as yet, no definitive evidence to point to the cause of Down's Syndrome, and the presence of the extra chromosome 21. However, research is continuing, and the International Human Genome Project has had some success in its work in sequencing chromosome 21 (*ibid.*).

Models of Disability

The way in which disability is conceptualised has had, and indeed, continues to have a significant impact upon people with disabilities and their families. A variety of definitions have dominated thinking around disability. Terms such as handicapped, mongol, and spastic are amongst those which have been used disparagingly in everyday language. Oliver (1990) categorises such definitions of disabled people as either offensive, as in spastic, cripple, or mongol, or depersonalising, as in the deaf, the handicapped and the blind. While Dale (1996, p.48) asserts that:

> '...the overriding viewpoint in modern Western industrial capitalist societies has been, until very recently, of disability as a separate and marginal condition, with disabled people perceived as less capable and less valuable than non-disabled people...'

In contemporary society, perceptions of disability may be organised according to two competing explanations: namely, the traditional model, or medical model; and the social oppression model (Sharkey 1995). Middleton (1999, p.1) notes that:

> 'Traditional explanations of disadvantage experienced by disabled children rest on the medical model of disability which holds that the trauma of impairment is in itself an explanation for the individual's failure to achieve a reasonable quality of life…'

This model is characterised by a number of distinguishing features including the viewing of disability as 'tragic', with individuals needing to adapt to their impairment, and also in order that they fit into society. Moreover, such individuals are perceived either pitifully, or in a heroic light (Sharkey *op.cit.*), a perception continually reinforced through media representations of disability.

In the social oppression model, however, there is an expectation that society adjusts to the person with disability. Here, the emphasis shifts '…away from pathologising the individual and stresses restrictive environments and attitudes.' (Middleton, *op.cit.*). This model is favoured by organisations for people with disability, its central features being that people with disabilities are an oppressed group, unable to achieve their full potential because of structural barriers. Society is seen to 'disable' individuals by means of environmental and also attitudinal obstacles. People with disabilities are viewed to have the same feelings and needs as the general population. However, access to public transport, forms of entertainment, and public places is restricted; and action is perceived to be needed on a societal level to enable those with disabilities to participate fully in their community. This model clearly illustrates '…how society denies disabled people the means to do what they are capable of…' (Sharkey, p.39).

In 1998-99 there were 289,000 full, and part-time pupils with special educational needs (SEN) in the UK. This figure represents 3% of all pupils, 96% of whom were in maintained schools. Just over a third (35%) of children with SEN are in special schools. In Wales, one of the specific objectives in terms of services for people with learning disabilities is the promotion and provision of support for '…most children to attend local schools...' (WAG 2004). In January 2004, there were 16,959 children with a statement of SEN in Wales, a decrease of 2% on the previous year (NAW Statistical Directorate 2004). In 2003/04, a total of 1,077 children had statements of SEN in the county in which the research reported here was undertaken; 225 of those were educated in special schools or units. A total of 21% (3,167) of children educated within their 'home' authority, received that education in special schools; 8,280 were educated in mainstream classes. Some 445 children were educated in special schools outside their 'home' authority. Oliver (1990, p.93), reflecting on the special education system notes that:

> '…it is not only the intrusion of medicine into education which creates dependency through an acceptance of the sick role. They also see themselves as pitiful because they are socialised into accepting disability as a tragedy personal to them. This occurs because teachers, like other professionals, also hold to this view of disability, curriculum materials portray disabled people (if they appear at all) as pathetic victims or arch villains and their education takes place in a context in which any understanding of the history and politics of disability is absent.'

The British Council for Organisations of Disabled People (BCODP), is also of the view that the special education system contributes to misleading representations of disability:

> 'The special education system, then, is one of the main channels for disseminating the predominant able-bodied/minded perception of the world and ensuring that disabled school leavers are socially immature and isolated.' (BCODP 1986, p.6)

Whereas the first half of the twentieth century is characterised by the institutionalisation and segregation of children and adults with disabilities, Dale (1996, p.49) argues that:

> 'From the 1960s onwards, an alternative 'model' has been championed of disabled people as a deprived and stigmatised minority group.'

Moreover, she adds that:

> 'The roots of this prejudice have been argued as lying in, amongst other factors, the predominance of medical ideas in the care of disabled people and the management of disability as a pathology; a general lack of contact with disabled people and the popular fear of the unknown, and the idealised images of 'normality' in the media and literature.' (*ibid.*, p.49)

There is evidence that moves are being made to confront such prejudicial attitudes. Indeed, to some extent, disability is now portrayed in a more positive light in the media; while people with disabilities are more vocal in their campaign for equal rights (*ibid.*). According to the author:

> 'There is a major shift in many Western societies away from a medical 'model' of interpretation of disability to an educational model linked to a human rights sociological approach.' (p.49)

In terms of theories of disability, Read (2000, p.12) notes that within contemporary society:

> 'Increasingly, there has been a challenge to what is seen as the overmedicalisation of people, experiences and events and there have been calls for theoretical frameworks which acknowledge that some of the most restricting

> and damaging features in the lives of disabled children, adults and those close to them are socially constructed.'

Structural factors play a key role in the way children with learning disabilities and their families experience life and varying forms of exclusion and oppression. For, disabling barriers such as poverty feature large in the lives of many of these families. In 1997, between one quarter and one third of children – 3 to 4 million children – were living in households in relative poverty (Sutherland *et al.* 2003). This figure represents three times the number in poverty in 1979. Moreover, one in three children in Wales live in poverty (Welsh Index of Multiple Deprivation 2000).

'...The right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social well-being...' is specified in Article 27 of the UN Convention on the Rights of the Child. Notwithstanding this, however, '...there is considerable evidence that the standard of living of families with disabled children falls below that necessary to satisfy this right.' (Rowntree 1999). The costs incurred in bringing up a child with disabilities are three times greater than those incurred in raising a non-disabled child. On average, it costs £125,000 to bring up a child with 'significant impairments'; while for a non-disabled child the cost amounts to £37,394 (ibid.). The difference is most marked where children are under 5 years of age. Bringing up a disabled child costs parents or carers an additional £99.15 a week.

Parents with children with disabilities have considerable difficulty in combining paid employment with caring for their child. There are a number of reasons for this: namely, first, a failure on the part of employers to take account of parents' caring role; second, the inadequacy of local support services; and third, the assumption by the health service and schools that parents do not work (Rowntree 1999). All this militates towards a diminished paid income, and subsequently an inability to pay for adaptations to their home; for equipment which may be needed to care for their child; for child care; or transport costs. Taken together:

> 'All this results in increasing vulnerability to social exclusion for the disabled child and their family.'
>
> (Rowntree 1999, p.3)

Inadequate housing provision also functions to 'disable' these families, approximately half of whom live in housing which is unsuitable for their needs. Families with children with severe disabilities are increasing in number, and they, together with families from black and ethnic minority communities are most likely to experience difficult living conditions. They are also most likely to lack information about their entitlements. Moreover, housing and other professionals with whom they come into contact often show a lack of understanding of their situation. This lack of financial support and advice results in a poor quality of life for children with disabilities living in inappropriate housing, with their right to privacy, to play, and to be fully involved in family life being adversely affected (*ibid.*).

Improvements in the legislative and policy arenas have undoubtedly raised awareness of, and challenged popular thinking to some extent with regard to disability issues. However, there is still much to achieve in working towards an equitable base and inclusion for those with disabilities. Much of this dissertation focuses on the way in which the latter's experiences of service provision are so often exclusionary in nature. Of course, the structural elements to exclusion compound their situation. This thesis is permeated by an attempt to understand the means by which differing forms of exclusion are manifested; how disability is conceptualised, and the impact that may have upon families and their children. Undoubtedly, the medical and social models are of crucial importance here. This exercise in understanding is undertaken with particular reference to the experiences of the 22 families who participated in this study, and also to the more recent research evidence.

Disclosure of disability – 'acceptance' and 'adaptation'

The manner in which a child's disability is disclosed to parents has a significant impact upon the way they perceive their child and their own situation. It shapes their view of their world, and also their future interaction with professionals whom they come into contact with while caring for their child (Beresford *et al.* 1996). It is because disclosure plays such a significant part in the lives of families with children with disabilities that it is given such detailed consideration here.

Given the changing belief systems evident in relation to disability for some years now, it is unsurprising to note that parents, when told that their child is disabled, are likely to react in any number of ways, some of which may be positive, others negative. In many cases the reaction accords with what has for many years been the traditional societal response to disability, one predominantly negative in nature. Of course, parental reactions will differ according to personal beliefs, and value systems.

Dale (1996) writes that there is a '...widespread assumption that professionals are 'neutral' carriers of 'standard' empirically based knowledge...' (p.50). However, the

The discovery of a handicap plays a significant role in the development of family relations, and the decision as to how and when the news is given is crucial. The following recommendations regarding disclosure were put forward by Cunningham (1984):

- Disclosure should be made as soon as possible after disability is suspected or diagnosed

- Parents should be told in a private place, where there are no interruptions; they should be with, and thus supported by a partner, friend or relative

- The child should be present at the time, thus implying value rather than exclusion on the part of the professional

- Parents should be allowed sufficient time to absorb information and ask questions

- The person who will provide support to the family following diagnosis should be present

- Another interview should be arranged within 24 to 48 hours, thus enabling parents to ask further questions and reflect on the information received

- Written information should be provided, which parents can draw on when necessary, and pass on to friends and family

- Parents should be allowed access to a private place following disclosure

When diagnosis is made some parents may be unable to comprehend the situation until words like 'handicap' and 'spastic' are used (Dale 1996). A sense of shock may result, with selected information only being recalled (Ley 1979). In some cases, parents remember vividly how disclosure was made, even though many years may have passed (Cunningham 1984).

Indeed:

> '...the manner in which the news is broken to parents continues to arouse great dissatisfaction and anger in parents...Parents complain about delays and evasions in the telling, being given false assurances, being told in an abrupt and uncaring way, having the negative consequences of the child's condition emphasised, each parent being told separately, being left to break the news to the other parent, being told in a public place, and not being given access to a private place afterwards.' (Dale 1996, p.51)

Writing of disclosure, Ayer and Alaszewski (1986, p.113) note the inequality of the situation; of the practitioner who understands all, as opposed to the parent who knows so little:

> 'Many professionals make the error of thinking of the discovery of mental handicap as an event...in which a skilled practitioner who understands about the nature and implication of a child's condition and handicap explains it to a vulnerable and uninformed parent.'

Partington (2002) undertook research on maternal responses to the diagnosis of learning disability. The author identified a number of key themes: namely, first, that there were differences in reactions between those who received diagnosis in the antenatal period and those who received it post-natally. For, where diagnosis was given in the antenatal period, mothers faced the dilemma of the termination option, which they often felt pressurised to pursue. Second, participants' reactions were comparable to a recognised cycle of bereavement; and finally there was evidence of poor interpersonal skills on the part of medical staff.

Of course, there are an increasing number of screening tests now available to women, all of which aim to detect disability in the unborn child. However, women face a dilemma in undergoing such tests, as the detection of an abnormality necessitates a decision as to whether or not the pregnancy should be terminated. The 1967 Abortion Act, while not referring to disability, sanctions abortion in the case of an unborn child who is 'seriously handicapped'. However, Partington (*ibid.*) notes that:

> 'This term is open to a wide range of interpretations and judgement and the decision as to whether the handicap is serious is entirely in the hands of the medical services.' (p.165)

Indeed, for the women in Partington's study who received an antenatal diagnosis of disability:

> 'There were no examples of the medical services presenting any positive aspects of disability. The information that mothers received was therefore framed within a pessimistic outlook...it appears that the medical services viewed the identification of disability as part of a process that would ultimately conclude with a termination.' (p.167)

Clearly, discovering a child is mentally handicapped is a process which is complex and fraught with emotion. In some cases, as noted above, it may be obvious that there are 'problems' in the antenatal period; in others it may be evident at the moment of birth; in yet other cases, it may be only when certain developmental milestones are not reached at the appropriate time that suspicions are aroused.

All of the women who participated in Partington's research experienced a range of emotions following the birth of their child, or the diagnosis of disability; included amongst these were anger, blame, and guilt. Such emotions were not restricted to the period immediately after diagnosis or birth, but returned sporadically as their child developed.

Ayer and Alaszewski (1986) note that 3 phases may be identified in the discovery of mental handicap. First, there is an awareness that something is wrong with the child, perhaps due to a failure to reach a particular milestone. The second phase is characterised by uncertainty and confusion, as professionals and parents attempt to understand and define the child's behaviour and condition. A period of negotiation and communication occurs, and will differ in duration according to the child's condition and the experience of the professionals involved. It is in the third phase that 'discovery' occurs; here an agreement is reached between parents and professionals as to the nature of the handicap. The professionals take the dominant role in this agreement, within which there is acceptance of the term mental handicap.

The child's status changes during this process of 'discovery', along with the attitude and behaviour of 'significant others' (ibid.). Until a problem is noted, the child is treated as any other. When a problem is detected but the exact nature of the problem is unclear, the child's status becomes marginal. There are uncertainties about the future, and attempts are made to agree on some form of definition. However, when agreement is reached between parents and professionals as to a categorisation, the child takes up a new position as mentally handicapped. The future is assessed in terms of a life-long dependency, as the parents adapt to a role which differs to the norm.

Much research has focused on the stages which parents pass through in attempting to understand the birth of their child with a disability (Drotar *et al.* 1975; Bicknell 1991; Hornby 1994). First, shock, resulting from parental expectations that a normal child would be born, is experienced; this is followed by denial of the reality of the situation; then sadness, guilt, anger and anxiety, all of which epitomise grieving. A time of adaptation, when parents feel able to care for their child; and finally reorganisation, when some form of acceptance emerges are the final stages in the process. According to Bicknell (1991) four stages are implicit in such acceptance, namely: fantasy, when parents continue to hope that their child will achieve in some way no matter how small; duty, when parents acknowledge their responsibility and duty of care; a sense of resignation at their situation; and finally their love for their child.

For those parents who are unable to successfully work through the stages outlined above, and reach some form of 'acceptance', other responses are evident (Bicknell 1991). They may 'shop around' as in a state of denial they search for further professional opinions which they feel able to accept. Should a family become fixated with grief then there is a possibility that they may over-protect or reject their child.

Although rejection is not commonplace today, a sense of ambivalence – a mix of rejection and over-protection – is.

Other components of the failure to make the psychological journey to acceptance include Olshansky's (1962) 'chronic sorrow', which will be further discussed later in this Chapter, and which Bicknell refers to as '…the sadness that pervades the family' (p.28). Moreover, isolation may result as parents set themselves apart from each other, from other family members, and also from professionals. Parents may blame each for their child's disability; their subsequent anger perhaps resulting in 'disharmony'. The child may themselves become a scapegoat, and be perceived as the cause of all problems within their family. There may also be a form of 'late rejection', when parents realise that their child will not after all achieve a particular milestone. Finally, infantilisation may occur; although the handicapped child is accepted, it proves far more difficult to accept the handicapped adult, and their physically developed body (*ibid.*).

Hornby (1994) writes of the 4 most widely known models in terms of adaptation to disability. First, the stage model, which involves people's reactions at various stages in their attempt to come to terms with disability. Here, initial shock, is followed by denial, anger, sadness, detachment, reorganisation, and finally adaptation. None of these, however, are discrete stages. For, parents may experience different reactions to a differing extent at any number of points in their child's development. Anger and denial, for example, may be experienced at the same time as sadness, with the latter portrayed as eliciting the greatest reaction, as grief and sadness are pervasive to the entire process. The author notes that:

> 'Just as for any major loss it is considered that most people will take around two years to come to terms with a disability.' (p.20)

Of course, for others the process is more protracted, while some parents never completely adjust to the situation.

In reviewing the literature on disclosure of disability, and the process of parental acceptance of, and subsequent adaptation to disability, it is clear that an over-arching professional negativity predominates; the theme is one of loss, grief, disappointment, and despondency. In the next section of this Chapter, the focus is upon the experience of having a child with disabilities, and an attempt is made to tease out the extent to which that experience can be said to be positive in nature.

The experience of having a child with disabilities

The assumption exists that :

> '...to have a disabled child is an unmitigated tragedy for all concerned.'
>
> Stainton and Besser (1998 p. 68)

As noted, the research literature on parental reactions to having a child with disabilities focuses in the main on the stages of denial, and the guilt, anger, depression and shame experienced; in essence all that is negative. Russell (1983) equates the birth of a child with a disability with a 'family crisis'. While Bicknell (1991) like other commentators, talks of the 'bereavement response' exhibited by parents with children with disabilities, when the focus is very much upon a sense of loss, dying and death, even though, of course, the child is still present within the family '...a constant reminder of imperfection, its antecedents and consequences...' This is compounded by the '...extra work, disturbed nights and continued disappointments as milestones fail to be achieved' (p.26). For Bicknell, the well-used phrase amongst professionals that '...a handicapped child is a handicapped family' is appropriate in working with:

> '...families who are socially isolated, where the siblings are maladjusted, where the home is broken and where splitting has occurred between generations.' (p.22)

There is increasing recognition that people with learning disabilities are family members, and as such the aim is to provide support which is effective in promoting 'family cohesion'. Notwithstanding this, however, there is evidence that some professionals continue to hold negative, stereotypical views of families as being 'in need' and firmly locate them within the pathological model (Maxwell and Barr 2003).

Prior to the 1980s, it was assumed that family dysfunction would result from the birth of a child with disability. Olshansky (1962) purports that the majority of parents who have a mentally retarded child will:

> '...suffer from a pervasive psychological reaction, chronic sorrow, that has not always been recognised by the professional personnel – physicians, psychologists, and social workers – who attempt to help them...' (p.2)

As mentioned earlier in this Chapter, according to Olshansky, many of the parents of mentally defective children will suffer 'chronic sorrow' whether the child lives with them at home or is institutionalised. The intensity of the sorrow experienced will vary according to individual personality, social class, ethnic group or religion. In some parents the sense of sorrow will be obvious; in other cases attempts may be made to conceal it. Intense feelings of grief may be experienced often, and over many years as developmental milestones approach but are not attained. Here, rather than successfully traversing the various stages relating to adaptation, anger and sadness become part of the everyday lives of parents, albeit to a differing extent according to significant periods in their child's development, for example, puberty, and school leaving age (Hornby 1994).

Professionals have tended to view 'chronic sorrow' as a '...neurotic manifestation rather than as a natural and understanding response to a tragic fact' (*ibid.* p.2). However, some commentators note that '...A parent who continues to feel sadness about a child's disability can still be competent and caring...' (Dale 1996, p.58).

Indeed, Beresford *et al.* (1996, p.7) argue that:

> 'The great majority of families with a disabled child experience the same emotions, bonds, joys and pleasures of family life as families with non-disabled children, as well as the same pains, conflicts and disappointments. Such feelings and experiences are the 'stuff' of family life.'

Yet, the pathological or 'sick' family model has pervaded the field of learning disability for some years. As noted in Chapter One the birth of a feeble minded child was associated with moral degeneracy initially, while in later years the hereditary argument took precedence. The creation of the National Health Service in 1949 led to the medicalisation of disability. People with disabilities were considered to be ill and in need of medical treatment. Their families were perceived to be suffering adversely as a result of having a disabled family member. Younghusband *et al.* (1970) write, as many other commentators have, that the family with a handicapped child is a handicapped family. Siblings were thought to be harmed by the experience of having a disabled child within the home, and thus the latter were dispatched to mental handicap hospitals.

Dale (*op. cit.*) points out that:

> 'The Pathological Model encourages a view of families as homogeneous, and because they are assumed to have similar reactions and needs, these can be met by a uniform set of services.' (p.106)

It is clear that such theorising can work only to the disadvantage of families with children with learning disabilities, who differ as much in terms of their characteristics and needs as families with non-disabled children.

Several research studies indicate that high levels of stress are experienced by mothers of children with disabilities (Burden 1980; Beckman 1983). In particular, Burden (*op.cit.*) notes that mothers were likely to exhibit high levels of depression following the birth of their child. However, other research contradicts such findings. Gath (1973), for example, found little difference in rates of depression between mothers of children with Down's Syndrome and those with children without a disability, in the first two years following birth.

Less attention has been paid to fathers of children with disabilities. Seligman and Darling (1989) note that withdrawal from family life is one of the coping mechanisms employed by fathers. They argue that the resulting increased burden on the mother leads to resentment, and anger on the part of family members; this further compounds the task of caring.

Research also indicates that in some cases siblings may feel resentful of the child with special needs. The former may feel angry at the amount of time their parents expend on their disabled sibling, and may experience a sense of rejection at the subsequent lack of parental attention. (Sourkes 1987). They may have difficulty understanding the disability and do not feel able to express their anger at the situation. Dale (1996) notes that:

> '...a variety of factors (including the nature of the child's disability, the behaviour of the child with special needs, the quality of relationship with the siblings, the openness of communication between the parents and sibling, the mental health of the parents and quality of relationship between the parents and child with special needs) intervene or mediate in complex ways to affect how a brother or sister develops.' (p. 105)

What is clear, is that families with children with disabilities differ significantly in terms of the levels of stress and difficulties they experience in caring for their child. In some cases, marital breakdown might result, and families might feel isolated from the community in which they live. Moreover, some siblings will adapt well to the family situation, whilst others may feel resentful.

Notwithstanding the above, Dale (1996, p.60) writes that:

> 'Two disturbing experiences on becoming the parent of a child with a special need are described by some parents: a sense of meaningless and a sense of powerlessness.'

Feelings of meaningless and powerlessness are a central feature of the sociological concept of anomie or normlessness, and according to Seligman and Darling (1989) are often experienced by parents of disabled children. The authors draw on symbolic interactionist theory – whereby knowledge, values etc. are socially determined by interaction – to explain this sense of meaningless and powerlessness. Here, the focus is upon social processes: the reactions of parents with a child with a disability are interpreted in relation to their interactions prior to, and following the birth of their child.

The reactions of 'significant others' to parents' situations will have an impact upon how the latter define their position in society. Diagnosis and additional information on their child's condition might help to alleviate feelings of meaningless, however, the sense of powerlessness will persist until a parent is able to achieve something positive in relation to their child's disability. As time passes, many parents regain control of their situation, and begin to accept, and understand the disability. However, the extent to which family life becomes normalised will differ greatly between families, and will be dependent upon factors such as the severity of the disability; the support network available; and the perceptions of others.

Three models of family functioning have played a key role in work with families with children with disabilities: namely, the transactional model; the ecological model; and family systems theory (Hornby 1994, p.25). In the transactional model:

> 'The type and severity of the disability is likely to play an important role in how parents are affected and the kind of people parents are will have an important bearing on the child's behaviour and development. Also, as people

> with disabilities pass through different developmental stages they will affect their families in different ways.'

Clearly, the extent and nature of the disability, individual characteristics, and the process of change all feature here.

The ecological model of family functioning proposes that human development and behaviour can be understood only within the social framework in which it occurs (Bronfenbrenner 1979). Our social environment has an influential effect on behaviour on a number of levels, to the extent that parents' experiences of caring for children with disabilities will be affected on the one hand by the attitudes of their extended family, and their community, and on the other by the availability of services (Hornby 1994).

Hornby's ecological model consists of 4 systems of influence: namely, the microsystem of child, parents and siblings; the mesosystem containing their community and their extended family; the exosystem comprising social settings, for example, education, the mass media, the voluntary sector; and finally, the macrosystem, defined as societal beliefs, attitudes and values, all of which will impact upon the child and family.

In family systems theory, family members' behaviour results from the family system of which they are a part, the implication being that:

> '...intervention with a person with a disability will have an impact on the whole family to which that person belongs.' (*ibid.* p.34)

Indeed, according to Abbott and Sapsford (1988, p.47) there are 'costs' incurred by families of children with learning disability; one of the main costs being:

> '...the reactions which the family will have and will encounter to the fact that their child is handicapped. The family has to come to terms with altered expectations for the child, an altered perspective for the future, and the cultural stigma which attaches to the label.'

While Ayer and Alaszewski (1986, p.238) in their study of mothers of handicapped children in North Humberside write of the 'costs' in the following terms:

> 'All mothers experienced relative deprivation. There were activities or opportunities that they would have undertaken or had if their child had been normal. The family as a whole experienced deprivation. Some mothers became preoccupied with their handicapped child and other members of the family were deprived of the attention they would otherwise have received.'

According to Booth (1997, p.156) the act of caring leads to over-protectiveness:

> 'The experience of caring for a person with learning difficulties over many years frequently leads to a strong sense of protectiveness on the part of parents that can, in turn, hamper the development of independence...'

Clearly, the strain placed on family members, coupled with the uncertainty about the future needs of the child with a learning disability, and the anticipated greater demands on parents' time in addressing those needs, result in a situation which is fraught with anxiety. Abbott and Sapsford (1988, p.45) note that:

> 'The policy of 'community care' for mentally handicapped children has non-financial costs for families: work which in institutions would be wage-labour becomes unpaid work for 'Mum' when the burden of care is transferred to the family.'

Further, they point out that the entire family pays a price in having a mentally handicapped child:

> '...a price made up of shattered expectations which have to be rebuilt, the disturbance to family life, the reactions of others, the constraints on the mother's life, and the disturbance of normal expectations for the family's future.' (p. 46)

Of course, the 'price' paid by families will differ according to the extent of a child's disability. Families need in the first instance to learn to cope with their own reactions to their child with a disability, and the sense of 'loss' that results from a personal acknowledgement of that disability. They also have to cope with the reactions of others – both within their family network and external to that network – which may often be overtly negative. Families might experience pity; other people might avoid them; and perceive them as different. Expectations that they might have had for their unborn child will be dashed; the future will be uncertain; and their lifestyle will be subject to constant change as they adapt to the needs of their child at differing stages of development. In addition, families with children with a disability will be subject to a labelling process, and the resulting stigma of having a child who does not conform to the norm.

Hughes and May (1991, p.96) note that:

> 'The notion of the 'handicapped family'...is a powerful label that transforms the family into an object of concern or pity, while simultaneously denying its members either control over, or understanding of, their own behaviour.'

While according to Suelzle and Keenan, (1981):

> '...how society perceives and socially positions the family with a child with special needs may affect the family's functioning and the possibilities open to it.

> Negative views of disability in society may, for instance, reinforce a sense of powerlessness and low self–esteem in the family as well as expectations of rejection of their child from friends and neighbours…'
>
> (cited in Dale 1996, p. 100)

In the early stages of their disabled child's life, the mother's role is similar to that of a woman whose child does not have a disability. In the long-term, however, the 'cost' to the former will be greater. She will often give up work to care, or organise her employment patterns to fit in with the caring task. Here again, parallels with women whose children are not disabled. However, the essential difference lies in the fact that the mother of a disabled child will not experience that child growing up, and moving towards independence. The caring task is more intense, and may be characterised by their child's acute health problems. This Abbott and Sapsford (1988) perceive to be the '…non-financial cost of community care' (p.65).

Dickerson and Brown (1978) argue that the parents of a disabled child are never released from the responsibility of caring for that child. Moreover, long-term plans need to be made in the event of the death of parents. Goffman (1963) points to the 'spoilt identity' of family members; their closeness to someone with a disability resulting in stigma. Families may attempt to engage in normal social relationships. However, as the child becomes older and their disability becomes more pronounced in relation to other children of a similar age, this attempt at maintaining normality is made more difficult.

Caring for a child with a disability may become more labour intensive as the child grows older. The task is made more difficult in the physical sense, and that will be compounded by the fact that as the parents grow older, they will perhaps themselves suffer with poor health as a result of caring, and/or ageing, and thus will no longer be able to cope.

Beresford (1995) in a national study of 1100 households with a child with a disability found that in the majority of cases (96%), mothers provided most of the care. Moreover, Read (2000, p.52) argues that:

> 'Even when fathers are unemployed or at home for other reasons, the caring workload and responsibility is not distributed equally.'

Indeed, welfare provision today is to a large extent dependent on the willingness of women to care for children under school age; those with learning disability; and older relatives. This is the position in which women find themselves in a contemporary capitalist society. For, they are expected to undertake a caring role without payment, and this expectation is actively reinforced by the existence of such policies as Community Care, within which the community - essentially its women - cares for its own. The predominance of such policies takes on even greater significance when one considers that when comparisons are made with the general population, a larger proportion of households with children with a disability have lone mothers (Beresford *op.cit.*). The financial implications of lone parenting then, are compounded by the task of caring.

The possibility that a positive impact could arise from having a child with a disability has often been dismissed by professionals as a form of denial or an attempt to ease feelings of guilt on the part of parents (Behr 1990). Turnbull (1985) points to the dearth of reference in the professional literature to the positive contributions which children with disabilities make to their families. In the popular literature, however, there is evidence of a much more positive approach. Both the benefits and the problems associated with bringing up a child with disabilities are highlighted in publications written by parents (Turnbull and Turnbull 1986; Maxwell and Barr 2003).

Research on positive contributions by Behr (1990), indicates that levels of family stress, and well-being where there was a child with a disability were similar to those found in the general population. Moreover, children with disabilities were more likely to make a positive contribution to their family in terms of enabling learning through personal experience of disabilities; a sense of fulfilment and happiness; strength; and family closeness. It was least likely that positive contributions would arise in terms of parents' careers, or in taking pride in children's achievements.

Stainton and Besser (1998) in their research on positive impacts, identified 9 key themes as a result of interviews with parents of children with an intellectual disability such as Down's Syndrome. Those themes were:

- Source of joy and happiness
- Source of increased sense of purpose and priorities
- Expanded personal and social networks and community involvement
- Source of increased spirituality
- Source of family unity and closeness
- Source of increased tolerance and understanding
- Source of personal growth and strength
- Positive impacts on others/community

- Interaction with professionals and the service system.

In spite of the fact that the researchers stressed their interest in the positive impacts of having a child with a disability, Stainton and Besser (1998) report that every family who participated pointed to a negative interaction with professionals and the service system. They write that:

> 'To a large extent this was related to the families' need to get over the negative perceptions of professionals to begin to recognise and accept the positive aspects of having a child with a disability.' (p.66)

According to the authors, for some parents there was a gradual realisation that they were able to question professional opinion. They write that one of their most disturbing research findings focused on the negative manner in which a child's disability was disclosed, and the lack of information following disclosure. This finding is consistent with the parental views reported in this dissertation. While Beresford (1995), found that only half of participants in her study perceived their relationship with professionals to be positive and supportive in nature.

Earlier in this Chapter, the disabling barriers encountered by families with children with learning disabilities were considered. In bringing the discussion on the experience of having a child with a disability to a close, those issues are revisited briefly. Amongst such barriers, poverty is of central importance, and is closely associated with parents' inability to fully participate in the employment market due to their caring responsibilities.

Beresford *et al.* (1996, p.44) note that:

> 'The evidence that the demands of bringing up a disabled child affect parents' employment and earnings is very strong. The effect is particularly marked in relation to mothers.'

The authors highlight the fact that:

- mothers of children with a disability are less likely to be in employment than other mothers in the general population
- mothers of children with a disability who undertake paid work, work less hours, and are less likely to work full-time
- mothers of children with a disability are less likely to work on a full-time basis as their children grow up

Fathers' earnings are also affected, but to a lesser extent than mothers. The former too, are less likely to be in paid employment. Where they do work, their earnings were found to be 9% lower than those of men in the general population (OPCS 1989). Whereas for women who work part-time there was a 7% difference when compared to the general population. It should be noted that even when disability benefits were taken into account the OPCS found that all families with disabled children had lower incomes than those in the general population. The implications of this cannot be over-stated.

Professional power

The issue of professional power, and its potential to impact negatively upon the lives of children with learning disabilities and their families plays a central part in this dissertation, as illustrated in Chapters Four and Five. Harris (1997, p.28) in considering the concept of power, defines it as '...having the capacity to act in such a way as to control others.'

Of social work and the power dimension, the author writes:

> 'Any discussion of social work not underpinned by an analysis of power misunderstands what social work is. Social workers operate at the boundaries of the public and the private. They intervene in families and communities in a manner both supportive and controlling: their power and influence are such that their judgement... affects the lives of many.' (p.28)

Although this dissertation is concerned with a professional base broader than merely social work, each of the factors referred to in Harris' comment are equally as applicable to other professionals involved with families, and in particular to the FST members.

Swain and Walker (2003, p.549) note that:

> '... the relationship between clients (whether disabled people themselves or their parents) and health and welfare professionals has never been an easy one. Notions of power have underpinned analyses of professional-client relationships, and their social and historical context.'

While according to Hugman (1991, p.1):

> '...social power is an integral aspect of the daily working lives of professionals. The centrality of power in professional work has been increasingly recognised...'

Handy (1985) notes 5 sources of social power as a means of influencing others: namely, physical power, as illustrated by State intervention in cases of child protection, for example; resource power, or control over services, budgets etc.; position power, accorded by means of professional role; expert power, or the possession of information not readily available to the parent; and personal power, or charisma. Issues around resource, position, and expert power are of crucial significance to the research reported here; each of these will be explored in more detail in subsequent chapters of the dissertation.

Dale (1996, p.4) defines a professional as someone who:

> '...holds a specialised body of knowledge and skills and has undertaken a period of training (often prolonged) to acquire them. This expertise distinguishes and distances the professional from the lay person and also from members of other professions. Those with a particular qualification may hold an exclusive right to practise the profession, and are permitted to control their own body of knowledge.'

In terms of disability, professionals perform 4 key functions:

- 'Communicating the diagnosis of disability, or the results of assessments, to parents, in a sensitive and constructive manner;
- Providing information about the disability, services available, and on facilitating the child's development;

- Providing emotional support, and helping parents to understand their feelings and reactions; and,
- Linking parents with others who are in a similar position to themselves.'

(Hornby 1994, p.6)

The issue of disclosure has been discussed earlier in this chapter, and it is clear that where parents encounter a negative experience in their initial contact with a professional involved with their child's care, that '...can sour parents' attitudes to future relationships with other professionals...' (Hornby 1994 p.6). Following disclosure, parents' greatest need is for information about their child's disability, and how they can enable development. Although such information is widely available it is '...quite alarming to discover how often it does not get to the people who need it.'(*ibid.* p.7).

The author argues that in many cases members of the extended family, friends or other parents will provide emotional support following disclosure, and also in the years that follow as the process of coming to terms with a child's disability is worked through. Nevertheless, professionals need to provide counselling support, so that parents are able to successfully adapt to the situation they find themselves in. That process of adaptation can be greatly aided when parents link up with others who have children with disabilities. Indeed, as is shown in Chapter Four, parents often perceive other parents to be their only source of support.

Hornby (*ibid.*) further notes that:

> 'The attitudes which professionals require in order to work effectively with parents are ones which are consistent with the development of a productive partnership.' (p.9)

The issue of working in partnership with parents is a central feature of the Children Act (1989), in which the needs of children with disabilities were addressed for the first time. The question as to how far this is transferable to the reality of everyday working with families and their children with disabilities, however, is the subject of much debate. The Warnock Report predates the Children Act, and emphasised the need for professionals to listen to parents and to consider their needs:

> 'Professionals have their own distinctive knowledge and skills to contribute to parents' understanding of how best to help their handicapped child, but these form a part, not the whole, of what is needed. Parents can be effective partners only if professionals take notice of what they say and of how they express their needs and treat their contribution as intrinsically important...'
>
> (DES Warnock Report, 1978, para.9.6)

Mittler and McConachie (1983, p.38) note that there are 5 key components to partnership:

- 'Mutual respect and recognition of the essential equality between parents and professionals
- Sharing of information and skills
- Sharing of feelings
- Sharing the process of decision making
- Recognition of the individuality of families and the uniqueness of the handicapped child.'

In recent years the concept of partnership has dominated thinking around the provision of health and social care services which are 'seamless' and integrated (Swain and Walker 2003). There are however, '...considerable barriers to working in partnership...' (*ibid.* p.549). Such barriers may present between groups of professionals and also between professionals and service users. Organisational, attitudinal, geographical or financial barriers may present; all of these may be further compounded by the differing languages used in health, social care and education, resulting in a rivalry between professionals. Swain and Walker (*ibid.*) further argue that to '...then bring parents and disabled clients into this equation further serves to add to the complexity of these relationships.'(p.549).

Moreover, the authors note that:

> 'Partnerships between professionals and parents or 'service users' are predicated on some expectation of an increase in choice for those receiving services. Any real choice, however, may be a mirage, as choice can be seen as a threat by professionals who act as gatekeepers by continuing to make the decisions about access to provision.' (p.549)

Cunningham and Davis (1985) identify 3 models of partnership: namely, the 'expert model', where professionals have control over interventions and parents passively receive services; the 'transplant model' where professionals' skills and expertise are passed on to parents; and the 'consumer model' where there is a more equal partnership, and the rights and knowledge of parents are recognised. Dale (1996, p.14) identifies a fourth model, the 'negotiating model'. Here there is evidence of:

> '...a working relationship where the partners use negotiation and joint decision making and resolve differences of opinion and disagreement, in order to reach

> some kind of shared perspective or jointly agreed decision on issues of mutual concern.'

According to Mittler and Mittler (1983, pp.10-11), in order that professionals work in partnership with parents there must be:

> 'A full sharing of knowledge skills and experiences...partnership can take many forms, but it must by definition be on a basis of equality, in which each side has areas of knowledge and skill that it contributes to the joint task of working with the child.'

Baxter (1989) undertook a study involving the parents of children with moderate to severe learning difficulties at 6 Australian schools. The focus was upon parental perceptions of professionals' attitudes. Baxter reported that some of the parents who participated in her study felt 'inferior', 'insignificant', or 'put down' by the professionals they interacted with. Indeed, there was an:

> '...underlying assumption that professionals had the information required by parents, but were unwilling to share this information with them.' (p.262)

Dale (1996, p.66) argues that language has played a part in the maintenance of professional power:

> 'One way in which professionals have traditionally maintained their expert power is through their use of language, and one example of this is through labelling.'

For, professionals have in the past labelled parents as unrealistic, over-anxious, dysfunctional and demanding. In doing so they have categorised the latter, and set them apart from others. It is possible to identify a number of problem areas in the relationship between parents of children with disabilities, and service providers (Beresford 1995).

Some of these may be indicative of the power dimension inherent in their relationship. First, professionals may have difficulty in accepting parental expertise, and there may be clear differences of opinion between both parties as to what constitutes the parent's and the child's needs. Second, there may be a lack of clarity in terms of the relationship between parents and providers; the former are often drawn upon as an additional resource, and this further compounds working relationships. Finally, the poor co-ordination of services for such families, many of whom are in contact with large numbers of professionals from a wide range of agencies, may play a part.

Strong (1979) refers to the control exercised by professionals over parents, and the way in which parents have been excluded from decisions about their children's care:

> '...even though parents might normally be considered to have the most extensive knowledge of their child and to be the best interpreter of their words, actions and feelings, such knowledge was treated as partial and as able to be overridden when staff saw fit.'
>
> (cited in Read 2000, p.63)

While Read (*ibid.*, p.64) notes that:

> 'When there is a dispute between mother and professional, one way of resolving it (for the professional) is to raise questions related to the mother's competence.'

Undoubtedly, such actions serve only to marginalize parents, and exclude them from any meaningful interaction with those professionals who may be involved in the care of their child. The research literature on relationships between parents and professionals is characterised by the exclusion of the former, and the dismissal of the knowledge they may bring to the caring process. This clearly militates against effective service provision for families with children with learning disabilities. The research findings contained in Chapters Four and Five provide an illustration of the power differential – in particular resource, position and expert power - evident in the interaction between professionals and service users. These issues feature in the discussion contained in the final chapter of the dissertation.

Multi-disciplinary teamworking – a proposed solution for families?

Multi-disciplinary teamworking is one of the central themes in this dissertation because, of course, of the very nature of the FST; issues relating to such ways of working are considered in some detail in Chapter Five. Research evidence points to the difficulties parents have experienced in working with professionals charged with the care of their child; and to the implicit and explicit barriers to working in partnership in its truest sense. Given this, of key significance here, is the question to what extent, if any, multi-disciplinary team working - in the form of the FST - provides a solution for families caring for children with learning disabilities?

Ayer and Alaszewski (1986) point to the difficulties encountered by those who care for mentally handicapped dependents as a result of inadequate and fragmented services. Multi-disciplinary teams have the potential to address such problems. Since the 1970s, community care policies have moved towards a 'one door' approach to service provision. The White Paper, 'Better Services for the Mentally Handicapped' (1971) paved the way for the establishment of the National Development Group, and the National Development Team for the Mentally Handicapped in 1975. These two groups established the framework within which Community Mental Handicap Teams (CMHTs) were to operate. Further, the Court Committee Report (1976) proposed the setting up of District Handicap Teams (DHTs) for all handicapped children. By 1981, two thirds of English health districts had either established or were planning to establish DHTs, and CMHTs. In 1981, most CMHTs consisted of 3 or 4 team members. They included social workers, community nurses, psychologists, and consultants, and were in the main health-based. The majority of CMHTs served all age groups, while 12% focused specifically on children.

In recent years, as already noted, there has been a clear emphasis on professionals working together with other professionals and agencies in the planning and provision of services for children. Under the Children Act (1989) Social Services Departments were required to work collaboratively with education, health and the voluntary sector. This interprofessional collaboration was perceived to be best achieved by means of multi-disciplinary teamwork (Kumar and Parkinson 2001). The move towards this approach is particularly marked in services for people with learning disabilities, due to the fact that so many professionals are involved in their care. A number of other factors have proved influential in this: namely, the complex needs of people with learning disabilities; the modernisation agenda pursued by government; the search for cost effectiveness; and an increase in user participation in service provision (*ibid.*).

Inquiry reports have regularly drawn our attention to professionals' failure to collaborate in the provision of services, with the Laming Report (2003) being one of the most recent examples of this. In spite of the numerous policy initiatives which have emphasised a collaborative approach, Dale (1996, p.281) argues that:

> '...co-operation between multi-disciplinary professionals and multi-agencies continues to be patchy and haphazard.'

There is little evidence of inter-agency working in relation to children with disabilities and their families. In addition, there are few examples of a co-ordinated approach to family support, with parents or carers often having to engage with large numbers of professionals (Rowntree 1999). Amongst the problems identified in inter-agency working have been those which have occurred on an interpersonal level, between colleagues (Cunningham and Davies 1985), and those which are organisational or political in nature (Hanvey 1994).

The research literature on inter-agency collaboration highlights organisational issues and differences in professional perspectives as problematic areas (McGrath 1991). Bruce (1980) notes the poor relationship between social workers, health visitors and general practitioners, with social workers lacking understanding of the health visitor role, and general practitioners being unsure of social worker competence. Further, McGrath (1981) highlights the wide gap which can often exist between schoolteachers and social workers. While the Royal Commission on the National Health Service (1979) highlights the problems inherent in multi-disciplinary working as being associated with inter-professional jealousies rather than anything more tangible.

Furnham *et al.* (1981) point to the tendency of professionals to perceive their own profession in a more positive light than others. Although there will be core skills which are specific to a professional grouping there will also be skills which are more difficult to categorise and which occupy a 'grey area', overlapping with other professional responsibilities. Pluckham (1972) argues that such grey areas can result in professional conflict, or 'professional territoriality'.

McGrath (1991, p.1) writes of the potential for multi-disciplinary team working to alleviate such problems:

> 'Multi-disciplinary teams offer a way of reconciling the rapid growth in knowledge and specialisation among professionals with the increasing appreciation of the inter-connectedness of many problems and the effect of fragmented services on the consumer.'

While, according to Kane (1975), in addition to allowing service users easier access to services through a 'single door' principle, the advantages of multi-disciplinary working include a more efficient use of staff resources; and a more satisfying work environment for individual workers.

McGrath (*op.cit.*, p.13) notes that such teams:

> '...can be defined as having three common elements: members with shared aims, distinct roles for members and a structure to facilitate joint working and communication.'

Kumar and Parkinson (2001), however, in their study of multi-disciplinary teams report that communication difficulties amongst professionals prove the greatest obstacle to interprofessional working. Moreover, a lack of integration; a lack of resources and the personal characteristics of professionals also prove significant. Interestingly, the most effective interprofessional working relationships were found to exist between managers and staff who shared a '…common professional ideology…' (*ibid.*, p.328), in this case, a nursing background.

Wilson and Pirrie (2000, p.2) note that '…issues of territory and professional boundaries impact on multidisciplinary working.' According to the authors, a number of factors facilitate multidisciplinary teamworking: namely, personal commitment, which is perceived to be essential; having a common goal and a 'shared vision' of the future of an organisation or team; clarity with regard to role and communication; and institutional support. The development of a multi disciplinary team can on the other hand be inhibited by logistical issues such as the difficulties encountered in providing accommodation for a team and bringing them together in order that they can problem-solve together. Moreover, professional bodies may function as barriers to effective teamworking. One of their key functions is to maintain professional standards and ensure competence. However, in spite of the fact that their members may work closely with each other with the same groups of clients, '…in practice, there is little liaison between different professional bodies…' (*ibid.*, p.3). Finally, the attitudes of team members play a crucial role in enabling teamworking.

Effective communication is only one aspect of good teamwork. In addition, there is a need for a '…mutual understanding between professions…' (*ibid.*, p.3). For, only then will staff develop an awareness of others' roles; understand their strengths and weaknesses; and thus break down the barriers which exist between professionals, not least the ideology that individual professions hold specific knowledge which allows them to interact effectively with service users, while excluding other professionals from doing so. (*ibid.*).

Stevenson and Parsloe (1978) point to the importance of the quality and style of leadership in working in teams. While Wilson and Pirrie (2000, p.4) also take up that point, noting that '...leading and managing multidisciplinary teams requires increased skills and sensitivity.'

Amongst the specific leadership skills required in multi-disciplinary teamworking are the following: the ability to organise and lead a cohesive team and maintain morale; and to meet the personal and professional needs of team members. Further, the latter should be enabled to explore differences of opinion; discuss their concerns; share their expertise; and solve problems (Liberman *et al.* 2001).

Moreover, Wilson and Pirrie (*op.cit.*) argue in order that teams function effectively, training in multidisciplinary working should be provided. The authors comment on the influential part resources play in the way teams work, and call for further investigation of the relationship between a team's physical space; and the way in which that space is used. Again, each of these issues are of relevance to the research reported here, and will be further considered in Chapter Five.

McGrath (1991, p.54) notes the following as being essential components in effective team working:

> '...competent and committed staff; agreed goals and priorities; agreed definition of members' roles; open communication system and shared

> information; task centred/ problem solving approach; participative management; creative stimulating environment; supportive informal, member-oriented environment, staff self-critical, self-managing and able to cope with conflict.'

A commitment to teamwork is seen to be essential in overcoming individual, professional and agency barriers (Lowe and Herranen 1981; McGrath *op. cit.*) In terms of team integration, also of importance is a shared work base and regular team meetings; one individual taking on the role of co-ordinator; and the provision of management support to the team (*ibid.*).

Conclusion

Many of the issues highlighted in this Chapter of the dissertation are of significance to the research reported here and these will be further explored in some detail in subsequent chapters. In this Chapter, the relevant research literature has been considered, and the numerous barriers to working together in service provision have been identified. In particular, the nature and extent of learning disability; and the social oppression model as opposed to the medical model of disability have been considered. Attention has been paid to the process of disclosure, and the subsequent stages of 'acceptance' of, and 'adaptation' to disability. Moreover, the experience of having a child with a disability has been explored; as has the concept of professional power; and the potential for multi-disciplinary team working to provide a solution for parents who are so often confronted by inadequate and fragmented services. In Chapters Four and Five, the reality of multi-disciplinary teamworking is explored. There, the views of individual members of the FST, and also the parents of children for whom they provide a service are considered in some detail. Next, in Chapter Three the focus is upon the methods employed in undertaking the research.

CHAPTER THREE - METHODS

Introduction

As already mentioned, this dissertation focuses on the extent to which multi-disciplinary team working, and the establishment of a FST in West Wales provided a solution to the problems experienced by families with children with learning disabilities. In the previous Chapter the nature of such problems were considered. Here, the focus is on the methods employed in undertaking the research. Issues relating to the process of selecting the research method are discussed; the data collection exercise is outlined; and finally ethical issues are examined.

Selecting the research method

Blaikie (1993, p.4) notes that social research is about engaging with the world we live in. Essentially it involves:

> 'Exploring, describing, understanding, explaining, predicting, changing or evaluating some aspect of the social world.'

In undertaking research one is faced with a number of choices at each stage of the process.

According to Williams *et al.* (1995, p.273):

> '...selecting a data collection method is a matter of deciding what has to be measured and choosing the most direct and appropriate method of making the measurement, giving due consideration to the available resources and the characteristics of the research participants.'

In the first instance, a decision needs to be taken as to whether a quantitative or qualitative approach is more appropriate. Denscombe (2003, p.231) draws our attention to the fact that:

> 'The terms 'qualitative research' and 'quantitative research' are widely used and understood within the realms of social research as signposts to the kind of assumptions being used by the researchers and the nature of the research being undertaken.'

Qualitative research differs from the quantitative approach in that within the former, it is expected that theory and methods will emerge as the study progresses. In the 'grounded theory' approach of Glaser and Strauss (1967), theories develop and can be tested as the research process unfolds. Quantitative research on the other hand is characterised by …'a predetermined research design…and…a definite sample or experimental procedure to be undertaken.' (Denscombe 2003, p.234).

Bryman (2004, p.20) notes the emphasis in qualitative methods …'on an inductive approach to the relationship between theory and research…' Here the focus is upon the generation of theory, and also upon the manner in which individuals interpret the social world around them; social reality is an ever-shifting concept. Quantitative research, on the other hand, is characterised by a deductive approach, with the emphasis upon the testing of theory; social reality is external and objective.

Although these approaches appear to be in total opposition, in practice, researchers often make use of both quantitative and qualitative methods within a study, placing emphasis on one approach more than the other in analysing, and reporting their data. Essentially, qualitative research is characterised by its focus on words as units for analysis, as opposed to numbers (ibid.); it is this qualitative approach which was adopted in the research reported here.

Gilbert (1993, p.18) notes that:

> 'There are three major ingredients in social research: the construction of theory, the collection of data and, no less important, the design of methods for gathering data. All of them have to be right if the research is to yield interesting results.'

In this chapter we consider each of Gilbert's 'ingredients'. First, what of the place of theory in social research? The author argues that all research is dependent upon theory:

> 'Seeing the world in different ways is the essential and fundamental role of social research and the ability to see these differences and to make sense of the different points of view that a researcher can take is the basic contribution that theory makes to the research process.' (p.11)

All social science research is located within a theoretical framework. This framework provides a starting point for discussion, and exploration, and a means of contextualising the impending research. In this study, for example, theory relevant to the social versus the medical model of disability, and the concept of professional power play a central part. Moreover, sociological perspectives on the informal caring role; and the labelling process also feature. This dissertation is in every sense about different ways of seeing the world. For the focus is upon two groups of people who occupy very different positions in the scheme of things: namely, service users and service providers. They differ as much in the way they experience the world they inhabit, as in the life-experience they bring to that world. The common thread, however, remains the children for whom a service is to be provided. Making sense of the often conflicting foci of each group's attention in terms of service provision presents something of a challenge in theoretical terms, and these issues are considered in greater detail later in the dissertation.

Bryman (2004, p.281) notes that:

> 'Qualitative research tends to view social life in terms of processes…there is often a concern to show how events and patterns unfold over time…'

The unfolding of patterns and events is of particular significance in terms of the development of the FST over the 12 month research period, and this is a key feature of Chapter Five.

In the case of the research reported here a decision was taken to adopt a qualitative approach in order to facilitate an in-depth examination of issues of relevance to the FST and the families they were to provide a support service for. Having made that decision, a number of other considerations then featured, for example, how should data be collected? Should individual, face-to-face interviews, telephone interviews, or focus groups be undertaken? Should observation be utilised? A decision needed to be taken as to whom should be included in the research sample; and who should be excluded, and why; how data should be analysed; whether, for example, interviews should be fully transcribed, and if transcribed how that material should be managed, and reported to optimum effect. Each of these questions were fully considered at the outset of this research. For, implicit in the research task is the requirement that researchers are able to justify their chosen method of enquiry to their peers in any process of review.

Of course, key to this process is the need to select a method which is appropriate to the research question(s) to hand. How best will a particular question be addressed? What method(s) will result in the most valid, reliable findings? A clear definition of the research problem to be addressed is essential. Having conceptualised the research problem, and considered their research question(s) or hypothesis, the researcher faces the task of selecting and operationalising their chosen research method. The hypothesis or research question will guide an entire study. It is essential that the choices made at this stage in any research study are sound, for they will have implications for the validity of the eventual findings. Undoubtedly, the emphasis should be upon a structured, and systematic approach to the process.

As already noted, a number of key decisions needed to be made at the outset of this research study. In making these decisions, the following were borne in mind:

- relevance – the research should build on existing knowledge, and be of significance to others in the field

- feasibility – it should be possible to design the research; gain access to participants; collect the data and analyse the results

- coverage – care should be taken to ensure that the questions asked will elicit the appropriate information; and that a sufficient number of respondents are included in the study

- accuracy – the ultimate aim of research is to produce results which are detailed, precise, and honest

- objectivity – the research should provide a balanced report of a particular problem. The researcher should be aware of the possibility that individual values, and beliefs might impact negatively upon the research process. Moreover, the limitations of the research must be acknowledged

- ethics – the rights and feelings of research participants are of paramount importance. Their anonymity should be assured at the outset, and guarantees of confidentiality given. There can be no place for deception in the research process, and respondents' views must be accurately reported.

(Denscombe 2003)

Ethical issues are a central tenet of social science research, not least because such research is undertaken with human participants in the social world they occupy, rather than in a controlled environment. Researchers need to gain access to that world, in order that they can address their research questions(s). Yet, they have very little control over the access process. They rely heavily upon gaining the permission of 'significant others' who may be 'gatekeepers' to a particular setting. Clearly, with so much resting on negotiating access to participants, and upon subsequently collating data which may be analysed, the potential for respondents to suffer harm is considerable. When the subject matter under scrutiny is of a sensitive nature, as much social science research is, the need for a scrupulous, transparent approach is of even greater significance. Given the nature of the research reported here, attention will focus on ethical issues in greater detail later in this Chapter.

Williams *et al.* (1995, p.17) define research as:

> '...a structured inquiry that utilises acceptable scientific methodology to solve problems and creates new knowledge that is generally applicable.'

While this research adopted the …'structured inquiry'… approach proposed by Williams *et al.* (*ibid.*), it was essentially a small-scale, exploratory study, which as mentioned earlier, was qualitative in nature. The study sample cannot be said to be representative of the larger population, and thus generalisations may not be made in terms of findings. In spite of this, however, a picture has emerged of the experience of having a child with a disability, and of the service response to that at a particular time, and in a particular geographical location. Of particular interest was the fact that the inception of a new team to support families with children with learning disabilities was accompanied by an evaluative component; the latter being funded for the first 12 months of the team's life. The results of this evaluation process form the basis of this dissertation.

Initially then, in research terms, the intention was to provide a 'snapshot' of service provision for families with children who have learning disabilities, both before and some time after the establishment of the FST. Research participants were to fall into two categories: namely, team members and families. Given the sensitive nature of the topic under investigation, and the need to work in close proximity with team members in order to chart development, a decision was taken to adopt a qualitative approach, using methodological triangulation in an attempt to gather information on the 'truth' of the situation as perceived by service users and providers.

According to Denscombe (2002, p.104):

> 'Triangulation provides social researchers with a means for assessing the quality of data by coming at the same thing from a different angle.'

In this case, informal discussion, observation, and semi-structured interviews were all employed as data collection mechanisms in relation to the FST, both as the team became operational, and again approximately nine months later. This multi-method approach provided a degree of triangulation which allowed variant accounts of the same problems and experiences to be compared. It was intended that semi-structured interviews would be undertaken with families, at the identical points in the developmental process. However, the research design was amended to take into account organisational and professional difficulties as they emerged, and affected both service providers and service users. As a result of these difficulties, families had less contact than had been envisaged with the FST during its first year in existence, and were therefore interviewed only once towards the end of the evaluative process. These difficulties are discussed in detail in Chapter Five.

Interview guides comprising open-ended questions were designed for use with both families, and team members and copies of these may be found in the Appendix. Mark (1996, p.248) notes that:

> 'The major advantages of open-ended questions are their flexibility and depth. In an interview, they allow the interviewer to probe into respondents' attitudes and knowledge that may help to explain the response...Open end items are especially useful for measuring complex attitudes for which standardised scales are not available. In an exploratory study, respondents may give unexpected answers that can lead to new research hypotheses or theoretical explanations.'

In a study such as this, it is imperative that such techniques are used in order that the optimum data are obtained on an individual face to face level. For, open-ended questions while perhaps being representative of a less structured and 'scientific' approach, and also presenting greater difficulties in terms of analysis, clearly offer the flexibility highlighted by Mark (*ibid.*).

Williams *et al.* (1995, p.255) point out that:

> '...the purpose of research interviews is to gather the data needed to answer the research question – a research interview is *for* the researcher...'

Yet, it could be argued that in open-ended questioning, the agenda is much less the researcher's than is the case in the more structured, closed-ended approach. Although, of course, in the former the researcher has initially framed the questions, the approach is less prescriptive in nature; it offers respondents a greater element of control over the interview; and is more likely to yield interesting data, which can often surprise. The converse to that, of course, is that as mentioned earlier, data can often prove difficult to analyse.

Data collection - the FST

As mentioned previously, in terms of the FST, data collection took the form of informal discussion, observation, and individual interviews. At the beginning of the research process, a substantial amount of time was spent in establishing relationships with team members who were suspicious of the objectives of the research, and who clearly could not foresee any value in its undertaking. It had been intended that the researcher would be located with the team, however, a lack of space at the team base meant that this was not possible. Nevertheless, the researcher spent a considerable amount of time with team members, both at their office, and at meetings with external agencies.

Informal discussion - occurred between the researcher and team members, on both an individual and group level throughout the study. Such discussion proved particularly useful during the initial stages of the research as a means of highlighting issues which were to prove significant in the team's development.

Observation - played a crucial part in the project. Team members were observed at their base, daily. While interaction between team members, and external agencies at a variety of meetings, and in a range of settings was also observed. Notes were made at each of these encounters. These provided a clear illustration of the dynamics of both team, and inter-agency working. Observational material was cross-referenced with that obtained through interview, and informal discussion. Data collated by means of observation, and informal discussion were written-up in diary form. This material proved an invaluable data source which was heavily drawn upon throughout the research process.

Some interesting methodological issues arise from use of the observational method. Firstly, acknowledgement must be given to the fact that in observing someone, a 'researcher effect' may occur: namely, those under study may '…alter their behaviour to take account of the purposes of the research.' (Denscombe 2002, p. 19). This, however, is also a common occurrence in other elements of the research process, including individual interviewing, and reflects the concept of social desirability; the need to conform to that which is expected. Second, the problem of maintaining detachment, and an appropriate 'distance' from research participants must also be considered. In this study, issues around detachment, objectivity, and the researcher remaining 'outside' the team proved central features of the research; these will be discussed in greater detail later in this Chapter.

The concept of 'objective' social science research raises some interesting questions, and reflects the split in sociological analysis between the positivist school of thought, and the interpretivist. In August Comte's positivism, the natural science model of research can be applied to studying social phenomena, and explaining the social world. Sociologists such as Durkheim, Spencer, and Parsons are numbered amongst proponents of positivism where:

> '...society can be explained 'scientifically', according to laws and rational logics – whether these be based on social stages (as with Comte), social facts (as with Durkheim) or on social systems (as with Parsons).'
>
> (Gilbert 1993, p.7)

Here, then, there is a reliance on empirical observation, and an expectation that the researcher remains detached and impartial. The approach is totally objective in nature. Yet, its critics would argue that it is not possible for social researchers to be totally objective, as their personal value base, and the expectations they bring to the research process will play an influential part in its eventual outcome (Denscombe 2002).

Interpretivists, on the other hand, contend that as explanations are influenced by researchers' expectations, claims cannot be made that their research is objective. For:

> '...the interpretive tradition, seeks not so much explanations and predictions of social events as understanding what meaning and what significance the social world has for the people who live in it.'
>
> (Gilbert 1993, p. 7)

An interpretive approach was adopted in undertaking the research reported here in the hope that a real understanding of issues of relevance to families with children with learning disabilities would emerge. However, implicit in the undertaking of social science research is the notion that it can only hope to offer a partial insight, for it is a time-limited exercise; it reflects the reality of a participant's situation as they perceive it at a specific point in time. The researcher is merely the vehicle by which that reality is reported to a wider, interested audience in as objective a manner as possible.

The above reflect some of the dilemmas central to the task of undertaking research in the social world. For, here there are none of the advantages of enquiry within a laboratory setting. Social research cannot be as prescriptive in nature, although it aspires to standard, scientific procedures. Moreover, there are significant ethical difficulties in adopting experimental designs on sensitive topics with research participants who may be vulnerable. Thus, the optimum approach is of necessity one which is rigorous, and systematic, while at the same time one which acknowledges the inherent limitations in researching social science issues.

Clearly, in making use of observational techniques one of the most difficult tasks is that of remaining detached, and retaining some sense of objectivity. In the study reported here, the FST initially felt that the researcher would impinge upon the successful development of the team. As time went on, however, the team became more isolated from external agencies, and in a sense from each other; problematic team issues dominated their thinking, and interestingly, perceptions shifted. For, as the team perceived their problems increasing, both on an internal and external level, they attempted to draw the researcher into their 'world', inappropriately involving the latter in team issues. Indeed, a constant effort had to be made on the researcher's part to re-draw boundaries, and remind the team of the purpose of the research, and the role of the researcher. However, in the eyes of team members, the researcher became an 'ally' whose reporting mechanisms could be drawn on as testimony to their plight; to the lack of management interest; and the hostility of external agencies.

Semi-structured interviews - were undertaken with team members at the start of the research study, and again 9 months later. An interview guide was designed for use with team members, and at the initial interview, they were asked to describe their role; to provide an indication of the number of families on their case-load; to reflect on how they were adapting to the concept of multi-disciplinary team work; and to comment on the geographical boundary problems they were experiencing, and which informal discussion with, and observation of the team had identified as an issue.

At the second interview, team members were asked to assess their progress to date; whether multi-disciplinary working was presenting any particular problems; whether they felt they were achieving the aims and objectives originally set; and whether they felt that they had made good links with other agencies. They were also asked to reflect on management and accommodation issues. All the interviews were taped, and fully transcribed. Data were analysed thematically, with close attention being paid to the frequency of occurrence of a particular theme. The resulting material is reported in Chapter Five, where verbatim quotes are used in an illustrative capacity.

Data collection – the families

The sampling process

It was not possible to interview all those families receiving support from the FST, as the life of the project spanned only 12 months. Prior to the team becoming operational, an initial caseload of 120 children had been identified by the FST co-ordinator, and two senior doctors as falling within the remit of the FST. Using the caseload as a sampling frame, and bearing in mind issues such as timescale for completion of the project, and available resources, 25 families were subsequently sampled for interview; their children's ages and the extent of families' contact with the team forming the basis of selection.

Of those families sampled, 10 had children over 10 years of age; 10 had children under 10 years; and 5 families had been contacted by the team but not yet visited. No information is available as to the nature or extent of the children's learning disability – other than that disclosed at interview by the parent(s) - as the FST did not think it appropriate that the researcher had access to the case files. In terms of process, in the first instance, the team co-ordinator wrote to each family on behalf of the researcher; a copy of the letter is to be found in the Appendix. Where families agreed to be interviewed, they were contacted directly by the researcher who arranged to visit them in their own homes at a time convenient to them. In one case, the parents concerned chose to be interviewed in the researcher's office; all others were interviewed at their home.

Families who did not wish to participate in the study were replaced by another from the same category. One follow-up reminder letter was sent to the 9 families who did not reply within the specified period to the initial request for interview; five of those families subsequently agreed to participate. A total of 37 letters were sent out, and 22 families were interviewed between January and June 1992. Fourteen parents had children under 10 years of age, and 8 over 10 years. Interviews were tape recorded in all but one case, where the family expressed concern at the use of a tape recorder. Interviews lasted between one, and one and a half hours and the flexibility of the interview schedule allowed families an input in terms of the agenda for discussion.

As mentioned previously, families participated in individual interviews on one occasion only, due to their limited contact with, and experience of the service provided by the FST during the first 12 months of the team's life. As was the case in interviews with team members, interviews with families were undertaken using an interview guide; this was divided into 2 sections. The first section focused on family life, and on their wants and needs, while the second sought to elicit their views on the service provided by the FST. In the first instance, an attempt was made to create a 'map' of family life by establishing whom the family had regular contact with, and who they received help from, be that professionals or non-professionals. Their child's developmental history was explored from the moment of diagnosis through to critical milestones in their life, such as talking; walking; school entry; and adolescence. The impact upon the family of having a child with a learning disability was considered; and relationships with siblings, friends and extended family were explored. Parental views on their child's behaviour were sought. While their thoughts on contact with professionals, and the extent to which they were involved in decision-making were also elicited. Section two of the interview guide focused on their contact with the FST, and the service the team provided. Interview data were analysed thematically. As was the case with data collected from team members, close attention was paid to the frequency of occurrence of particular themes. This is reflected in the research findings reported in Chapter Four, where again verbatim quotes are used in an illustrative capacity.

The families' characteristics

As mentioned previously, a total of 22 families participated in the study. In 14 cases mothers were interviewed. They ranged in age from 20 to 58 years, while their children were aged between 2 and 15 years. Four mothers were lone parents; two had divorced the father of their child, and had subsequently remarried. Four lived with their extended family, while another two were supported by family living close by. Eight families had recently moved into the area.

Eight fathers, or step-fathers were present during the interview, and they provided an additional, and often contrasting perspective on service provision. Indeed, many of them openly vented their anger at a 'system' which they perceived as inadequately meeting need. Four respondents were adoptive parents of children aged between 7 and 15 years, whilst also being natural parents of older children. Only two families lived in an urban setting, the majority living in rural areas. In terms of occupational status, seven fathers were in full time employment; three fathers were self-employed, and a further three unemployed. Two mothers were professionally qualified; one worked full time; and the other worked on a part time basis. A third mother was involved in the family business. Two families came from a farming background, and continued to live on working farms.

Two of the 22 families interviewed were actively involved in service provision, as parent representatives on specific working groups. While another respondent was involved in the local planning mechanism.

Ethical considerations

All researchers have a responsibility to their participants to fully consider the ethical issues of relevance to their enquiry at the very outset of the research process. A failure to do so may result in harm to respondents, and the significance of this cannot be over-stated in research of the nature described here. Indeed, Denscombe (2003, p.134) notes that there is an expectation that social researchers are ethical in the way they collect, and analyse their data, and also disseminate their findings. In particular they should:

- 'Respect the rights and dignity of those who are participating in the research project
- Avoid any harm to the participants arising from their involvement in the research
- Operate with honesty and integrity.'

Robson (2002, p.69) identifies ten questionable practices in social research:

- involving people without their knowledge or consent
- coercing them to participate
- withholding information about the true nature of the research
- otherwise deceiving the participant
- inducing participants to commit acts diminishing their self-esteem
- violating rights of self-determination (e.g. in studies seeking to promote individual

change)

- exposing participants to physical or mental stress
- invading privacy
- withholding benefits from some participants (e.g. in comparison groups)
- not treating participants fairly, or with consideration, or with respect

At the very heart of the research process reported here was acknowledgment that in inviting parents to participate in individual interviews which focused in part on the disclosure of disability, 'mental stress' might be incurred. Clearly, the need for a sensitive approach in terms of introducing the research to parents, and also in framing interview questions was essential if the project was to be successful both in eliciting information, and in enabling respondents to exit the process unharmed. Indeed, the researcher was often reminded of the need for sensitivity as many of those interviewed became tearful, and angry as they recalled their experiences. It is imperative in such interviews that a researcher is comfortable with a period of 'silence', and not embarrassed by it. For, understandably, parents often needed a considerable amount of time to compose themselves, and gather their thoughts before they were able to continue with the interview, having reflected on a painful or disturbing memory. Of course, they were offered the opportunity to withdraw at any time from the interview process should it prove too difficult for them to proceed.

One interview proved a salutary reminder of the potential for researchers to do harm. For, one mother whose child aged 3 had only recently been diagnosed as having a learning disability should clearly not have been included in the sample for interview. Although she had agreed through the normal process of written contact with the FST co-ordinator to take part in the study, the experience obviously proved too much for her. As was the case at the beginning of each interview, the purpose of the study was explained to the mother, and the interview process outlined. Emphasis was placed on the confidential nature of the exercise, and the ability of participants to withdraw from the process at any time. However, shortly after the interview began, it was clear that all was not well. When the issue of disclosure was raised the mother became very distressed, insisting that her child was, as she put it 'normal', and that there was nothing wrong. She refused to participate any further in the interview, and asked me to leave her home. Of course, her request was immediately complied with.

It is important in a situation such as that reported above, that research participants are not left to cope alone with the aftermath of involvement in a research interview. Thus, I immediately informed the FST co-ordinator of the parent's distress, in order that appropriate support could be provided. One of the team members subsequently visited the parent to offer that support.

It has to be said that I felt a great sense of guilt following that interview, and spent much time reflecting on how I could have prevented that situation, or alleviated the negative impact of the experience on the parent. My sense of guilt was exacerbated by the reaction of the FST who were angry that I had upset one of 'their parents', and as they saw it, had obviously been insensitive in the way I had handled the interview. This incident therefore confirmed their belief that in lacking a professional qualification, I was ill-equipped for involvement with 'their families'.

The above, unfortunately, provides an illustration of the way in which research participants may be adversely affected by their involvement in social science research. The mother concerned was clearly distressed by her experience. It is to be hoped that her distress was short-lived. As mentioned previously, all researchers have a responsibility to ensure that harm to participants is minimised, yet no matter how well-planned and executed a study may be, reactions such as that described may occur. Of importance is the way in which when problems do arise, researchers work to minimise the negative effects.

Within the social sciences, the differing disciplines have their own associations, for example, the British Sociological Association (BSA), and the British Psychological Society (BPS). Each of these adhere to their own code of conduct. While there may be differences in terms of emphasis between ethical codes, there are similarities in the form of '... a shared sense of values in relation to research.' (*ibid.*, p.135). In essence, the following ethical principles are integral to the research process:

- the interest of participants should be protected –

with those who participate being no worse off at the end of the process than they were at the start. There should be no long-term implications of their involvement in the research process. Researchers need to ensure that participants do not suffer psychological harm as a result of their involvement. Thought should be given to the nature of the subject matter, and the extent to which the process is intrusive, and touches upon sensitive issues. This, of course, was of particular significance for the research reported here.

Moreover, researchers should offer protection to their respondents by ensuring that all information is confidential, that it is reported anonymously, and stored securely.

- researchers should avoid deception or misrepresentation –

and should be open and honest about their research, in an attempt to obtain a balanced, unbiased account of a particular situation. Respondents should be clear as to the purpose of the study, and what use is to be made of the findings. Indeed, it is considered good practice to offer participants feedback at the end of the process; sometimes this may be in the form of a copy of the research report. All those who participated in this research were offered the opportunity to receive a copy of the final report.

- participants should give informed consent –

and should never be pressurised into participating in a research study. Implicit in the principle of informed consent is the notion that potential respondents have enough information upon which to base a decision to take part in the project. It is important that respondents 'opt in' to the research voluntarily, in writing. For, indicating consent in writing provides a security mechanism for the researcher should the need arise, as by doing so, participants are acknowledging that they have been sufficiently informed about the study to make a decision to participate.

The letter inviting families to participate in this research study was both produced and distributed by the co-ordinator of the FST. Families were informed that any queries about the research were to be addressed to the team co-ordinator. In terms of gaining access to research participants, the assistance of a 'gatekeeper' can prove invaluable. Such 'gatekeepers' may be managers in a relevant service or agency who are familiar with, and often well known by both staff and service users. Denscombe (2002, p.71) notes that 'gatekeepers' are a crucial element in the research process. For:

> 'In formal settings, they [gatekeepers] exercise institutional authority to permit or deny access.'

In this case, the FST co-ordinator functioned as a 'gatekeeper'. S/he was of the view that as the families knew her/him, this would have a positive effect on their decision to participate in the study. Implicit in this according to the co-ordinator, was the element of trust which had developed between her/himself and the families.

All social science researchers need to be aware of the legislation relating to the collection and use of personal data. The Data Protection Act 1998 refers to personal data as that '...relating to living, identifiable individuals...' (Denscombe 2003). The author notes that if data collated as part of a research study are anonymous, and cannot be traced to an individual, then the legislation does not apply. Notwithstanding the above, even when exempt from provisions of the Act, it is nevertheless good practice for researchers to acknowledge its principles by:

- collecting and processing data in a fair and lawful way
- using data purely for the purpose specified
- only collecting data that are needed
- ensuring data are accurate
- keeping data only as long as is necessary
- keeping data secure
- not distributing the data
- restricting access to data

- keeping data anonymous

(*ibid.* p.142)

Keeping the above requirements in mind, all data collected as part of this research study were held anonymously and securely at the researcher's office, which was located at a site separate from the FST base. Every effort was made to ensure the confidentiality of the material, with access to the material being restricted to the researcher. All interviews were allocated a number, and information relating to the identity of respondents was held separately from the tapes and transcripts.

Conclusion

In this Chapter of the dissertation the focus has been upon the methods employed in undertaking this small-scale, exploratory study. A qualitative approach was adopted in order that as far as possible, the reality of having a child with a learning disability could be explored; and the experience of being part of a new multi-disciplinary team documented. The process by which the research method was selected was considered, as was the data collection exercise. Moreover, detailed consideration was given to ethical issues, and their implications for research such as that reported here. In Chapter Four, attention shifts to the views of those families who participated in the research.

CHAPTER FOUR – RESEARCH FINDINGS: THE FAMILIES' VIEWS

Introduction

In the previous Chapter of this dissertation the methods employed in undertaking the study were considered. Here, the views of those families who were receiving support from the FST, on issues relating to the experience of having a child with learning disabilities, and also on their contact with the FST are explored. The issue of disclosure is considered; relationships with 'significant others' are explored; siblings' experiences are highlighted; the differences between biological and adoptive parenting are examined; consideration is given to the issue of other parents as sources of support; contact with professionals is explored; and finally attention is drawn to the areas of education, and respite care.

As mentioned in Chapter Three, a total of 22 families participated in the research which forms the backdrop for this dissertation. The majority were interviewed in their own homes between January and June 1992. Fourteen parents had children under 10 years of age; in 8 cases children were over 10 years. The data collected as a result of those interviews are presented below mainly in the form of verbatim quotes.

Disclosure

Earlier in the dissertation attention was drawn to the fact that the research literature on parental reactions to having a child with disabilities focuses in the main on the stages of denial, guilt, anger, depression and shame experienced (Russell 1983; Bicknell

1991) There is very little attention paid to the potential for a positive impact. Indeed, Ryan and Thomas (1980, p.19) note that:

> 'The presence of a mentally handicapped person in a family is almost always problematic in some way. Faced with an unusually difficult child...many families cannot cope or only do so at immense cost to themselves.'

They further argue that, within the family, it is the mother who is most affected:

> 'Not finding it easy to either grow up or grow away, the 'eternal children', as they are sometimes called, can lock their mothers in a never-ending maternal role.' (p.20)

Undoubtedly, a diagnosis of mental handicap is a traumatic experience for parents, and one which those who participated in this research remembered well even though in some cases several years had elapsed since diagnosis. The difficulties faced by parents who have children with a learning disability, however, will vary according to the nature and severity of their child's disability.

The change in official attitudes towards mentally handicapped people and their families is evident in the way the focus of services has shifted from care provided within an institutional setting to that provided within the community and the family. Advances in technology in terms of neo-natal care have resulted in many more children with complex needs surviving, and living longer. Whereas previously, the birth of a handicapped child would have met with the advice that perhaps the child would be best placed in a mental handicap hospital, more current thinking proposes that the child is cared for at home just as any other child would be. Although, of course, what must be added to this equation is the potential for termination as a result of screening during pregnancy. Indeed, the women in Partington's (2002) research reported implicit pressures from medical staff to take this route.

It is clear that the parents who took part in this study were faced with insensitive responses and negative attitudes on the birth of their child with a disability. As already noted, Ayer and Alaszewski (1986) amongst other commentators write that professionals often define parents of children with mental handicap as 'ill' or 'handicapped' themselves. Further, the former may be suspicious of parents' motives in attempting to establish what is wrong with their child.

Often, the fact that a child has a learning disability will only become obvious as they approach the various developmental milestones laid down by medical professionals. A failure to achieve a particular task at a certain age provides an indication that there may be a developmental delay. It is common for the child's parents to notice such a delay in the first instance and then to inform their health visitor or GP. For some parents, however, there are clearly problems at birth, and in this section of the dissertation, the focus is upon those parents for whom this is the case.

The availability of relevant information, and the manner in which it is conveyed to parents and carers of children with disabilities is crucially important to their well-being (Rowntree 1999). Common to all families who have children with disabilities is the need for information about the disability; about services which may be available to them; about the means of supporting a child's development; and the financial benefits they may be entitled to (Beresford *et al.* 1996). In spite of the fact that the research evidence abounds with examples of the value parents place on information provided by professionals, this is a need that is frequently unmet (Social Services Inspectorate 1994; Beresford 1995). Beresford *et al.* (1996, p.26) note that:

> 'Information and knowledge are central to people's efforts to manage the difficulties they encounter in their lives. Without sufficient information, they are likely to feel helpless and lacking control. This, in itself, can lead to distress and depression. Working with families in a way which enables them to exercise control over their lives requires that they receive sufficient information about all aspects of their situation.'

This need for information is at its greatest when disability is diagnosed and parents are often struggling to come to terms with an uncertain future, both for themselves and their child. Read (2000) in her study of 12 West Midlands mothers, and their experiences of caring for a child with a disability reported how for one mother, the fact that her daughter had brain damage was perceived as justification for death '...being in the natural order of things...' (p.38). In this case, a mother recalled how:

> 'The chaplain had come to see her and suggested that if a flower were not perfect, it was better for it to wither and die.' (*ibid.*)

One mother in Partington's (*op.cit.*) study recalled the insensitivity of the paediatrician following an examination to determine the extent of her child's visual loss:

> 'He [paediatrician] asked me if I had heard the test results, and I said no. He said, oh, minimal. And I said, oh great, minimal damage? And he said no – minimal response. He's completely blind.'

Garth and Aroni (2003) note that although the insensitive manner in which professionals have communicated with families has been well-documented in the research literature over many years now, it is still the case that in terms of diagnosis, frustration is a recurring theme in interviews with parents. For, they point not only to the delay in diagnosis, but also to the '...poor communication in the delivery of that diagnosis...' (p.569).

Undoubtedly, the task of informing parents that their child is mentally handicapped is one of the most difficult that medical professionals have to undertake. At a time when the norm is of great happiness and celebration, such parents experience shock, loss, grief, and sometimes the negativity of relatives and close friends. Hornby (1994, p.6) notes that in terms of disclosure:

> 'The vast majority of people prefer to be told diagnostic or assessment results by a professional who communicates empathy, sensitivity, openness, and a positive yet realistic outlook.'

The author asserts that:

> 'When communication is handled in this way family members tend to adapt more quickly and establish more positive relationships with each other, the child with the disability, and professionals.' (p.6)

Case (2000), in a survey of 114 parents of children with disabilities throughout the United Kingdom, found that the former did not receive sufficient information from doctors either as to the cause or nature of the disability. Moreover, there was little attention paid to the issue of outcome. Parents felt that doctors showed a lack of concern for their feelings; that often any feedback given was negative; that their manner was abrupt and rude; and that there was a tendency to use jargon in communicating with them.

Garth and Aroni (2003, p.569) found that for mothers in their study, information:

> '... regarding care management was lacking, and they were left wondering how the disability would affect their child and the family.'

Moreover, they report that:

> 'Some doctor's communication skills were also perceived to hinder parental ability to make informed decisions regarding treatment options for their child.' (p.570)

The responses of parents who participated in this research provide further illustrations of the above. They talked of the insensitive way diagnosis was made at birth, and of the sparse information provided to them by medical staff. They spoke also of often suspecting something was wrong due to the actions of nursing staff, who isolated and segregated the mothers in hospital. One mother's request to speak to a doctor in order to allay her fears following the birth of her child was denied. As a result, she experienced a night of 'hell' while she questioned her own sense of reasoning:

> 'The sister must have guessed something because they rushed him off. I thought because he was small. They put me in the side ward. I went to see the sister and I said is there a doctor available I can talk to? She said, you go back to bed and doctor will come in the morning. Well, to be perfectly honest with you, if somebody's been to hell and back, I went to hell and back that night. You hear of people going off their heads after having a baby and I was convinced. I wish to God they'd said yes, somebody's available to talk to you now, and doctor can confirm it in the morning.'

Another mother spoke of the constant activity around her and her baby, with no confirmation that anything was actually wrong:

> 'Some of them were a bit odd, some of the nurses. I knew there was something wrong because they shunted me into a side ward. I went to the loo and when I came back my bed had gone into a side ward...I went in and there was a fuss...There's always this flurry all the time and nobody said anything.'

Many parents have been critical of the pessimistic and negative approach of paediatricians and other professionals. Beresford *et al.* (1996, p.28) note that:

> 'Such views may be compounded by professionals' own discomfort in having to convey 'bad news', and result in an over negative attitude, which fails to value the child, being conveyed to parents.'

Parents who participated in this research were clearly of the view that the attitudes of professionals were crucially important:

> 'You need a positive attitude from the start and they [the professionals] need to handle the child like it's a normal baby. I hope things have changed.'

According to one parent the sense of resignation on the part of medical staff was obvious:

> 'The attitude seems to be the damage is done, there's nothing you can do about it.'

One father was incensed by the attitude of his wife's consultant who, following the birth of their child commented coldly that the mother was young enough to try again:

> 'It's a bloody good job I wasn't there or he'd have gone out on a stretcher.'

Parents expressed concern at the manner in which the diagnosis was given. Several women had been given the news whilst alone and then had to tell their husbands themselves:

> 'The following morning my husband phoned the hospital to ask if I was alright and they asked him to come in to the hospital. He thought the baby had died because he knew he was small. And I had to tell him – that I found difficult.'

> 'They didn't tell me until 3 or 4 hours later [after the birth], and then they waited until my husband had gone. It was 5.30 in the morning. I was devastated. Of course my husband had gone home and they rang him up and told him over the phone. Twenty minutes it took him and it should have taken him at least 35 minutes to get back to the hospital. He went through every red light. That is the only hour I can remember and I probably always will. That was the worst time of my life because I was on my own you see.'

> 'It was up to me to tell my husband the next morning. We didn't know where to go from there or what was available.'

Ayer and Alaszewski (1986) note that whereas most professionals accept that parents should be told the truth about their handicapped child, many withhold information until they feel it is appropriate. Two families spoke of the shock of having initially been suspicious that something might be wrong, at being reassured that all was well, and subsequently finding that their fears were well-founded:

> '...We couldn't believe it because we did at one stage think there might be something wrong with her. But when we asked they said no there's nothing wrong. We believed them so it was a shock really for both of us. We couldn't believe it.'

> 'They took him away when he was born but because he was the first I thought they were just taking him to be checked. But then when I saw the doctor asked for Dr A, I thought there must be something if he's getting a second opinion. But they didn't tell me until about 2 days after. It came as a bit of a shock to the rest of the family.'

Two mothers spoke with great feeling about their experience in hospital following their child's birth and their concern to return home as soon as possible. For one, the view from the maternity ward on the hospital site proved distressing, serving to compound the difficulties she already faced:

> 'I still think in (that hospital) they put you in a side ward and where you look out is (a special unit). God, those children, they were the worst at that time. You'd see them going to school, you'd see them coming home, you'd see them going out in wheelchairs. If I felt like rejecting it, there was reason for me, because that's all I could see. That's what you were looking at. The worst kind. If you were frightened of the situation in future years, you could see that baby in the cradle being one of them. As far as I was concerned, mentally handicapped, I didn't know much about it. I've learnt since, like everybody else. My reaction was to get out of that place as fast as I could, I couldn't stick it there.'

Another woman found the more routine problems of the newly-born and their mothers in the surrounding ward difficult to cope with:

> 'I came home as soon as possible. I got fed up listening to mothers on the fourth and fifth with minor little things like dirty nappies and couldn't breast feed, moaning, when they could've had something like I had. I just wanted to get out.'

Discovering your child is handicapped:

> '...can best be seen as a negotiation between parents who have a 'problem child' and official agencies, who are recognised as having special knowledge about this type of problem. The negotiation is complete and the handicap is 'discovered' when the parents and agency agree on a 'label' for the child and some, at least of the implications of this label for the child.'
>
> (Ayer and Alaszewski 1986, p.99)

For several of the parents who participated in this research, diagnosis was not confirmed until later in their child's life. Although parents realised there was a problem, their concerns were not acknowledged by professionals. Glendinning (1983, p.24) reports similar difficulties encountered by parents in her study:

> 'On the one hand their own judgement, based on their familiarity with the child, told them that the child's health or development was a cause for serious concern. On the other hand, medical expertise, with all the weight of professional authority behind it, denied the validity of that concern and anxiety.'

Understandably, the parents who took part in this research had been anxious that their child's condition be recognised in order that they could achieve some 'peace of mind': for these parents, public recognition, together with a label confirmed that their child's problems were not all figments of their imagination:

> 'The most frustrating thing, it sounds terrible wanting to put a label on it; but you don't know what's wrong and you need to be told there's something wrong by somebody who knows.'

When the long awaited diagnosis eventually came for this family, the shock was none the less severe. They found it difficult to accept, particularly as their child's physical appearance seemed healthy and normal:

> 'It was as though the chair had been kicked from underneath you and the whole world had come crumbling at your ears. They were telling me there was something wrong with my seemingly perfect child. He looked so healthy, he didn't look handicapped at all. I suppose had he looked handicapped, it would've been easier to cope with, but he looked so perfect.'

Dale (1996, p.5) writes that:

> '...parents in their parental role (although not necessarily in their other occupational or socio-economic roles) occupy a lower social status than professionals. Although frequent rhetoric has been made of the immense importance of parenting, minimum practical recognition has been given to the validity and usefulness of their expertise and experiences. The unpaid and unlimited hours of parenting contrast with the professional's role, where there is remuneration for specific hours of employment.'

In terms of this research, parental expertise appeared in several instances to be ignored by professionals. One mother was told '...take this valium, you'll be alright...' by her GP when she expressed her worries about her son. While others felt that their views were dismissed out of hand:

> 'If you're wrong in suspecting there's something wrong with the child, then it reinforces the doctor's idea that you're neurotic.'

> 'You're just a parent; you've got jelly between your ears.'

For another family, the fact that it was their first child meant that there was no previous parental experience to draw upon. This proved significant and caused confusion. Like most parents, this mother was not prepared for the possibility that something could go wrong:

> 'Because he was my first and I didn't dream, I was quite young myself, you don't imagine there's anything wrong with them. He didn't sort of wake up one day and he was a monster, he sort of gradually became one. I didn't know what I was dealing with. It was strange. I was confused, nobody tried to put the jigsaw together for me.'

For another mother, the eventual diagnosis was not accompanied by any real explanation. Once again the whole process was permeated by a sense of shock, although there was also a feeling of relief for this particular family in the knowledge that there was a problem which had been recognised:

> 'When diagnosis came nothing was explained. I knew what (the condition) was, but not the range or the extent of damage it could cause. In a situation like that you only take in part of what's being said anyway, you usually need it repeating a couple of times over a few days for it to sink in, because you're in shock. But I was relieved because I knew there was something wrong and I'd been proved right. And it wasn't me that was going round the twist, there was an actual problem.'

For the mothers in Read's study (2000) there was very clearly a sense that their children, in having a disability, were of less value than other non-disabled children. One parent spoke of this experience as '...hurtful and dehumanising' (p.38). In the research reported here, one child was the focus of '...a clinical demonstration and compared with her non-disabled brother.' For several other mothers, concerns about their children's health were simply not acknowledged by professionals. In one child's case, a condition originally diagnosed as a heart murmur, was in fact discovered to be a serious heart condition some years later when he was admitted to hospital for dental treatment.

One of the families who participated in this research acknowledged that the difficult task of acceptance was a crucial part of the coping process:

> 'It takes a while for you yourself to accept it and to realise you've just got to take it as it comes. I suppose at the start is the worst, accepting it yourself is the worst.'

Ayer and Alaszewski (1986) note two contrasting viewpoints in terms of the impact on a family of having a child with a disability. First, the pathological model, in which the negative effects are emphasised, along with the abnormality of the family. Second, the 'normal' family model in which the focus is upon the similarities between families with mentally handicapped children and other families.

According to some writers, the family of a handicapped child is in some way damaged by virtue of having a handicapped member. Kew (1975) in a study involving the siblings of handicapped children, uses the term 'handicapped families'. Pinkerton (1970) outlines the processes relating to parents' inability to accept the diagnosis of handicap. In the first instance there may be a sense of denial, or rejection of the diagnosis, and this will often result in the search for a second opinion; then there may be a feeling of impotence, followed by over-reaction or smothering the child emotionally. Parents may feel stigmatised at what they perceive to be a genetic failing, while a sense of ambivalence completes the process.

Other writers however, favour the 'normal' family model. Here the normality of families having a child with a learning disability is emphasised. It is however the pathological model which pervades professional theorising about the care of people with mental handicap and the support provided to their families.

Other family members, in particular grandparents, often provide one of the main sources of support for families with children with learning disabilities. However, Seligman and Darling (1989) note that many are unable to adapt to having a grandchild with a disability, and may either deny the reality of the situation, or reject the child. Many of the parents interviewed in this study were fortunate to have the support of their families, which they perceived to be the best source of help during the difficulties encountered whilst caring for their child. One mother was not alone in her comment '... My main help is my parents'. For, many respondents openly questioned their ability to cope without such support and this finding highlighted the extent to which informal networks underpin formal services:

> 'I've got a very good family. They [the professionals] said with children like [yours] you could have someone to take them for a day or two for me to have a break. But I don't need that because I've got my family. They do it.'

Of most significance, however, was that many of those extended family members who provided additional help were themselves getting old and were in poor health. For such families, this called into question the whole issue of their future coping strategies:

> 'My mum, although she's got Parkinson's, she's brilliant. What would I have done without her? I don't know. She's getting older, she's frail, she's a great support.'

> ‘My mother helps out quite a lot. My mother's 84 years old, so the help we got from her is rather limited, but she's always available. She's always there. If I didn't have my mother, I don't know where we'd be, I really don't.’

Ryan and Thomas (1980, p.20) purport that:

> ‘A mentally handicapped person shows up both the strengths and the weaknesses of the nuclear family in our society. The social isolation – the lack of outside support from the state, or of shared responsibility with relatives, neighbours or friends – can make a handicapped child an impossible burden.’

Many of the parents involved in this research expressed concern at the lack of professional support in the early years, following disclosure. They spoke time and again of their feelings of isolation, and of the sense that no-one was listening to them. They reflected on the desperation, and dejection they had experienced. Moreover, several talked of the futility of a situation where, desperate for help, all that was available was an answering machine:

> ‘It’s very difficult to explain. Oh God! But nobody did anything. I felt as if I was on the verge of a nervous breakdown because nobody was listening. What did I have to do to get their help? It was a nightmare. I’ve forgotten a lot of the things because I wouldn’t wish them on anybody.’

> ‘You can have as many social workers, nurses etc, as you want, but there's nobody you can phone up and say if somebody doesn't stop that, I'm going to murder this kid. That's the greatest need, especially for someone whose husband is working away. If you pick up the phone what do you get? An answering machine.’

> ‘It was like banging our heads against the wall and we didn’t know what direction to go next, really. It was a very difficult period. We could have done with some advice but whoever we asked, they didn’t have any answers. This is

> what other families are finding as well. So everybody more or less has got to paddle their own canoe and find out what works for you.'

> 'You did need somebody then, but nobody seemed to appear and you weren't quite sure what to do about it.'

One family was unhappy at the support they received from their inexperienced health visitor:

> 'Our health visitor wasn't very good, she had no experience and there was no portage scheme. In fact she was quite negative really.'

Some parents felt, however, that the situation had improved in recent years and that they now had more support than had been the case in the past. Nevertheless, one family was concerned that even though there are now more people on hand to help, parents were not necessarily fully informed and given all the facts:

> 'Things are better, things are a lot better. When I had [my child] there was nothing.'

> 'I think I've got more support now because there's more people available now, there's new schemes come in. When [my child] was little, when [my child] was born, I didn't know the first thing, I hadn't even been involved with a handicapped child. I just had to learn as I went on and I think it's wrong. Now, you've got Breakthro', the FST, Downs, there's more people there to help you now, but do they explain fully?'

Relationships with 'significant others'

Case (2000) found there to be no significant change in the attitudes of friends and family following the birth of a child with a disability. Nevertheless, it was clear that those parents surveyed socialised less than they previously had done due to a lack of time, and energy on their part, and intolerance on the part of others. Dobson and Middleton (1998) undertook a study of the cost of childhood disability which involved 300 families with disabled children. Participants commented on the 'other costs' of having a child with a disability, outside those defined as financial and which have already been referred to earlier in the dissertation. Indeed, many spoke of being 'a disabled family'; of having a limited family life and no social life. This was in spite of their attempts to compensate and protect their other children from the effects of having a child with a disability in the family.

For the parents who participated in this research, one of the major impacts upon families of having a child with learning disabilities was the way in which social relationships were affected. The varying degrees to which social relationships were constrained seemed to depend on a number of factors: namely, whether or not there was a support network in the form of extended family, or a particularly close local community to call upon; whether the parent was single; or whether the parent/s were incomers to the area.

There is much research evidence detailing the social isolation experienced by parents of children with a disability (Read 1991; Malin 1994; Beresford 1994; Dowling and Dolan 2001). They are not able, perhaps because of the severity of their child's disability to draw on the support offered by other parents in terms, for example, of reciprocal arrangements for babysitting. The evidence suggests that there is a significant financial strain placed on a family in bringing up a child with a disability (Baldwin 1985), and this results in an inability to pay for child care as a form of relief.

Seed (1988, p.39) notes the often extreme isolation experienced by parents, which:

> '...can be a two-way process. The services may be lax in reaching out to families to relive their feelings of isolation, while families, in turn, can sometimes want to shield themselves, and perhaps other family members, from the implications of having a child with a handicap.'

Due to the intense nature of the caring role women who have children with a disability have less opportunity to engage in paid employment and thus the isolation experienced is further compounded. According to Dowling and Dolan (2001, p.32):

> '...whilst the question of whether to work or not, is often a choice for the primary carer of a child without disabilities...for the primary carer of a child with disabilities, one parent (usually the mother) has little realistic chance of finding a job that will fit in around all of her caring responsibilities.'

Moreover, while the parents of children without disabilities may increase the amount of time spent working as their child grows older and becomes more independent, this is not an option for parents of children with disabilities. Indeed, the latter may find that their caring role intensifies as their child grows and perhaps develops health problems.

Malin (*op.cit.,* p.14) writes of the experience of exclusion and its consequences:

> 'In many ways, their [carer's] role excludes them from public life and is also physically and mentally exhausting.'

One parent who participated in this research pointed to the isolation which had become an integral part of the process of caring for her child. All that those around her in the village could see was the work involved and the difficulties associated with the child. As a result, they chose to keep their distance:

> 'It's very isolating. All they see is .....the problems.... They're very wary of [the child]. Friends tend to shy away because it's very hard work.'

For some parents it was their child's behaviour which served to increase their isolation:

> 'I couldn't take him to playgroup. I couldn't take him anywhere. My friends, if they'd come in, he'd jump all over them, kick them, pull their hair, rip up anything if they were reading it. It was a real embarrassment and nobody wanted to stay long. I wouldn't want to if I had a child I wasn't sure of. I couldn't go anywhere. I was like a prisoner. He was very active and noisy so I couldn't even go out in my own back garden. I was shut in this little house. I just wonder how I kept as sane as I did.'

> 'I wouldn't take [my child] anywhere because they were so hyper-active. [They] were into everything and people don't like it.'

Other families said that there was no time for relaxation with a child with learning disabilities. Their social lives were constrained because they did not feel able to visit friends and as a result they went out very little. The extent to which families adapted to this clearly varied:

> 'You just can't go out and relax when you've got a handicapped child.'

> 'I feel we've got loads of friends, but we don't feel able to visit them.'

> 'We're not great socialites, but perhaps if it wasn't for [the child] we would be. You adjust to your circumstances. In the three-and-a-half years we've been here, we've had one evening out ourselves.'

> 'We haven't been anywhere for a year.'

Read (2000, p.58) notes that:

> 'Dealing with other people's negative, thoughtless or ill-informed reactions to their disabled children can be a distressing feature of the lives of many mothers.'

Indeed, it would appear that for those who participated in this research, other people's attitudes have played a significant role in the maintenance of social relationships. Parents recalled how friendships were lost as people found it difficult to understand the family's situation and overcome their fears. One mother had neither heard from nor seen some of those friends she had worked with since her child's birth, something she felt which '... does cause hurt at the beginning...' The same respondent also felt that her in-laws '...kept away more than they would have normally...' Moreover, she admitted that going out after her child was born '...was the most difficult thing I ever did.'

Other parents also found that friendships were affected:

> 'I suppose a lot of people were afraid. It was something they'd never seen before. I suppose if it had been someone else's child I would've been the same.'

> 'I lost some of them [friends] but then I thought if they're true friends they'll stick with me.'

> 'We have very few friends, those we have got remained friends, they've been involved with these children ever since we've had them. But it does mean that you do end up with just a handful of people who really do understand.'

> 'Perhaps at the beginning people don't know how to handle it, do they? We haven't got time for people like that. We can't just hide [the child], they're part of us.'

It appears from this research that family life itself could also be adversely affected by the impact of caring for a child with learning disabilities. Marital relationships were disrupted by the amount of time and energy which had to be devoted to the child with a disability. The OPCS survey (1989) suggests that in families where there is a child with disability, there is an increased possibility of a breakdown in relationships. Indeed, for one parent in this study it was the sheer strain of not having the freedom to function as a 'normal' family which contributed to the breakdown of her marriage:

> 'The child's condition was one of the contributory factors to my husband walking out, one of many things. We didn't have the freedom to do what we wanted. [The child] very much had to be thought about and everything had to be altered to fit in with her/him. It puts a lot of mental strain on you.'

For another mother, family life had been disrupted by numerous arguments over the management of her child whom she described as a 'burden'. She pointed out that not knowing whether the child's behaviour was normal or abnormal in the early years had added to the strain:

> '[The child] could've broken up the home many a time because we had so many rows about how to handle them. All the time the rows were over the child, three or four times a day, big rows... And there was no break from it. [The child] has been a real - I know burden sounds unfair - but it has been. Because I obviously didn't know what hit me. I wasn't sure whether (s/he) was normal or abnormal.'

Siblings' experiences

Glendinning (1983, p.90) notes that:

> 'Living with a severely disabled sibling can have a wide variety of consequences for other children in the family.'

Indeed, much of the research literature alerts us to the fact that the siblings of children with learning disabilities often experience problems themselves in managing their own situation within the family group (Kew 1975; Seligman and Darling 1989; Bicknell 1991). The sibling considered to be most vulnerable is the one next to the child with a disability in birth order, be that younger or older. Of course, siblings need to bond with their parents, need to be cared for and achieve independence. If, as a result of the pressure experienced by their family in caring for a child with a disability, such needs are not met, and the sibling is given insufficient time to grow and develop, maladjustment may result.

Siblings may feel that their education is hampered by their home environment; that their parents pay them too little attention; indeed, that all parental energy is expended on the brother or sister with a disability. Siblings may be too embarrassed bring schoolfriends home. They may also be concerned as to what might happen with regard to the future care of their sibling, and might be anxious that a hereditary condition will impact upon their ability to have a healthy child themselves in later years (Bicknell 1991). Moreover, according to Seligman and Darling (1989), siblings may be responsible for much of the care provided for their brother or sister, and may feel under pressure to overachieve in order to compensate parents who have been disappointed by their child with a disability.

The parents interviewed as part of this study were well aware of the difficulties experienced by siblings, and talked of the way in which over-concentration on the child with disabilities could result in other children in the family being ignored. For although some children appeared to cope in spite of all the trauma, others were drastically affected by the stresses this could create:

> 'My other child's really weathered it well, because (s/he) had to take a back seat. [The child with a disability] took up so much of my time and everybody's attention that (s/he) really didn't get much attention, but (s/he)'s come out of it alright.'

> ‘My other child can’t stand the child with disabilities. (S/he) would be happy if they [the child with a disability] were never to come back into their life.’

Differences between biological and adoptive parenting

Four of the parents interviewed as part of this research study had adopted their children, and it was interesting to note how their perceptions differed to those of biological parents. Adoptive parents were very aware that their situation involved an element of ‘choice’ and preferred to be as self-sufficient and as independent of services as possible:

> ‘We’ve got these children by choice. We knew what the problems were going to be and so we’ve only got ourselves to blame if we moan about it, but parents who have a child born to them with a disability, they don’t have a choice and they’re the people who really need all these services because they didn’t ask for it to happen to them and somehow they’ve got to cope with it and they need an awful lot more support.’

Indeed, this adoptive parent was adamant:

> ‘We don’t need people to look after the children.’

Adoptive parents felt that some biological parents might harbour feelings of guilt over their children, and thus might not be able to have such a positive outlook. There are interesting parallels here, and in the quotes below, with professional theorising and interpretation of the behaviour patterns of parents with children with learning disabilities:

> 'Parents who actually give birth to these children are very susceptible because of guilt feelings. They're very worried about what people are going to think about how they're handling it all.'

> 'We as a family, because we adopted our children, we've tried to look fairly positive. I'm not saying we don't admit that [the child's] a handicapped child, but we try not to treat [the child] in lots of ways as that, and we've tried to be positive with them. A lot of parents can't do that.'

> 'A handicapped child in the family means the whole family's handicapped, it can cause tremendous problems for other children in the family.'

Another adoptive mother felt that 'natural' mothers could be 'very touchy' over the terminology used in relation to their child and found it difficult to admit that '...their children are very handicapped.'

One adoptive mother spoke of her 'job' and the need for biological parents to be given information, even though she felt that she herself did not need it:

> 'I hope parents are given more information early on now because going on, not knowing what the problem or the prognosis is, that must be quite disturbing for parents. In a sense it didn't matter too much to us what had happened, our job is to care for them. I can imagine for parents who suddenly have a handicapped baby born to them it would be very important for them to have as much information as possible right from the beginning.'

Biological parents were also aware of apparent differences between themselves and adoptive parents. As one 'natural' father commented:

> 'If you adopt a child you know what you're getting up to a point, I think there is a world of difference. They start off with such a different perspective don't they? I can't really quite understand why people want to adopt children with special needs.'

Other parents as sources of support

Several commentators (Case 2000; Garth and Aroni 2003) have noted that parents were most likely to receive useful advice and help from other parents with children with disabilities as opposed to professionals such as health visitors, social workers and doctors. Indeed, where professional advice had been forthcoming it was viewed as inadequate. In the study reported here, time and time again other parents were described as providing help, support and information. Indeed, other parents were seen to possess expertise and skills which professionals had learnt only during a period of training. It was clear that the knowledge and information gained by many parents over the years was a highly valued resource which was frequently drawn upon by their peers.

Parents clearly saw themselves as a resource for others, to be called upon to provide advice and information which would counteract the lack of professional support, and this is very much reflected in the comments below. One family recognised the potential benefits of parental support and felt that parents should be encouraged to come together as a body more often:

> 'We've had no help really, in telling us what we're entitled to, what help we're able to have. Possibly it's that people themselves don't know. It's from other

> parents that we've found out what we're entitled to have and we've assisted other parents similarly. There's a great lack in professionals advising parents. It's enough of a hardship having a handicapped child, without having to fight continually, when there is a system to be had.'

While others noted:

> 'All the best support and the best advice and information you get is from other parents. X is right in that respect to encourage us to meet more.'

> 'I found the best one was somebody that had gone through it themselves.'

> 'Those are my best friends. Parents know what you're going through, much better than anybody else.'

> 'They've [parents] got the experience. Professionals know it because they've learnt it, it's all out of a book.'

> 'If we suddenly needed support we'd probably end up going to another parent.'

> 'We have to find out and usually through other parents.'

Contact with professionals

Case (2000) found that service provision - mainly in the form of multi-disciplinary teams - lacked a co-ordinated approach. There was evidence of professional conflict; a failure to share information; and a lack of acknowledgement of parental perspectives. Moreover, Beresford (1995) argues that in many cases parents point to their contact with service providers as being the most stressful factor in caring for their child with a disability. Problems encountered include a lack of empathy; having to fight for services, and experiencing delays in service provision. One third felt poorly informed about the availability of services; and one in five reported that they did not always understand what was being said to them. Moreover, 25% of those surveyed had experienced either a reduction or withdrawal of services at some point.

Many of the families who participated in this research study were concerned about the level and nature of the support provided by professionals. The issue of a lack of trust seemed to underpin much of families' contact with professionals. One parent preferred to discuss difficulties with friends rather than with professionals, in the knowledge that problems discussed with the former would remain within that circle, and there would be no general discussion amongst a large group of professionals:

> 'When I was going through a bad time, I had two friends who were a great support to me, because I could only discuss it with them and you knew it wasn't going any further.'

Parents were clearly unhappy that they were discussed at various meetings without their knowledge and in their absence:

> 'They're [professionals] not supposed to hide anything. At the end of the day, it's us as parents who look after the child. If we don't know the truth, it's difficult to cope.'

One parent felt that meetings with professionals were never productive; this family had become so disillusioned that it had distanced itself both from professionals and the services they provided:

> 'When it's all behind closed doors, it does make you very paranoid. They have these meetings about you but they never do anything for you, they discuss you behind your back. That's what made us cut ourselves off more and more from it. It would be nice if all those people in meetings got out, didn't spend so much time talking and spent a lot more time doing. They get paid a lot of money for being there. Parents are treated with tremendous disrespect [in meetings about their children]. If it's all above board why aren't you in there for the whole of the meeting. It's not an interview for a job is it? If you ask for help you feel degraded by the response you get. It's almost as if, if you've got a mentally handicapped child, you're mentally handicapped too.'

Another parent commented that there are often people present at meetings who are strangers to the family concerned. This parent had therefore adopted the successful strategy of making a point of knowing all those present:

> 'I remember going to a meeting once, three-quarters of the people there I had never met so how could they discuss my child when they hadn't met me? Since then I've made a point that I know every face and they know me and it's worked.'

A further set of concerns related to other aspects of parents' relationships with professionals, particularly social workers. Some parents found their social worker unsympathetic and responsive only in times of crisis:

> 'The only time we've seen the social workers is when there's been something drastic. They've come in ready to accuse us. I don't think a lot of them.'

> 'Until you reach a crisis point. Social Services don't want to know. They don't want to know about the child abusing the parents.'

> 'I've called the Social Services everything because I felt they'd done me an injustice. I'd told them problems and whatever. But I feel that there just wasn't any support for me and it was an uphill struggle and I had to work it out on my own.'

When Social Services did eventually get involved with this family, the parents were unhappy at the extent to which the social worker imposed upon and disrupted family life:

> 'It took a long time to break free of them and get them off my back. They were actually as much of a nuisance as [the child] in the end. They were there all the time, there was never five minutes, they were into this, into that, turning up on the doorstep, and it was actually being a nuisance in the end. It was from one extreme to the other, all they'd do is sit and talk. When I wanted to talk, nobody wanted to listen.'

For one family, a pattern of regular visits by professionals served only to place them outside the societal norm. This family wanted above all to be 'normal' and found it distressing to be subjected to what appeared excessive visiting, while other families in the community were not. Other families too, did not seem to want to be constantly visited by professionals. They wanted to retain an element of control in their relationships with professionals, with someone on hand whom they could contact if and when they needed help or support:

> 'I was finding that the health visitor was coming to see me often. And I used to look in the window and she never used to go and see the neighbour across the road. And then I used to think, why is she coming to me, we're the same, why is she coming to me? Is she making sure I'm looking after [my child] alright? That used to upset me. If she'd only gone across the road. Little things are so important, they make you feel that you're different.'

> 'I don't think you need to have someone on the phone every tiff and turn or visiting, but just to know you've got someone like that there, to help out. I think it's very important.'

> 'To have, if possible, somebody that's more sort of a friend, a shoulder rather than just coming checking, somebody that you know that is on hand, not twenty four hours a day but somebody that you can ring and you know that they will do something for you, a bit of action.'

Many of the issues relating to the availability of support seemed to be linked to what could be seen as a perception gap between parents and professionals. Little seems to have changed in this regard in the years since this research was undertaken, for according to Case (2000, p.287):

> '...the parent-professional relationship remains one of disparity, with the professional persisting in the expert role.'

While Hornby (1994, p.77) makes a similar point:

> 'Whenever I have discussed parent-professional relationships with groups of parents who have children with disabilities one area has unfailingly emerged as the focus of greatest dissatisfaction. This is the poor quality and limited

> amount of listening which professionals engage in when interacting with parents. From the parents' perspective professionals do too much talking and too little listening.'

It is clear that several parents in this study felt that they were not listened to; that their wishes were not taken into account; and that any attempt at communication with professionals about services for their child was ignored. There are parallels here with more recent research undertaken by Swain and Walker (2003), with regard to a newly established conductive education centre in the North of England. The researchers focused on parents' experiences of existing services noting that:

> 'With very few exceptions, parents felt that services for their children were inadequate and that their concerns about existing services were not listened to...many felt that it was a constant battle to obtain adequate services or resources for their child...A recurring theme for parents was the fight to get the best for their child, especially from physiotherapists, doctors and health visitors.' (p.553)

Swain and Walker's study highlighted poor communication with professionals as an issue for parents:

> 'Communication was a major issue for parents and they clearly stressed the failure of professionals involved with their child to communicate with each other and with parents...' (p.553)

In addition parents in that study cited a '...lack of information, lack of support and conflicting information...' (p.553). Such difficulties were in part caused by the large number of professionals involved with a family.

In the research reported here, one parent became resigned to the futility of their situation and saw no further point in conveying information to professionals as it was not acted upon. Several other parents expressed concern about their children being provided for in a manner which they deemed inappropriate:

> 'I used to tell them what I thought was wrong with him, but they never used to listen to what I said. They used to make up their own diagnosis. So what was the point in the end of me telling them anything? I used to tell them what I'd like for him and they'd say yes, and go and do their own thing, totally different to what I used to say. It was just like they weren't listening to me.'

> 'We have been to all of the meetings in school and given our views but whatever we've suggested, they haven't always brought them up.'

> 'We talked about occupational therapy [with the professional], five or six weeks passed and we hadn't heard anything. So I rang her [the Occupational Therapist] myself, I managed to get hold of her and her colleague hadn't contacted her. As I understand it, we had discussed it and we had suggested that she do.'

> 'Somebody said we'll look after [my child], and to me that isn't what I want. I can look after them, I don't want them looked after, I want them educated. I want whatever can be brought out of them to be achieved, whatever it is. You just want whatever potential they've got to come out over the next ten, fifteen years.'

One of the key roles undertaken by mothers of children with disabilities is that of liaison and negotiation with professionals. Many of the families interviewed were concerned that, in their experience, information was rarely passed on from professionals. The overall impression was of professionals as 'gate-keepers' to both services and information. Several families were angry that they were not given very basic information about their entitlement to nappies, for example:

> 'I'd been paying for nappies when I should have been having them through the Health Authority. Nobody lets us know. I was quite annoyed.'

> 'No-one ever told me what was available.'

Another parent was concerned that a report on the results of various tests carried out on their child was not passed on:

> 'My child had been seen by the child psychologist, speech therapist, he'd had blood tests done, lots of different things and I never, ever got a report. I went back to the doctor, because they'd been involved in this as well. Oh yes, he said, I have had the report. The social worker said the same. The doctor had her report, where the hell was my report? All the people that were concerned had reports, but the very person who had to live with him twenty four hours a day had nothing.'

One of the key problems for parents seemed to be a lack of direction and the denial of access to options which might be available to them:

> 'There's nothing, people don't know what to do or where to go and the authorities are very loathe to tell you.'

> 'It's all office hours stuff, all meetings with nothing much actually happening. Nothing gets filtered down, not as far as I'm concerned anyway.'

> 'What I don't like about the system is, I'm his parent and I think I've got a right to know everything that is wrong with him. Because if they don't tell me everything how can I cope with it?'

One family felt there was a real need for specific information to be passed on to parents who may be too preoccupied with caring for their child to have the time to find out what they are entitled to or which direction to take next:

> 'You need people in the background to tell you what you're allowed, or you need some information to tell you what to do at each stage. Because you're so busy coping at home, you just can't take it all on board, or you haven't got time to.'

There appeared to be little or no continuity for families in terms of service provision. Many spoke of the high turn-over of staff involved with them, and also of the erratic nature of services provided:

> 'Until I met X I didn't see many people before that, see them once and then it went months and months and you wouldn't see anyone. I did have a social worker, I saw her about twice and then I think she left. It seemed to be everybody all at once when it first happened and then you didn't hear from anybody for ages, then. It was quite a lot to take in all at once, but then you didn't hear much at all.'

> 'I felt as if everybody was walking out on me. I knew they weren't doing that, but everybody was going onto pastures new.'

> 'We had to fight to get help and we got it and we just got somebody there who was experienced and things changed... She left her job and we were left back to square one again.'

Dowling and Dolan (2001, p.26) in their research into the unequal opportunities and outcomes faced by families with children with disability highlight the fact that many of their interviewees:

> '...reported that the process of obtaining social services (or funding for social services) was often long, slow, time consuming, complicated and the source of intense anxiety and frustration.'

While Seed (1988) points out that:

> '...research generally has shown that in all too many cases, parents only come to receive the social work, education and health services they need after a struggle that they have had to initiate in the face of fragmented, uncoordinated service responses.'

Commentators have noted that where parents exhibit '...certain types of behaviour...' this is '... more likely to yield positive results...' in terms of service provision (Swain and Walker 2003, p.554). Garth and Aroni (2003) point out that as a result of the frustration experienced in their interaction with professionals, mothers in their study '...perceived themselves as having developed a sense of assertiveness that they did not possess...' (p.570) prior to the birth of their child with a disability. For one mother this new-found assertiveness had a positive outcome; it resulted in a more straightforward response from the medical staff caring for her child, and the prompt undertaking of tests.

Time and time again, those who participated in this research pointed to the fact that those who shouted loudest received the most in terms of services. The need to be vocal and to 'fight' for services was referred to in the majority of interviews, where the 'battle' analogy was frequently repeated. Parents felt the need to adopt a more aggressive stance than they would normally in order to gain access to the services they felt their child needed, as illustrated in the following comments:

> 'If you don't shout, you don't get anything at all.'

> 'It's awful, you've got to fight for everything.'

> 'We have to fight all the time to get what we want. We've got to make a fuss to get noticed.'

> 'I was never this cheeky years back. I've learnt the hard way. I think you've got to look after number one, and if you don't push nobody else will, and if you don't fight for what you want, nobody else will fight for you.'

> 'Now I know there's nothing I won't do. Now I'm like a bull in a china shop. I want to know and I don't care who I have to mow down to find out because I got nowhere being meek and mild. So I've got really hard and aggressive over the years, and now I don't like being messed about. But now, when they tell me you can't do that I say I don't have to do anything and I don't have to listen to what you're telling me. I do what I want. There is nothing that goes past me that I don't know about. If I don't know about it, I want some answers.'

> 'I just hope to God this never happens to anyone else because quite honestly if we hadn't been so stubborn and determined and willing to tackle it as we have, then I just don't know what would've happened to our child.'

> 'If I was the type to sit back and get on with life, I don't know where my child would be. I believe in giving them the same chance as everybody else. I'm determined. I believe in equal rights for these children. We're in the 1990s aren't we? I think they've got a right. They didn't ask to be born the way they are.'

One professional had admitted to this parent that:

> 'It's those that make the most noise that get seen to first. He admitted it himself and it's too bad. You don't like nagging and nagging and nagging but if you don't nothing ever seems to happen.'

For this parent, however, there was little relief from problem-solving:

> 'This is our battle at the moment. You get one problem sorted out and something else rears up and this is the thing at the moment.'

It was clear that the more forceful and articulate parent received a more positive response:

> 'We've been involved very much with the decision-making. But again I think that possibly it's because of the sort of people we are. Maybe it wouldn't have been so good if we weren't quite so able to put things across very well. It's an area for concern I think.'

> 'You make a point of knowing what's happening. If you sit on the fence or just look and then criticise I don't think that's fair. You have to be in there knowing who's going to make the decision and what people are involved.'

> 'We make decisions and defy people that contradict us.'

Indeed, for one parent it has become easier to challenge the professionals:

> 'Things have improved, I think. I don't think always you've got to listen to what other people say. In the end, we know her better then anybody, especially the mother more than anybody. And if I felt that what they said was wrong, I'd say, I'd disagree.'

As already noted, parents' need to fight for services is well documented in the research literature and raises a number of issues: it not only undermines the notion of people's rights to receive services; it also raises the possibility of even greater inequity for those families who are not able, for whatever reason, to fight for services for their child. It appears from this research, that parents' ability to make their feelings known to professionals was a significant factor in their obtaining services. This provides a clear indication of the unequal position which parents find themselves in when working with professionals; it is also an illustration of the power dynamic which so characterises their relationship.

Educational issues

In terms of education, Ryan and Thomas (1980, p.21) note that:

> 'For most of their history mentally handicapped people have either not been educated at all, or else have been educated in special schools and classes, or in hospital.'

The authors go on to argue that:

> 'Central to the act of exclusion from ordinary school is the IQ test...This cultural underpinning implies that the common definition of the mentally handicapped, as those with an IQ of less than 70, largely reflects how well they fit into the prevailing educational system.' (p.21)

There has been much debate, both on a political and popular level, around the policy of integrating children with disabilities into the mainstream education system. It is anticipated that integration results in improved interaction with children who do not have disabilities; thus, the subsequent familiarity results in a lessening of the stigma associated with disability (Cullen 1991). Under the Education Act (1981) children with special educational needs are entitled to a statement of their needs. This, in itself, is intended to result in appropriate educational provision.

In addition to experiencing problems with health and social work professionals, however, many families in this study had encountered problems with both schools and the Local Education Authority (LEA). The main areas of concern were levels of communication; the statementing procedure, referred to above; the lack of choice; and the process of integration, to which some parents felt only 'lip service' was paid.

Some parents appeared to have few communication problems with their child's school:

> 'Any problem and I can ring them or call in.'

> ‘We all know within the special schools you can pop in and see anybody at any time. I don’t think many of us do that because you feel that unless it’s really important you’re disrupting the class anyway. Generally within the special schools I think communication has been usually quite good.’

> ‘They send a book back with [the child]. I write and they write in it. They’re excellent.’

Others, however, were less happy about various aspects of their child's educational provision, communication with both school and the LEA appearing to pose a real problem:

> ‘There is very little information coming back from the school after [my child’s] been there...By talking to other people you find out. But talking to education hasn’t achieved anything for me.’

> ‘There was no feedback coming from school, but that’s one of those things.’

> ‘[We've] got fed up with writing messages now, because it’s all one way, messages never come back.’

Some parents had either kept their child at home as a form of protest, or had threatened to do so:

> ‘So I kept my child home from school and did threaten them. I was going to draw the media’s attention to it, or TV AM.’

> 'In the end I wrote to the Director of Education and said we'd keep [the child] home until a decision could be made about the future, because there was no way we could carry on in that situation.'

> 'I have to tell you, the education system I find appalling here.'

> 'They do seem to be a law unto themselves the Education Authority, and you either like it or lump it. That seems to be their attitude and I think that's got to change. A friend of mine said you are going to hit your head against a brick wall with education, you have to keep knocking. You don't realise how bad they are, until you start asking.'

One family hoped that the situation would improve with the arrival of the FST, which they saw as a form of security for parents, a sort of 'watchdog':

> 'All the parents that I know, education causes them all a tremendous amount of problems. I believe on the FST there's someone representing education and I just hope that with this person's involvement that education has someone to keep an eye on them a bit.'

The statementing process proved to be a bone of contention for many parents. They were unhappy about the length of time taken to prepare the statement of educational need, its content and its validity, given that they were not party to any consultative process:

> 'These statements, they're not worth the paper they're written on. It was a year last November that we rejected the draft statement, we've never had meetings with anybody since about doing another one. It was a total load of rubbish.'

> 'We've had the statement back yesterday which is bloody pathetic to say the least. We've had a statement done twice and we're going to have to have it done again because it's all wrong.'

Other parents were concerned that so few children had been statemented:

> 'The Education Authority has never seen us at all. They're still working on the old statement from his last authority. He's never been statemented in this.'

> 'I don't think many children have been statemented. They're all supposed to be.'

This family was also concerned that they had difficulty in gaining access to the information about their child which would form the basis of the statement:

> 'Education and the teacher at school are supposed to submit a report and anyone else who you think has been involved with your child, you're supposed to see them all. That was a bit of a carry-on. We did in the end or we think we did. We think we saw them without being edited, I'm not really sure. We were told you can't see those, they're private.'

Several parents expressed concern about the lack of choice of school setting for the child with learning disabilities compared with the options available to a 'normal' child. One parent was concerned that there was no advice given as to possible options, and another pointed to a lack of resources, making choice in any real sense of the word an impossibility:

> 'With a handicapped child... you don't have a choice.'

> 'I decided my child would go to the Unit, not that I particularly wanted him to, it was just a case of having to.'

> 'If we'd let things follow their natural course, [the child] would certainly be in Special School. They automatically send them there unless you say otherwise. There's no pre- school advice as to what your options are.'

> 'It was always basically down to lack of money, because [the child] would have needed a care assistant constantly and they would have needed special equipment at the school.'

Integration was yet another issue for parents. One family was concerned that in placing children in special units, a new cycle of segregation was beginning which would prove difficult to break:

> 'By any of these children not being in the village school, we've started off right at the beginning doing what the Strategy [AWS] says we're not supposed to be doing. We've started off segregating them straight away. We're spending millions of pounds transporting these bloody kids all over the countryside and closing the village schools, it doesn't make a lot of sense. Once we 'bus' them away to special schools, we segregate them from the society they're supposed to be part of.'

Another family believed that their children had progressed due to the very fact that they were totally involved with 'normal' people and were not segregated in any way:

> 'We're totally into integration. That's how our handicapped children come on so well because they live with normal people doing normal things.'

This family talked about the negative way in which their request for mainstream education for their child was received. They felt that attitudes should become more positive as far as integration is concerned and that there should be more input from the Education Authority to bring this about. They were concerned that the support given within a mainstream setting was purely tokenistic, and were unhappy at the level of support their child currently received, feeling that it was inadequate to help them adapt to their situation:

> 'We decided we wanted [the child] to go to mainstream school and we got a lot of negative attitude... The attitude is, it's your choice that the child's there and they've got to adapt to the school, which is true to a point, but ... I think there should be a more positive attitude towards integrating children and there's not enough input to achieve that. It's rather sort of grudgingly, OK if you really want your child to go mainstream then O.K. we'll provide .... It's a two-way thing .... going to the local primary school, not only for the disabled child's benefit but for the benefit of your children, that they know there are children in this world that are a little bit different from them.'

The issue of the parental segregation which occurs when children attend a special school was also raised. For children with learning disabilities, the journey to and from school is carried out independently of their parents. Moreover, the beginning and end of their school day is not marked by a social gathering of parents or grandparents. As a result, parents can feel isolated from other parents at the school, as they are not engaged in routinely meeting at the school gate as is the case with parents of children in mainstream schools. One family in particular was concerned more about lack of communication between parents than lack of communication with staff:

> 'Unlike primary schools where you take your child to the door and collect them, if you're new in the area within the special unit you never see the parents. You could walk past them in the street and not know them. That's where it's lacking, in that you don't meet the parents quite as much as you'd like to. I think perhaps that's what's lacking in schools is communication between parents, not necessarily between staff and parents.'

The Welsh Assembly Government's Education and Lifelong Learning Committee's policy review of Special Educational Needs (2004) highlights the fact that '...many children's special needs are never properly identified, leaving a blight on their lives…' (Western Mail 25.11.04). The Committee reported that in some cases, children are not receiving appropriate support because their needs are identified too late. For others, an acute shortage of speech therapists, particularly those who speak Welsh, proves another barrier in terms of access to services. It is of concern that so little has changed in terms of availability of a core service such as speech therapy since the research reported here was undertaken. For, parents who participated in this research expressed real concern about the speech therapy service, which in their opinion was characterised by a lack of availability and continuity. One parent talked of the possibility of sharing speech therapy skills with others in order to reduce dependence on a trained speech therapist:

> 'Speech therapy is the bug-bear down the line for most parents. I think you no sooner start then somebody'll decide to leave an area. What we really feel is a better way round it, is that speech therapists taught the schools, taught parents, taught anybody and then rather than always doing the job themselves, at least have this great thing of teaching other people. So if there comes a time when there isn't any, as there isn't now, you're not just suddenly cut off and nothing now for another twelve months.'

Many families were clearly anxious not only about their children's development and the possible deterioration in their health, but also about future service provision. One family expressed their fears at seeing an older child with the same condition as their own child:

> 'It frightened us a bit to be honest with you. When we ... saw older children [with the same condition] we thought. Oh God! our child's not a bit like that. There was one child who was spitting at people as they went by. We thought our child's never going to be like that, is s/he?'

A number of parents expressed concern that there was little provision after the age of nineteen years; this they felt was a time when families might need a great deal of help and support. One parent who was cynical about the extent to which families could contribute to the decision-making process, given the lack of services available to meet need, pointed to the extension of education as an answer to the problem. The creation of specific courses would avoid a sense of abandonment at the age of nineteen:

> 'I think that the biggest concern, is what people must feel, having to still cope with their children when they get into their 60s, 70s and beyond. My concern is there's going to be nothing at the moment, unless something gets going. It's alright saying have your input into decisions, but you can't make decisions if there's nothing there to make decisions about. I think some of us would like to see the education field extended for another five years so that they could go to the colleges and have courses specifically designed for their needs whether it be social, academic, numeracy etc, to improve it, not to be cut off at nineteen.'

> 'I know what is needed and the sooner the better really. When they come out of school there's nowhere for these children to go. They've been to school every day of their life and then at nineteen, where are they? They're at home and that's when the parents need help most.'

> 'We could've done with more support in the early years. I hope in the future years, when it comes to deciding for a life placement for [the child] that something suitable is going to be found.'

Respite care

Cocks (2000, p.508) notes that:

> 'One of the ways in which many disabled children experience childhood is through the provision of respite care.'

The author defines respite care as:

> 'Provision for disabled children in a purpose built setting away from their home environment. The concept that families and disabled children need a break from each other.' (p.514)

One of the characteristics of such care is that it separates a child from its parents and community at an early age. This occurs in spite of the dominant view that wherever possible children should remain with their families. Cocks (*ibid.*) points out that this goes unchallenged for two reasons. First, because disabled children are perceived to be a 'burden', and thus their families are in need of a break; second, disabled children face an adult life where separation is the norm. The author further notes that critics of this form of provision '...see it as the beginning of a life of exclusion.' (*ibid.* p.513). For, these children are denied life experiences in the world of the non-disabled; and are also denied experiences that allow them to achieve in any meaningful sense.

Conyon (2004) draws our attention to the 'ambiguous' nature of respite care (p.17) and the multiple forms of classification. 'In-home services' are defined as family based schemes or shared care. While 'out of home services' are characterised by respite provision in hospitals, residential units or community facilities. Children with learning disabilities or challenging behaviour are most likely to receive residential respite care, and thus to be excluded from their families. Like Cocks (*op.cit.*), Conyon refers to the perception of disabled children as a 'burden' from which their family requires relief. Removing children from their family in such a marked way serves to perpetuate the 'personal tragedy' model of disability (*ibid.*), and the isolation experienced by children. Indeed, Middleton (1999, p.51) notes that:

> 'Respite reinforces the status of the disabled child as a 'problem' for a family, rather than an individual with needs of her own.'

For, the identification of a child with a disability as a 'child in need' under the Children Act (1989), implies incompleteness, vulnerability, and dependence; subsequently, the child is viewed as a 'burden' on society (*ibid.*). Yet, conversely, it could be argued that respite is the vehicle by which family life is maintained for the child, as many parents articulate being able to continue caring only because of the support provided by out of home respite (Beresford *et al.* 1996).

In a study involving the families and/or carers of 75 children with Autistic Spectrum Disorders (ASD), Bromley *et al.* (2004) found that almost all respondents highlighted significant areas of unmet need in terms of service provision. Most often cited was the need for support during school holidays and in particular, for respite care.

Clearly, the shortage of respite care facilities was an issue for some of the families in this study, particularly those whose children were perceived to be difficult to place and who could not be accommodated through the usual respite channels. One family wanted a respite facility in the locality to be staffed not by professionals but by a rota of parents:

> '[Professionals] seem to have given up the ghost as far as our child's concerned. It's the parents with the difficult children, the ones who don't sleep at night, who need the respite care. It's not the parents of the easy children with no problems.'

> 'More respite [is needed], for the children who are difficult to place, the problem children; there's got to be a small residential unit. We really feel there should be a small residential unit. When it comes down to the bottom line, everyone is willing to have the more able children, the ones who can do a bit for themselves, the ones who are quite mobile, the very young and attractive ones, but when you get to the older ones with a bit of a problem, challenging behaviour or whatever you want to call it, the parents are still left with nowhere for those kids to go. It's really, really bad. There should be a small residential unit somewhere, in case of emergencies. Then I think everybody would feel a bit more safe and secure.'

Cocks (*op.cit.,* p.514) writes that respite care:

> 'Protects vulnerable children from the 'big bad world' justifying segregation in moralistic terms.'

Yet, Middleton (1999), along with many other commentators notes that children with disabilities are as vulnerable - if not more vulnerable - to abuse as other children when placed away from home, be that in a respite facility or otherwise. For, their isolation is increased when they are at a distance from their family and community, and thus they present as targets for those whose aim is to perpetrate abuse. Indeed, Stuart and Baines (2004) in a review of progress on safeguards for children living away from home since *People Like Us* (1997), report that such safeguards do not sufficiently address the needs of more marginalized groups such as children with disabilities. The authors note that although there is now a recognition of these children's vulnerability, there is inadequate guidance as to how to ensure their protection.

In the preceding section of this Chapter the views of 22 families who had clearly had less than satisfactory experiences of services for children with learning disabilities prior to the inception of the FST have been reported. Many expressed concerns not only for their child's future, but also for their own, and in particular their capacity to continue caring. Given the above, it was hardly surprising to find almost overwhelming support for a new service which could provide them with additional help. It is at this stage of the dissertation that attention shifts to parents' views of the service provided by the FST - albeit that the extent of their contact with the FST had been minimal at the time that the research was undertaken - and consideration of the extent to which the team could potentially provide a solution to the problems so often experienced by these families in terms of service provision.

Current Experience of Services: The Family Support Team

Prior to exploring parental views of the service provided by the FST, some time is taken to consider the background to the establishment of the team. In 1989, against the back-drop of the policy developments outlined in Chapter One, a South West Wales Local Planning Group - a constituent of the District Mental Handicap Steering Group - commissioned a study of the needs of children with learning disabilities in their area. As a result, needs assessment and the co-ordination of services were felt to be best placed within the framework of services for other children with special needs, as opposed to being situated within the inappropriate framework of the CMHT. McGrath (1989) recommended the FST be set up. The team was to provide additional support to families, and also to generic children's services. McGrath's report recommended that the FST role should include:

- the co-ordination of services through individual planning processes

- the establishment of a data-base to facilitate planning, monitoring and evaluation

- the provision of a base for the 'co-ordination and development of domiciliary support and respite services'
- service development
- liaison with other agencies
- training

It was intended that the FST would function on a 'single door principle', providing an access point for families whose needs would be co-ordinated by a key worker. McGrath recommended that the team should comprise a co-ordinator; specialist health visitor; specialist community nurse; specialist social worker; specialist teacher, and a secretary. Links with generic services would be facilitated by the team co-ordinator who would also co-ordinate the local Child Development Team (CDT). The establishment of a small Team Support Group was intended to resolve inter-agency difficulties and provide a link with senior management.

Having accepted McGrath's recommendations, the District Planning Team successfully sought funding from the All Wales Strategy on Mental Handicap to establish the FST. The co-ordinator was appointed in April 1991, and by the end of June that year, all team members were in post and '...available to provide direct support to families and specialist advice to professionals...'

The FST was to:

- facilitate a proactive individual needs-orientated service
- emphasise continuity of service over time and place
- develop individual plans, promote integration and attempt to furnish each child with the skills necessary for an independent future

The team was to provide support for children with significant learning disabilities/developmental delay and their families. It was not the intention that existing generic services be replaced, rather, that an additional support network would be provided, with the aim of co-ordinating services for children with special needs in order to allow them to achieve their full potential. The service was to be available to those who met the above criteria, from the time of referral to the age of between 16 and 19 years, when the CMHT would become involved.

Each team member was to have a specialist role, while also acting as care plan co-ordinator/key worker for a number of families. The four field workers were funded by the AWS, while the co-ordinator and secretary were jointly funded by AWS and Health Authority monies, given their additional responsibilities in relation to the Child Development Team (CDT).

It was anticipated that referrals would be made from a variety of sources, including parents and carers; health care professionals such as GPs and health visitors; and by means of the Child Development service. An initial case-load of 120 children was identified through a process of consultation involving the team co-ordinator and two senior medics. Following the appointment of team members, a series of team-building sessions resulted in the production of a prospectus for parents, and colleagues in other agencies.

In addition to providing services, the team co-ordinator was:

> '...to participate in the planning of child services within the ... area.'

Consequently, the Children's Sub-Group was established, with the intention of facilitating parental involvement. Further, two Task Groups were formed to look specifically at issues relating to pre-school children, and the provision of respite care.

Having outlined the background to the development of the FST, parents' views of the service provided by the team are reported. As mentioned earlier in the dissertation, the views of parents were initially to be sought at the beginning of the research process, and again 9 months later, in an attempt to assess the impact which the introduction of the FST had on family life. However, due to factors which impinged upon the team's development, and which are referred to in detail in Chapter Five, it was not possible to follow through the intended approach. Consequently, the research design was amended to also include families' views of services received prior to their contact with the team; these were highlighted in the preceding section of this Chapter. Next, parental experiences of the service provided by the FST are charted.

Respondents were asked for their views on, and contact with, the newly established FST. They were also asked whether or not their wants and needs were being met by the team. Of those families interviewed, 7 were receiving 'regular' visits from the FST; one received 'irregular' visits; and twelve had been visited anything from one to six times. Both of the remaining families had been contacted but chose not to be visited. In addition to home visits, several families had had informal contact with team members through various support groups.

Only two out of the 22 families interviewed expressed negative feelings about the team, the majority seeing the development of the FST as a progressive move which would fill a gap in service provision as far as their children were concerned:

> 'The FST is a great leap forward ... It's essential. You need someone with a specialist knowledge that you require, not someone who's got general training in everything.'

> 'They're the best thing that's happened as far as I'm concerned and they're based in one place.'

> 'It's [the FST] long overdue and I think it will be very useful and I'm sure it's much needed.'

Time and again, respondents spoke of the team as most usefully providing a point of contact and a means of support, whereas in the past the former had felt isolated from any support network. The FST was perceived by many families to be a source of help and advice which would be available when needed as illustrated by the following comments:

> 'Just having a phone number is something.'

> 'Help and advice. Great help and great advice and just being there to help me if I need it. Just advice and just being there.'

> 'In a way I suppose you'd call it a life-line. You just know they're there.'

> 'It's been nice that I've had somebody I could fall back on. Because I couldn't before.'

> 'I don't know what I'd do without [the team member]. S/he's always there on the end of the phone. Sometimes s/he may be out, but s/he always gets back to me.'

Several families were of the opinion that the FST would be able to provide direction, where that had been previously lacking, in addition to facilitating access to other services:

> 'It's nice to have somebody that knows what I should do next. It's difficult knowing where do I go from here. It's knowing who to get in touch with.'

> 'The problem has always been, you know what you want or you think you know what you need, but where to get it from? And when you phone people up they say, that's not my department and they pass you on and on.'

> 'It can be very hard finding out just what you're entitled to and who's to supply it. If they [the FST] can't get it, at least they can tell me who to go to without me making endless phone calls.'

One mother, who felt that the FST would provide a support service for parents, was anxious that the service was used in order to justify its existence:

> 'Over the years we as parents get our information from parents; we've not got it from professionals very often. Now we've got a service that's provided for the under sixteen year age groups, it needs to be used so that the Welsh Office and everybody else don't think that the service isn't valid, if not for us, because our children are a bit older, certainly for the children that are up and coming. There's support for the parents there.'

Another parent was happy at the thought that the FST would represent continuity of service where it had previously been lacking. This particular family also felt more secure in the knowledge that a team was in post:

> 'For anyone who uses them regularly there'll always be a familiar face. You've got more protection when there are more people. That's the advantage of a team.'

Two parents felt that because the team would look at the whole family and not an isolated part of it, this would prove advantageous. According to one:

> 'They're going to be dealing with all the family problems and they'll treat the family as a family. Doctors don't see the whole child, leave alone the whole family. That's why I like the idea of the team.'

Only two families had misgivings about the development of the team. One was resentful that they had received no support when they needed it most, prior to the development of the FST. They felt that the service had come too late to help them:

> 'The support group I feel has come along a bit too late. But I suppose they've all got to start somewhere. I had nothing, nothing at all.'

The other family was of the opinion that they were now being given less support because other agencies had relinquished responsibility assuming that the FST would step in; this was seen to be particularly the case in relation to education:

> 'Quite honestly, I think we were better off hammering away on our own, than the support we've had from the FST in that particular area, in school. I don't think, even if you have an education advisor on the FST that it's enough, because the work-load is too great. I think you need several people. Ideally there should be an input coming out of the special school where they're supposed to be specialists.'

This family, who had previously had two people helping their child in school before the introduction of the FST, was concerned on two fronts: namely, that support had diminished, and that no information had been passed on to them regarding the withdrawal of certain services. They felt it was imperative that parents were aware of developments concerning their children, and believed that passing on information should be an essential component of FST working practice. Without this, they could see no point in the existence of the service:

> 'Because the FST was set up, they [the two 'helpers'] were just withdrawn and we weren't told, it was assumed by everyone that the FST person was going to step into their shoes. But we weren't told, so in fact because the FST was set up, we were really receiving less support than we had before it was set up. I think that was partly because everything was new and the FST person didn't know what s/he was supposed to be doing at first. S/he didn't know what her

> role was. S/he's got two bosses and I think s/he finds that confusing. I don't think s/he's positive enough, I don't think s/he's got enough balls really to do the job. Of all things, what really must be done, parents must be informed what's going on. If we don't know what's going on then you might as well forget the bloody service all together.'

Conclusion

In this Chapter of the dissertation, detailed consideration has been given to data collected from individual interviews with parents. The issue of disclosure was considered; relationships with 'significant others' were explored; siblings' experiences were highlighted; the differences between biological and adoptive parenting were examined; consideration was given to the issue of other parents as sources of support; parents' contact with professionals was discussed; and finally attention was drawn to the areas of education, and respite care. Chapter Four concludes with parents' views on the newly established FST, the majority of which were positive.

The data collected made clear the extent to which families felt let down by the services which were supposedly in place to help them and their children with learning disabilities. From birth onwards, many of these parents found their problems exacerbated by the lack of appropriate information and support. Disclosure and diagnosis were frequently handled insensitively. Following diagnosis, many parents became isolated from, and abandoned by, both friends and professionals. Information and services, at the point of their child's birth and also in later years, were frequently in short supply, leaving parents to cope as best they could. Often they were left feeling that professionals paid little or no heed to parental knowledge and experience.

If past experience was less than satisfactory, the future was clouded with anxiety for many. In some cases, the support provided by relatives was under threat from either age or infirmity. For others, there was concern about what would happen when their child left school. Having explored the views of parents in relation to their previous experience of services and also their contact - albeit limited - with the newly-formed FST, the focus now shifts to FST members and their views on the early stages of their development as a team.

CHAPTER FIVE - RESEARCH FINDINGS: THE VIEWS OF FST MEMBERS

Introduction

In this Chapter of the dissertation the views of FST members on issues relating to their development during their first year in existence are explored. The data presented here were elicited by means of informal discussion; semi-structured interviews with individual team members; and observation of the team at both internal meetings, and at those involving other agencies. All served to highlight a range of problems which were of relevance to the team, and their future development, and also to the families for whom they were to provide a support service.

Here, then, the FST brief is considered, and team members' roles are outlined. Management issues, and geographical boundary problems, together with the reality of multi-disciplinary teamworking are explored. Moreover, consideration is also given to accommodation problems; resource and professional boundary issues; and matters relating to working with families.

As already noted, the FST was a new multi-disciplinary team established to support children with learning disabilities and their families. The team was to operate within the Social Services boundaries of 2 counties in Wales, covering a large geographical area with 2 main centres of population. One of those centres lay within A Health Unit but related to B Division of the Social Services Department. The intention was that the FST would provide a service across the existing health service boundary and thus serve both geographical areas. Therein, however, lay the cause of many of the difficulties encountered in providing a service to families; these will be explored in some detail during the remainder of this Chapter.

FST members subscribed to the 3 main principles of the AWS, that children with learning disabilities:

- have a right to ordinary patterns of life within the community
- have a right to be treated as individuals
- have a right to ask for additional help from the communities in which they live and form professional services in order to allow them the opportunity to develop their maximum potential as individuals.

(AWS 1983)

The team aimed to work in partnership with families and other agencies to provide a service that would '...enable each child with special needs to have equal opportunities, choices and rights in their own community...' ('Working in Partnership', FST Prospectus 1991). In enabling each child to achieve their potential, the FST aimed to '...work with and for children and their families...':

- helping them identify their wants and needs
- identifying effective ways of involving and empowering them, and where necessary, advocating on their behalf
- developing strategies to minimise the effects of any problems facing them
- acting as a resource for all services relating to children with special needs

- co-operating with other agencies and groups in offering appropriate services
- providing a bilingual service where appropriate

(*ibid.*)

This way of working reflects the aims of the Children Act (1989), and required team members to:

- work flexibly within agreed guidelines
- identify resources needed as highlighted by service users, providers and purchasers
- work collaboratively with children and their families to evaluate the effectiveness of the service provided
- ensure that they, their colleagues, and service users were aware of current developments with regard to the care of children with learning disabilities

In particular, the FST was to have a co-ordinating role. It was to provide a service from the point of referral to school leaving, i.e. 16 to 19 years of age, and was to function as part of the Child Development Service which was based at a local hospital. There, a multi-agency team met monthly to ensure comprehensive assessment and access to appropriate advice and support for children with special needs. The FST co-ordinator was also to co-ordinate the Child Development Team, together with the Senior Clinical Medical Officer; this, it was hoped would facilitate optimum interaction between teams.

Each child and their family were to have a named FST worker – a care plan co-ordinator – whose role was to:

- act as their main contact point, providing support and establishing a relationship with them
- work in partnership with parents/carers to prepare a Personal Profile on each child
- identify the child and family's wants and needs and create a shared action plan which was to focus on individual need. Parents and professionals were to meet regularly to review need - both present and future - and agree a plan of action
- provide information on available resources to children and their families; team members; and other professionals
- identify the services required and the resources needed to facilitate their provision, for example, in terms of speech therapy; psychology; self-help groups; respite care; the Family Aide scheme; welfare rights; and the Challenging Behaviour Service
- liaise with other relevant agencies, sharing information, and developing and maintaining channels of communication.

(FST Prospectus 1991)

In particular, the team planned to:

- facilitate effective working links with other service providers by means of monthly meetings to which representatives of other agencies would be invited.

These meetings were to focus upon issues of relevance to the development of the FST

- establish local planning fora in conjunction with other voluntary and statutory agencies. Parents/carers would play a full part in these, and information would subsequently be fed back to the Local Planning Group
- establish a register of children with special needs; this was to complement existing child health and Social Services information systems. The maintenance and development of the resulting data base was the responsibility of the team secretary

The FST was to function on an open referral system. It was anticipated that the majority of referrals would result following assessment undertaken either in the Paediatric Department of the local hospital, or by the Community Medical Service. These referrals would reach the team by means of the Child Development Service. The FST, however, would also take referrals from parents/carers, as well as from other agencies, for example, from child care teams, GPs, and health visitors. All new referrals were to be considered at the weekly team meeting. Following that, individual team members would contact the family concerned to arrange a home visit. Where possible, this would be undertaken together with a professional already known to the family.

Team members' roles

As already noted, the FST comprised a social worker; community nurse; health visitor; and teacher. The team was led by a co-ordinator who also had a health visiting background. In addition to their general role within the FST, each team member functioned in a specialist professional capacity.

The FST co-ordinator's key role was to provide advice and support to the team with regard to their interaction with the Child Development Service. Other central features of the role included:

- strategic planning
- operational management on a daily basis
- professional management of the 2 specialist health workers in the team
- liaising with other team members' professional managers
- liaising with other agencies
- co-ordinating individual team members' training needs
- maintaining the philosophical base and the profile of the team

Each FST member was charged with providing advice and support to children with learning disabilities and their families. With regard to the *social work role*, there was a particular focus on the following:

- counselling
- gaining access to community resources
- developing support groups
- enabling user participation in service planning and delivery
- liaising with Social Services

For the *community nurse*, the focus was upon the provision of advice and support with regard to:

- medical problems, both physical and psychological
- behavioural problems
- self-help skills
- social and independent living skills

The *health visitor* focused on:

- early counselling
- child development
- developing support groups
- co-ordinating the Portage Home Advisory Service
- liasing with the School Medical Service

While for the *teacher,* the following were key responsibilities:

- educational progress from playgroup to school leaving age
- implementation of the 1981 Education Act
- the process of liaison between home and school
- identification of appropriate learning packages

Above all, the new service was to provide additional support for families, some of whom had received scant help in preceding years. However, a number of factors intervened in the provision of that service, all of which served to compound the difficulties faced by families in caring for their child. The remainder of this Chapter focuses on these issues.

Management Issues

Throughout the research period, management issues proved problematic in terms of the development of the FST. The policy shift towards care in the community charted earlier in this dissertation meant that in a philosophical sense, team members believed the FST should reside within generic paediatric and community services:

> 'I think that in the long term the community is where we belong, that we should be part of a community setting.'

Commitment to this philosophy led to the FST being located initially under the management of community health services. Practically, however, this led to many problems, not least, a seeming lack of interest on the part of managers:

> '...sometimes I don't feel they know we exist. I definitely don't think we're a priority.'

McGrath (1991, p.42) notes that:

> 'Like elderly and physically handicapped people, those with a mental handicap are frequently allocated to unqualified staff and regarded as a low priority group with much of the work, often inappropriately seen as maintenance.'

While Ryan and Thomas (1980, p.17) write that in terms of medicine, the field of mental handicap is of low status:

> 'There are very few prestigious careers in this field, relatively few consultantships, and no lucrative private practices.'

Moreover, the authors argue that:

> 'Medicine – its institutions, personnel, concepts, and modes of explaining behaviour – has been the main instrument for excluding mentally handicapped people from society. It is not just that hospitals have had to cope with people whom society has rejected, which is how many nurses and doctors see their role. It is also that the medical profession has sanctioned this rejection by producing a whole way of thinking that justifies it. To categorize mentally handicapped people as 'defective' or 'subnormal' is to describe them entirely in terms of their supposed pathology, what is wrong with *them.* Such descriptions effectively mask other aspects of their social existence, or even deny them one at all ... they are seen, in strict medical terms, as incurable and therefore hopeless.' (p.15)

The sense of hopelessness which has pervaded thinking around people with learning disabilities undoubtedly plays a significant part in their experience of life, of service provision, and, indeed, the manner in which professionals provide those services. Moreover, that sense of hopelessness is a useful starting point in any attempt to interpret the position which FST members found themselves in vis a vis management support, or rather lack of it. For, it would appear that management in this case did not perceive the FST to be a service deserving of priority. As a result, team members felt that they were left to develop virtually alone as a 'satellite service' in the face of increasing difficulties. Of course, the consequence for children and their families was that once again they were subject to a form of exclusion, as the service which had been established for their benefit was unable to function effectively, and they were denied access to the promised additional support.

Repeated requests from the team to management for stronger lines of communication and some form of support structure for the new service simply went unheeded. At the same time, the team co-ordinator became increasingly isolated and felt unable to tap in to the management support needed. Although s/he requested that a project monitoring group be set up, as recommended in the original commissioning report, this group did not meet for the first time until September 1992. Membership comprised one parent, together with representatives from the Local Education Authority, Health Authority, Social Services and the voluntary sector.

As a result of this lack of support, team morale plummeted and the FST became isolated, defensive and suspicious of other agencies. A decision was taken to relocate the team on an interim basis within the Mental Health Unit from 1 April 1992. The co-ordinator now felt 'buttressed' to a certain extent as the new line manager took on a certain amount of responsibility; as a result the former became more positive. Other team members, however, were less optimistic about the management changes. Indeed, one felt that things had not particularly improved as a result of the move. Over time, the team co-ordinator's positive stance also began to erode, and was replaced by feelings of helplessness and resignation about the team's situation.

Geographical Boundary Issues

Geographical boundary issues involving another FST in a neighbouring area proved a major problem for the team; this resulted in part from the lack of management support. The initial report which had led to the establishment of the FST whose development is charted here, had recommended that the team should work to social services rather than health boundaries. Thus, although families in the X area fell within the A health management unit, they were to be visited by the FST whose development is charted here, thus following social services boundaries. This, however, did not happen during the life of the research project, and it became clear that the resulting confusion not only undermined the team's credibility but also, more importantly, deprived families of the additional support which should have been available to them.

Initially, although team members had to cover the whole 'patch' in terms of their professional expertise, care plan co-ordinator case-loads were allocated on a geographical basis with the intention of cutting down on the extensive travel which is characteristic of rural areas. As a result, two workers could cover the east of the division around X, and two the west. This also made it possible to ensure that one of each pair was a Welsh speaker.

However, according to the FST co-ordinator, prior to the beginning of the research project in September 1991, a senior doctor had instructed her/him '...to leave [X area] alone...'. Since the co-ordinator wished to establish good working relationships with other agencies s/he was, at this stage, happy to comply. This meant, however, that an imbalance was allowed to develop with half the team members - through no fault of their own - carrying only half the care plan co-ordination case-load of their colleagues. In October 1991, therefore, the team co-ordinator vocalised the team's concern to management in what was to prove the beginning of a lengthy process in which attempts were made to resolve the situation.

The geographical boundary issue was raised again at an evaluation team meeting in November 1991 when a decision was taken to call an urgent inter-agency meeting to clarify the situation. This meeting was eventually held in January 1992 but the issue was still not resolved. Members of the neighbouring FST argued that as they were funded by the NHS they were not prepared to follow social services boundaries. They also expressed concern about the possibility that their service might be 'diluted' if they had to provide Occupational Therapy cover for the FST whose development is charted here in the event of them being allowed to take over the provision of services to X area. All that was agreed, therefore, was that the status quo would remain and that no referrals would be handed over. It was, however, agreed to hold another meeting in February.

At the meeting in February, ten months after the team was set up and five months after the boundary issue began to cause concern, it was finally agreed that the FST should take over families in the X area. Patterns of referral were to be discussed at a further meeting. However, at this meeting in March controversy continued to rage about who the families 'belonged to' and nothing was achieved apart from a further directive to '...leave [X area] alone.'

By the end of the research period in October 1992, the issue had still not been resolved. The FST were receiving no referrals from the neighbouring team, and both parents and social workers in the X area were expressing confusion and bewilderment about the situation. Meanwhile, families had to be referred back to the original referring agency since the FST could not provide them with the service requested. As time went on, this issue became an increasing source of concern for team members.

Although managers made some attempt to resolve the problem, the question must be posed as to what extent resolution was perceived to be a priority. Subsequently, this issue proved a major contributory factor in the team's low morale.

Indeed, one team member described it as a '... a very grave problem…' While the comments below provide some illustration of the frustration experienced by other team members:

> 'It's a continual frustration...It's all these issues that get you down. You feel as if you're going round and round in circles, you're not actually going forward.'

> 'I would have liked us by now to have been in touch with every single family in the area. The mess that's been created...I think it's just appalling that that hasn't been sorted out.'

> 'I think we've been bogged down by issues which should have been resolved before we came into post...I don't think there's been enough impetus to get a decision made.'

> 'There are things I'd like to do but I know I can't because of the politics.'

> 'I've been in post six months and I can't get involved with one area that we're being paid for.'

The geographical boundary issue highlighted above is a clear illustration of the potential for poorly managed services to have a harmful effect on the relationship between professionals and service users, and also between fellow professionals. For, central to the boundary problem were the elements of control over, and ownership of a particular group of service users; this together with the evident professional rivalries spelt only disaster in terms of the support received by families. Clearly, it was an issue which should have been grappled with and resolved at the outset.

Multi-Disciplinary Teamworking

In Chapter Two, the difficulties inherent in 'working together' with other professionals, and also with parents were noted. In many senses, multi-disciplinary teamworking was perceived to provide a solution, particularly for families caring for children with learning disabilities. McGrath (1991) however, draws our attention to the advantages and disadvantages of such working. In terms of the former, first, staff resources may be used in a more efficient way. In particular, an improved level of collaboration between workers is made possible through a clearer understanding of colleagues' expertise; subsequently services are less likely to become fragmented. Moreover, specialists are enabled to focus on their specialist skills, while unqualified staff may be used more effectively. Second, more effective forms of service provision result from a:

> '...holistic approach to client needs...Team practice encourages a focus on total problems rather than isolated aspects...' (p.4).

Problems in relation to service delivery may be identified and resolved using a multi-disciplinary approach. Moreover, planning and goal setting is encouraged in relation to service delivery. Geographical proximity to other professionals allows preventive work to be undertaken more easily, with referrals being made on a more informal level. Multi–

disciplinary team members are more likely to be aware of the knowledge and skills of their colleagues, and thus referrals are made more appropriately. Thus such teamwork has the potential to result in the development of new resources. Moreover, evidence suggests that a more accurate needs assessment results (Pfeiffer and Naglieri 1983, cited in McGrath 1991).

The third advantage to multi-disciplinary teamworking is that of an improved work environment, within which consumers' needs are more appropriately met. Moreover, individual skills are used to best advantage in an environment which is both stimulating and supportive.

What then of the disadvantages of multi-disciplinary working? Large organisational and professional barriers have to be overcome, as workers face the dilemma of dual loyalty and accountability (McGrath 1991). In order that multi-disciplinary team working proves effective, issues around individual roles, the mechanisms involved in team decision-making, and allocation of work need to be resolved:

> 'The establishment of a team, whether multi-disciplinary or not, may be viewed as a structural arrangement which in itself cannot guarantee improved service delivery. Equally important are the process elements, the ways in which the work of the team is undertaken.' (p.6)

This point is echoed by Dale (1996) who notes that effective team work with families is possible only when:

> 'The roles and functions of each team member are clarified, so that each team member has a clear idea of their responsibilities and what they can expect from other members.'(p.302)

As noted earlier, according to McGrath (*op. cit.,* p.63), several factors play a part in facilitating team integration:

> (a) 'a shared base and regular team meetings giving opportunities for frequent interaction.
> (b) commitment to team working.
> (c) one individual acting as a coordinator
> (d) management support to the team as a unit.'

One of the major problems faced by multi-disciplinary teams is that of dual loyalty and dual accountability (*ibid.*). Such problems were of crucial significance to the research reported here, for one member of the FST was unwilling to 'rock the boat' and risk offending the agency to which s/he was professionally accountable. Such loyalty, as McGrath indicates, can create real difficulties when a new team is committed to trying to influence service delivery to an already marginalised group.

It is clear that dual loyalty and accountability contributed to problems experienced within the FST in relation to information-sharing. For, team members found it difficult to share information, not only amongst themselves given that they were all from different disciplines, but also with non-professionals. At the same time, they experienced confusion about their own roles within the team. Taken together, such difficulties did not augur well for service delivery.

McGrath (1991 p.63) argues that it may take up to two years for teams to develop:

> '...into an integrated unit with their roles, philosophy and work processes established.'

Team-building is seen as an essential part of this process of development. Although the team building sessions which were held soon after all FST members came into post had specified the team's objectives, and also clarified team and professional roles, clearly, this work did not go far enough. An air of uncertainty continued to permeate the team, together with an individual rather than a collective ethos, as is illustrated by the following comments:

> 'We haven't actually specified what our aim is, what we actually mean, what the design of the whole thing is, about us being a team. By not having done that, we don't know how far we are along the way...As a sort of inter-professional team, we're not making the best of each other. We're each carving a little pigeon-hole that we can call our own.'

> 'Multi-disciplinary teamwork, there are complexities that need to be addressed more than working in your own professional field. I think that there are issues for us as a team that perhaps we haven't been able to address because we've been bogged down in other issues.'

> 'I don't think we've got there as a team completely yet, I think we've got a long way to go. I think we don't always share things with each other as much as we should maybe. But I think partly that's because there have been so many other things that we've all been thinking about.'

> 'I've got the freedom to do as I like really. The autocracy is very nice, but sometimes you can feel a bit isolated, especially when you've been used to working in a close-knit environment. Sometimes you feel you're on a desert island.'

Two team members had dual accountability, and it was they who articulated the greatest sense of confusion over their role and where they should relate to professionally. According to one:

> 'There's a massive assumption about what each other's roles are and I think we're probably quite ignorant about that. And maybe there should be an expectation on people who join a multi-disciplinary team that they understand each other's roles...You can end up beavering away and others are aware that you're busy doing your thing but are not necessarily aware where it fits in or why it's important. I think the onus is very heavily upon the co-ordinator to have a clear idea of what those professionals do.'

More than one team member expressed concern about the care plan co-ordinator role.

There were fears that this role might lead to professional de-skilling:

> 'We're all concentrating a bit more on our professional roles. I think because of the cut-backs we've had to. So in a way I feel better about that, more positive. I think we were all starting to lose our identity, we were concentrating on being a team and just care plan co-ordinators and I felt I wasn't offering people what I could.'

> 'I think we need to look at our individual roles within the team, especially the professional roles...I am mindful that in lots of teams they tend to develop a very generic role and there is a danger of de-skilling the professionals within the team.'

There were also doubts about the validity of a co-ordinating role:

> 'I would hope in the future I could do more 'hands on' work with individual children...I think it would bear more fruit really because co-ordinating services is fine if the services are there but you tend to get gloomy and despondent if it's a question of feeding back to parents information that services are not there.'

One team member felt particularly anxious about the prospect of a change of role:

> 'I suppose I've got a certain amount of control, I can always try and say no to different things. But it's also difficult without anybody in a senior position actually clearly defining what my role in the team is.'

This lack of role clarity within the team itself was coupled with a lack of understanding amongst external agencies about the FST's role. The latter was evident in spite of the fact that in their earliest days the team had undertaken a series of 'road shows' to publicise their existence and their remit to relevant agencies in the area. Given the above, it was highly likely that at times both team members and other professionals conveyed this sense of confusion to the families they were working with. This was particularly the case in terms of the geographical boundary issue.

Moreover, management problems; confusion about individual and collective roles together with other issues which impacted on levels of morale within the FST; accommodation problems; and a lack of resources, all militated against effective team working during the life of the research. Indeed, low morale had proved a constant problem from the very start of the research process, with team members feeling that planning issues had not been satisfactorily resolved before the team was set up. Team members constantly cited unresolved accommodation problems as an example of lack of management interest and support, and these are referred to in more detail below. All the above contributed to the frustration experienced, and more than one team member indicated that they had thought of resigning:

> 'Some months you feel really good about everything and other months you feel really down. I think with me it's when there's a lot of things going on, the

> political things, the cut-backs in services...If that course hadn't come up, I was ready to finish. I'd had enough.'

> 'I must be honest, I'm keeping my options open. If the future doesn't suit me, I'd keep that option of returning to my previous environment.'

> 'I don't know what else we can do, any of us, any more…It's lack of management, lack of money, lack of resources…In some ways, I'm amazed we're all still here.'

The team co-ordinator echoed the frustration articulated by her/his colleagues and was of the opinion that managers had no real grasp of the FST philosophy. At one point s/he expressed concern that the team was '…being attacked…' on all sides.

Accommodation problems

Poor accommodation, referred to time after time by team members, appears to have been one of the major contributory factors in lowering team morale. With three field workers sharing one room and the other field worker sharing another room with the co-ordinator, concerns centred around lack of work space, privacy and confidentiality particularly when families needed counselling. One team member felt that accommodation problems had prevented them extending their role over the previous twelve months, and another commented:

> 'I don't think sitting on top of each other in a couple of rooms is effective for communication. I think it's counter- productive actually.'

In an attempt to resolve these problems, the team was offered new accommodation in recently renovated offices shared by the CMHT and the Challenging Behaviour service. This was rejected by the FST on the grounds that it would be philosophically incorrect to share accommodation with adult mental handicap services. A suggestion that the team should be relocated in a unit on the local hospital site came to nothing and the issue rumbled on unresolved until another room in the building they occupied became vacant. This created some relief but did not fully resolve the issue:

> 'Accommodation has been an issue initially. It's still, I suppose, a priority although it's been resolved to a certain extent, the fact that we've been given this corridor.'

> 'For us three in a room, it's still just as bad, we're in exactly the same boat. It's really difficult.'

Resource issues

According to team members, a lack of resources played a large part in their failure to develop fully in the early stages:

> 'I don't think we can effectively do either the liaison co-ordination or helping them [the families] if we don't have the basic services that they need. I think we are wasting a lot of our time if we don't have practical help like Family Aide or the respite care that they need.'

> 'Where the role of the keyworker is concerned, I think we've all been affected really by the restrictions in finance. Here we are, co-ordinating services and I find it very hard to accept that we're co-ordinating services which are being curtailed.'

> ‘Resources are a problem. We’re developing our services at the same time as there seems to be a run-down in services.’

However, there was some recognition that resources were not the only issue:

> ‘One of the main things we can offer families is continuity. Resources are a problem but our team is not just about resources. It’s about offering support, offering a continuum of support. We can develop skills within the team that don’t rely on resources.’

Professional Boundary Issues

As a result of initial problems regarding the team’s development, FST members became to a certain extent both hostile and defensive towards others who were not considered ‘professionals’, and also towards professionals in other agencies. It must be said that at the same time, the latter appeared defensive and suspicious of the FST.

From the outset of the research project, the researcher was perceived to be a non-professional whose contact with families would be an intrusive imposition. Team members were clearly concerned that I would ‘upset’ families because I lacked the necessary sensitivity which derives from ‘professional training’. It was also implied that the lack of such training might make me gullible and open to believe everything the families told me.

Similar fears were expressed about other non-professionals such as the new Consumer Participation Officer (CPO). He was described negatively as ‘… a man with a mission…’ who might well alienate professionals in other agencies through his actions. Team members were concerned about the way in which he was amassing what they saw as confidential information. At the same time, they were unhappy about the way he had established a Parents' Association from which they received no feedback:

> 'I'm quite happy with what we've done in terms of involving parents and the children's sub-group. But I fear that has started to lose its way a little bit. It's political as much as anything else because the CPO has a different way of looking at things.'

> 'I'm totally confused now about what he [the CPO] is doing with his Parents' Association because we're not getting any feedback from him.'

Interestingly, team members' anxieties about being cut off from sources of information could perhaps be interpreted as evidence of fears of an inversion of existing power relationships: whereas in the past it had been parents who were unhappy at being denied information or feedback from professionals, it was now professionals who were worried about the lack of feedback from the Parents' Association.

One team member described the CPO as being '...on a sticky wicket'. For, on the one hand, his lack of professional training meant he was not fully accepted by the FST; while on the other hand he was seen by parents as a representative of the professionals.

Quite clearly, other agencies were suspicious of the FST and unsure of its role. This manifested itself in a variety of ways, none it must be said contributing to an improved service for families with children with disabilities. In the first instance, the researcher herself experienced a certain amount of hostility from professionals in other agencies because of her association with the FST. This unfortunately often led to a reluctance to co-operate with the research.

Second, although interestingly, when s/he joined the FST one team member had anticipated that the main difficulties s/he would face would be from '...cynical families', s/he found that in reality the major problems emanated from other professionals. According to this team member external agencies were both defensive and hostile towards the FST on the basis that the latter was impinging on the former's territory. Moreover, concern was expressed about the frailty of the new service within the structure of an already established framework of services.

According to team members, there was evidence of the educational psychologists' concern and confusion about the role of the FST. The former could not understand why other professionals were becoming involved with children they dealt with. Moreover, they appeared to resent the fact that the FST would be providing additional support to families and as they perceived it would be '...coming in without warning...' to detrimental effect. Unfortunately, the above at times led to a refusal to respond to requests from the FST for information, as is illustrated by the following comment:

> 'There are still problems with the educational psychologists. Just basic things like leaving a message, or you phone up and whoever answers the phone doesn't know whether they're going to be in the office again that week or where you can get hold of them. Sometimes it seems there's an awful lot of things we've got to try and do.'

One team member was left feeling that they had to break down '… a wall …' and that this whole situation represented '… the undesirable side of working with professionals.' Indeed, as time went on, some members of the FST became increasingly isolated from their generic professional colleagues. They found it difficult to obtain information about courses or meetings and one FST member '… doesn't feel one of them [generic colleagues] any more.'

Other agencies had expressed fears about how the relationship between themselves and the FST would develop. However, according to one agency representative, fears of '…poaching…' proved unfounded, and gradually subsided because the co-ordinator of the FST '…handled things sensitively…'. Team members themselves, however, seemed divided as to the extent to which things were in fact improving, with the fact that the FST were perceived by other professionals to be a threat uppermost in their minds:

> 'Maybe as people can see us getting involved with families they can see we're not the threat people thought we were.'

> 'I think as a team we've tried very hard to work in partnership with other agencies. I still feel a lot of agencies in the area see us as a threat and maybe don't use us in a partnership situation.'

> 'I don't really think things have improved, especially on a field-working level with the educational psychologists.'

Working with families

Although it may be said that some progress has been made in recent years in the move towards a partnership approach between parents and professionals in terms of including the former in decisions about their children and affording them at least some choice, there remains room for considerable improvement, as is clear from the research findings reported here.

Mittler and McConachie (1983, p.10) purport that:

> 'Partnership involves a full sharing of knowledge, skills and experiences. A commitment to partnership rests on the assumption that children will learn and develop better if parents and professionals are working together on a basis of equality than if either is working in isolation.'

Although team members appeared clearly deeply committed to helping the families they worked with, they appeared to have difficulty in accepting that families' differing perceptions might have validity. Where a family wanted something other than that deemed appropriate by a team member, there was rarely much negotiation, leaving one family with little option but to refuse any further services from the FST.

One team member commented:

> 'We've got a lot to offer but sometimes the family don't know what we're offering. Sometimes we know there are other things in the family that need to be concentrated on and we do that sometimes without telling the parents. You see the progress but they don't always know. Perhaps they think you're just calling and having a chat...Sometimes the problem is not accepting that there's a problem. Because you're working on something that they don't accept, then it's quite difficult.'

It was interesting to note how often the FST alluded to the difficulties of working with families who became too vocal in their search for services. Time and again team members were heard to say that if only a family were of a 'quieter' nature then professionals might find it easier to help them. This point was reinforced by one parent who talked of the difficulty of complaining about services due to fears of repercussions in service delivery.

Given the concerns expressed by FST members with regard to the problems faced in their interaction with other professionals, it seems appropriate to take some time to reflect on the issue of partnership. The concept of working in partnership - be that with parents or with other professionals - has taken centre stage in recent years, as outlined in Chapter Two. Moves towards more 'seamless' services, and the integration of health and social care (Department of Health 2000) have been dependent upon the ability of agencies to work together. Swain and Walker (2003) note the considerable barriers to working in partnership with service users and professionals. As highlighted earlier, geographical, financial, attitudinal, and organisational issues prove problematic. While further difficulties are encountered due to the language differences inherent in health, social care and education.

Handy's (1985) analysis of sources of power, referred to in Chapter Two, appears to be of particular relevance in terms of the factors inherent in the development of the FST. Clearly, the team was in a position to make a real difference to the lives of families with children with learning disabilities. Indeed, they were established to do that by virtue of the fact that they were to provide an additional support network to run alongside already existing generic services. The research evidence abounds with examples of the way in which families have historically been denied access to support, and also to information that would have assisted them in caring more effectively for their children, while lessening the impact upon their family of providing that care. The research reported here illustrates the way in which - both in terms of families' experiences of services prior to the establishment of the FST, and also their experiences of the service provided by the FST - resource power, or control over services; position power, attributed to the professional role; and expert power, which is characterised by the possession of information not readily available to the parent, all in their own way work to exclude parents from the care of their children, and to render them powerless to a great extent.

It is of concern that in the data elicited from FST members and reported above there are parallels with McGrath's (1991) analysis of ineffective team working which she argues is characterised by the following: namely, a lack of co-ordination resulting in confused messages being passed on to the service user; a failure to accept overall responsibility for the service user; the escalation of professional conflict; a tendency to be inward looking, placing too much emphasis on individual goals; increased social control over service users; and a lack of clarification in terms of team objectives and role boundaries. Indeed her assertion that:

> '...team insularity may result in poor liaison with service providers outside the team creating a more fragmented service.' (p.7)

appears particularly apt.

The FST should have provided a service for those families living in the X area of the county. Professional conflict and rivalries resulted in their being unable to do so. Their professional role accorded them power in terms of position and expertise which is so often evident in their reflections on their relationship with parents; and also in the way in which parents became 'pawns' in the power struggle between professionals in neighbouring geographical areas. Evident within the latter was the predominance of professionals' interests over those of service users. It is sobering to note that since the fieldwork for this dissertation was undertaken, more recent research indicates that little has changed in terms of the power imbalance between professionals and service users. The issues debated above are of crucial importance in terms of the provision of effective learning disability services to children and their families and will be discussed further in the final Chapter of this dissertation.

Conclusion

In this Chapter of the dissertation the focus has been upon the views of FST members on issues relating to the team's development. First, the FST brief was considered; team members' roles were outlined; and management issues; geographical boundary problems; and the reality of working in a multi-disciplinary team were examined. Moreover, accommodation problems; resource and professional boundary issues; and matters relating to working with families were all given consideration.

Having reflected on the views of both parents and professionals, in the final chapter of the dissertation an attempt will be made to draw out the messages from this research and establish what, if any, improvements have been made with regard to the issues raised. Moreover, the implications of these findings with regard to social welfare policy and practice will also be examined.

CHAPTER SIX – CONCLUSION: WHAT NEXT FOR LEARNING DISABILITY SERVICES FOR CHILDREN AND THEIR FAMILIES?

Introduction

There are two themes which are central to this dissertation: namely, the sense of 'difference' which characterises the lives of children with learning disabilities and their families, and sets them apart from others; and the subsequent inequality which they experience. Indeed, as the title of the dissertation – '"Different and Unequal": The Experiences of Families with Children with Learning Disabilities' – suggests, the work focuses upon the manner in which difference and inequality pervade the lives of these families on a daily basis, whether that be through their interaction with professionals; with their own family members; with their extended social networks; or with wider society.

In this, the final Chapter of the dissertation, the implications of the research findings are considered in terms of policy and practice. Indeed, given the evidence on the failure of services, not least the FST, to meet need effectively, together with the wide-ranging dissatisfaction which service users continue to express in spite of the numerous policy initiatives over recent years intended to improve their situation, the key question to be posed is: what next for learning disability services? Further, why has there been such little progress on issues which research evidence indicates continue to militate against effective service provision in this field? Why do parents still express concern and dissatisfaction with disclosure? With the amount of information available to them to make informed choices? With the process of working with professionals? Before moving on to consider the response to such questions, first, the research process is briefly reviewed and the findings summarised.

The focus of this dissertation has been twofold. First, an attempt has been made, by means of a qualitative approach, to examine the extent to which multi-disciplinary team working, and the establishment of a Family Support Team (FST) in West Wales could provide a solution to the problems experienced by families caring for children with learning disabilities. As already noted, this task was undertaken as part of the process of evaluating the development of the FST during the first 12 months of its life.

A qualitative, interpretive approach was adopted because of the need to establish, as far as is possible, what it means to have a child with learning disabilities. Moreover, this was also perceived to be the most appropriate means of charting the development of the FST, and of providing in-depth data on issues which might confront the team during the first 12 months of its life. Fielding (1993, p.9) makes the point that in the symbolic interactionist approach of interpretivists, open-ended as opposed to standardised interviews are favoured. For, the former:

> '... allow respondents to use their own particular way of defining the world, assume that no fixed sequence of questions is suitable to all respondents, and allow respondents to raise considerations that the interviewer has not thought of.'

This, then appeared to be the optimum choice of approach for research of this nature.

Second, the resulting data have been drawn upon in an illustrative capacity, and comparisons have been made between research participants' experiences at the time the study was undertaken, and other families' experiences of learning disability services today, in an attempt to establish change or improvement.

Some time has elapsed since the research reported here was undertaken, and this time lapse has proved beneficial in two ways: namely, the data elicited have been 'distanced' from the controversy which surrounded the 'birth' of the FST, and the professional rivalries which were so evident during the research period; it has also meant that a sufficient amount of time has elapsed since then to allow for a subsequent examination of other families' experiences of contemporary service provision in the wake of numerous policy initiatives. It should be noted that it would not have been possible to undertake further research involving the original participants as a means of establishing progress, as the research findings, when reported, were not well received by the FST. It would not, therefore, have been prudent to attempt to revisit original participants. Moreover, it is anticipated that further access would have been denied. There is, of course, also the possibility that both families and team members may have 'moved on'; the former geographically and the latter professionally.

In terms of content, in Chapter One of the dissertation the research was placed in context, and the concept of learning disability explored from a historical perspective. Definitions and labels, and the manner in which these have changed over time were considered, together with the move to segregate and 'contain' people with a learning disability in institutions outside their own community. Moreover, attention was paid to the policy framework; to the period of reform and the changes evident during the latter part of the twentieth century; and to the more recent initiatives intended to benefit children with learning disabilities and their families.

In Chapter Two, the emphasis was firmly placed on the experience of having a child with a learning disability, and in the spirit of qualitative enquiry, establishing what that actually means for families. The detailed review of the literature included an exploration of the nature and extent of disability. Further, the medical and social models of disability were considered, together with issues around disclosure of disability. Families' experiences of having a child with a learning disability, and the extent to which this might be a positive experience were explored; and the concept of professional power was also discussed. Finally, issues around multi-disciplinary teamworking, and the establishment of the FST as a potential solution to the problems experienced by families with children with learning disabilities in a particular geographical area in Wales were considered.

In Chapter Three the focus was upon the qualitative methods employed in undertaking the research. The process of selecting the research method was considered; as were data collection and ethical issues. The research findings in relation to the families who participated in the study were presented in Chapter Four. In Chapter Five, the views of FST members were reported. A summary of those findings follows.

Summary of research findings

Chapter Four of this dissertation focuses on the views of the 22 families who participated in this study. Their previous experiences of services, and also their views on the newly established FST were highlighted.

The issue of *disclosure* was considered, and it was clear that the parents who participated in this study had been confronted with insensitive responses and negative attitudes on the birth of their child with a disability. Diagnosis was often insensitively handled by medical staff, and very little information was forthcoming to enable parents to make informed choices. Parental expertise was often ignored, with many parents feeling that professionals simply dismissed their views. Many parents were fortunate to have the support of family members at this time, and perceived them rather than professionals to be the best source of help. Some of those who provided that help, however, were ageing and in poor health themselves. Consequently, families expressed anxiety at their future coping strategies. Parents were clearly concerned at the lack of professional support in the early years following disclosure. Indeed, for many it was a period characterised by isolation, desperation and feelings of dejection.

Relationships with 'significant others' were explored, and it was clear that, for those who participated in this research, one of the major impacts of having a child with a learning disability was the way in which social relationships were adversely affected. The differing degrees to which this was the case, of course, depended on families' support network, including familial and community support; and whether, for example, the parent was a lone carer. Parents again talked of the isolation experienced, which for some became an integral part of the caring process; and of the difficulties as opposed to the possibilities which other people associated with their child.

For some parents their child's behaviour proved a constraining factor in social relationships; many talked of losing friendships due to a sense of fear and a lack of understanding on the part of others. Family life, too, was adversely affected, with marital life disrupted by the amount of time and energy expended on caring.

Siblings' experiences were highlighted, and parents reflected on the manner in which the demands of a caring role often resulted in the needs of their other children taking second place. Moreover, while some siblings coped with the situation, it was clear that others were resentful and unhappy.

The *differences between biological and adoptive parenting* were examined. The latter were very conscious that their situation involved an element of 'choice'; they preferred to be self-sufficient and remain as independent of services as possible. They reflected on the fact that some biological parents might not be able to maintain as positive an outlook as they, and here there were some interesting parallels with professional theorising on disability, in particular with regard to the notion of the 'handicapped family'. Biological parents too, were aware of the distinctions between themselves and adoptive parents and of the differing perspectives each brings to the task.

Consideration was given to the issue of *other parents as sources of support.* Time and again respondents talked of other parents as a valuable resource; indeed, they were constantly drawn upon for advice and information to counteract the lack of support offered by professionals.

The nature and extent of *contact with professionals* was explored. For parents who participated in this research, there were concerns, as already noted, about the level and nature of support provided by professionals. There were also issues around the extent to which parents felt they could trust the professionals charged with the care of their child; the fact that the child and family were so often the subject of discussion at meetings of large groups of professionals to which parents did not have access, was a real concern. The seemingly unsympathetic and unresponsive attitudes expressed by professionals were also a cause for concern.

Parents expressed the need to retain an element of control in their interaction with professionals, and to have someone on hand whom they could contact if help or support was required. This was seen as necessary because their experience of professionals was in the main negative. Parents felt that they were not listened to; that there was little continuity in terms of services; and that any attempt to communicate with professionals over service provision was ignored. Indeed, they perceived professionals as 'gate keepers' to both services and information. Above all, what permeates parents' views on their contact with professionals is their need to fight for services and to adopt a more forceful stance than they normally would. This, unfortunately, provides a clear illustration of the power dynamic which so characterises the relationship between parents and professionals in the field of learning disability.

Attention was also drawn to *educational issues*, and here again, many families reported having experienced difficulty both in terms of their child's school and the local LEA. The main areas of concern were levels of communication between home and school; the statementing procedure, which was perceived by some to be the result of a lengthy process which resulted in an invalid statement, which inaccurately reflected their child's needs; and the lack of choice offered to families with regard to school when compared to the choice available to non-disabled children. Finally, families reflected on the process of integration, and the need for a positive attitude on this. For some parents, the special school system functions to perpetuate the segregation of their children outside mainstream society. Others talked of the way in which the system also segregates parents, by denying them the opportunity for interaction with other parents at the end of the school day.

Parents also expressed concern at the lack of *speech therapy provision,* and about *future service provision* in general. They were anxious about the level and nature of services which might be available to their child after the age of nineteen. Moreover, the shortage of *respite care* facilities was an issue, especially for those parents whose children were deemed to have complex needs and were thus difficult to place.

Chapter Four ends with consideration of parents' current experiences of services provided by FST. The background to the establishment of the team was discussed, and the extent of families' contact with the team explored. It was difficult to assess the impact which the team had on families' lives as problems encountered by the team during their first twelve months in existence – which are outlined below – meant that families had only limited contact with them during the research period. Notwithstanding this, however, only two out of 22 families expressed negative views about the team. This is unsurprising given families' previous experiences of services, or rather, lack of them. The majority of parents saw the FST as a positive development and one which they would hopefully benefit from. Parents were most appreciative of the fact that they would now have a distinct contact point and means of support, which would alleviate the sense of isolation which had pervaded their lives for so long. They looked to the team to provide direction, continuity, and also to facilitate access to other services. Only two families had misgivings about the introduction of the team into their lives. For one, the new service had arrived too late to be of any help. The other felt that the level of support they received had actually diminished with the introduction of the team, as other agencies were under the impression that the FST would assume major responsibility for the care of their child.

Chapter Five is devoted to the views of FST members on issues relating to the team's first twelve months in existence. First, the FST brief was considered; and team members' roles outlined. The new multi-disciplinary team had been established to provide additional support to children with learning disabilities and their families from the time of referral to the age of 19. It was intended that the team would work in partnership with families and other agencies in providing that support. Team members subscribed to the 3 AWS principles and there was to be a co-ordinating aspect to their role, in terms of bringing in other services where required.

The team comprised a social worker, community nurse, health visitor and teacher. It was led by a co-ordinator who was also a health visitor. Each team member had a general role within the FST and also functioned in a specialist professional capacity.

Having considered the team's remit and individual responsibilities, the focus then shifted to an exploration of the problems encountered by the team during the research period, all of which impacted upon the team's ability to provide an effective service to families.

Management issues proved problematic throughout the life of the research study. Team members did not feel well supported by management and as a result became increasingly isolated and dejected. Team morale plummeted and even a move to an alternative management structure – located within the Mental Health Unit – was of short-term benefit only.

Geographical boundary issues played a key part in the first 12 months of the team's development. The failure to address these issues was in part due to the lack of management support, and the team became locked in a 'battle' with a neighbouring FST over access to families in a particular geographical area. These boundary issues proved detrimental to the team's development and also denied some families access to a much-needed service. By the end of the research period the problem still had not been resolved. This had a detrimental effect on relationships with parents and other service providers. Central to the problem were issues of professional rivalry and the exercise of control over, and ownership of one group of service users.

Multi-disciplinary teamwork has the potential to address many of the problems commonly experienced by families with children with learning disabilities. There are, however, both advantages and disadvantages to this way of working. In terms of the former, staff resources may be used more effectively; more effective service provision may result; and an improved work environment leads to consumers' needs being more appropriately met. Amongst the disadvantages are the need to overcome both organisational and professional barriers, with workers facing the dilemma of dual loyalty and accountability (McGrath 1991). FST members experienced real difficulties with the latter, in particular with regard to the process of information sharing. It was clear that team members were confused as to their role and where they should relate to professionally.

Accommodation problems were continually pointed to as having a detrimental impact upon the team's development. According to team members, the lack of space at their team base resulted in an inability to extend roles and militated against confidentiality and effective communication. The offer of more spacious accommodation, however, was rejected as it would have meant the team being located with adult mental handicap services.

According to FST members, *resource issues* also played a part in the team's failure to fully develop in the early stages: the cut back in services in general being seen as impacting negatively on their development.

Professional boundary issues were a central feature of the research period. Over time, as a result of the problems they were experiencing, FST members became increasingly defensive and suspicious of other professionals, and also those they deemed non-professionals. Moreover, other agencies appeared equally suspicious of the FST and were unclear as to the team's role.

Although team members appeared committed to *working with families* they seemed to have difficulty with accepting that families' differing perceptions might have validity. Where families expressed a need deemed inappropriate by the FST, there was rarely much negotiation. Indeed, team members often pointed to the difficulty of working with families who were too vocal in their search for services.

Having briefly reflected on the content of the dissertation, and upon a summary of the research findings, attention now shifts to a more detailed consideration of the issues raised during the course of the research, and their implications for policy and practice.

Families' experiences of services

As already noted, for some years now, the problems commonly encountered by families with children with learning disabilities have included: a lack of information, both in terms of their child's disability, and the services available to them; an unco-ordinated approach to service delivery, and parents' subsequent involvement with numerous professionals; and the need to fight for services (Beresford 1985; Case 2000; Swain and Walker 2003). All these issues have played a central part in the lives of those who participated in this research. Indeed, the data reported here, together with the research evidence published in the years since the study was undertaken illustrate the way in which each of these problems contribute to the differing forms of marginalisation, exclusion and isolation experienced by families with children with learning disabilities.

The negative attitudes of 'significant others' play an influential role in the lives of these families in two senses: namely, in an internal sense vis a vis their extended family and social network, and also in an external sense, in terms of their relationships with professionals. Indeed, it would appear that they are *marginalized* first, by such attitudes and second, by the popular, and also to some extent professional perception that a disability renders an individual of little value to wider society. The concept of 'difference' appears to be a key factor in this marginalisation.

According to Race (1995, p.46):

> 'People with learning disabilities are typically marked out from the rest of their immediate society by an inability to cope satisfactorily in that society.'

While Middleton (1999, p.44) notes that:

> 'As a group disabled children are not conceptualised as future economically contributing citizens...Both they and the rest of society are conditioned to believe that disability equates with tragedy, burden and dependency.'

This failure to make a contribution economically, coupled with the belief that implicit in disability are the notions of tragedy, burden, and dependency, goes some way to providing an explanation for the seeming inertia on the part of service providers, and the failure to make significant progress in service provision in the years since the research was undertaken. It is accepted that in some ways progress has been made in the form of initiatives, such as Sure Start. Moreover, Mencap is currently participating in a feasibility study commissioned by the Department for Education and Skills focusing on the establishment of an early intervention centre. It is anticipated that such a centre would provide information about early intervention; undertake research on effective intervention; develop training packages; and publish key messages from research. Notwithstanding the above examples, however, much still remains to be achieved.

For, families continue to be *excluded* in a number of ways from participating fully in society, with professional power and the use of professional expertise and language serving as key factors in that exclusion. From the moment of birth, or diagnosis of disability, research evidence informs us that insufficient information militates against parents' ability to make informed choices with regard to their child. The insensitive manner in which disability is often disclosed, has long-term consequences for parents, many of whom have a detailed recollection of disclosure even though many years may have since passed. Moreover, the research literature abounds with examples of the negativity projected by medical staff and others at the birth of a child with a disability. All of these serve to exclude, and to place parents with children with disabilities outside the 'norm'.

A recent study funded by the Foundation for People with Learning Disabilities (2004) focused on the emotional needs of families with a child with learning disabilities, from the time of diagnosis to the age of five. The small-scale study took as its starting point the accepted knowledge that the way in which disability is disclosed is of crucial long-term importance to families. Amongst the findings of significance to this dissertation were that although in some cases disclosure was sensitively handled, half of the 22 families who participated reported negative experiences. Moreover, whereas some of the parents involved in that study received sufficient information on their child's disability, others received hardly any at all, having to resort to the Internet for help.

In terms of support, again, responses varied; some parents benefited from support from a range of agencies, while others received very little assistance. Indeed, the level of support received was often seen to depend upon where a family lived. The fact that the level of information and support received by parents is something of a lottery reflects badly on the policy and legislative initiatives of recent years and again provides examples of parental exclusion from services they should receive as of right.

A recent Mencap study reported that parents continue to feel they are 'kept in the dark' with regard to disclosure of disability, while health professionals continue to treat them in an insensitive and abrupt manner (Mencap 2004). Of the 85% of respondents who had been given a formal diagnosis, 61% had been '...told the diagnosis badly or very badly...'(p.22). Only 4% of parents felt that the diagnosis '...had been shared with them well...' Indeed, many of the parents who participated gave disturbing accounts of disclosure. One had been told by a doctor '...You have a beautiful daughter with the brain of a cabbage...'

SCOPE's Right from the Start project (2000) investigated parental satisfaction with disclosure of disability and found that of 103 parents, only 37% were satisfied with the process. The study highlighted the importance of parent-professional interaction and drew attention to the need for greater emphasis on communication skills in medical training. Respect for parents was called for as a starting point in establishing guidelines for professionals involved in disclosure. Recommendations were made that policies should be devised with regard to establishing guidelines by all health authorities, maternity hospitals and units. This would build on the good practice in evidence in a minority of districts. The Government was urged to support these recommendations through advice to health authorities and social services departments.

In particular the study points to increased levels of satisfaction on the part of parents if disclosure were to be made by a professional who was sympathetic, understanding and approachable; who was direct and communicated well; and who gave sufficient information in addition to an opportunity to ask questions. Given the above, it is encouraging to note that the Department of Health has recently produced a new resource for professionals working with children with disabilities – 'A Support Pack for Health Professionals – Working with families affected by a disability from pregnancy to preschool' (2004) – which offers guidance with regard to the period of diagnosis.

Of course, structural factors also play a part in the *exclusion* experienced. Indeed, '...Families of children with disabilities will tend to live on single incomes, by necessity rather than choice...' (Dowling and Dolan 2001 p.32). Their inability to fully participate in the employment market due to their caring responsibilities, and their subsequent decreased earning power often leads to inadequate housing; this being only one example of the means by which they are structurally disadvantaged.

Clearly, negative attitudes commonly feature in parents' interaction with service providers, and these together with an often diminished social network serve only to increase the *isolation* experienced in caring for their child. In the research reported here there have been numerous examples of the means by which families are marginalized, excluded, and subsequently isolated. Unfortunately, as already noted, more recent research evidence indicates that little has changed for these families since the study was undertaken. In the remainder of this Chapter, an attempt will be made to explore why this is the case.

The social inclusion of children with disabilities is premised on the notion that they are children first. Beresford (2002) notes that these children do not perceive themselves to be intrinsically 'different', rather they are made to feel that way through subtle, and more obvious forms of exclusion which promote isolation and lower self-esteem. Today, more is available to these children through Sure Start, and Early Years programmes such as the Liverpool Early Years Centre. The latter provides an integrated nursery environment for children with disabilities and non-disabled children; physiotherapy, speech therapy, occupational therapy, and medical and educational assessment; a specialist social work team; and an integrated after-school club and holiday play scheme. The Centre functions in partnership with Liverpool Social Services, and is supported financially by the City Council. It is an example of a progressive form of service provision.

Notwithstanding the above, however, children with disabilities often do not have access to mainstream childhood culture, or 'ordinary' forms of socialisation (ibid.). Indeed, respite care provision and the special school system also function to isolate them. This is the case in spite of the promotion of inclusive practice through legislation and policy.

In spite of the policy shifts and numerous initiatives in relation to learning disability which were charted in the opening chapter of this dissertation it appears that in practical terms little has changed. For families with children with learning disabilities the reality remains one of difference, exclusion and marginalisation. According to Ryan and Thomas (1980, p.27):

> 'Focusing on the differences between people, in preference to the similarities, is a form of exclusion – an exclusion from the possibility of a shared reality. In this way our common ways of thinking about mentally handicapped people reflect society's exclusion of them from any shared life.'

It is clear that policy makers and service providers face considerable challenges in addressing these issues, not least the means by which inclusion in the fullest sense is ensured. Read (2000, p.98) draws our attention to the fact that:

> 'Across a spectrum of opinion in the past 10 years, there has been an increasing consensus on the need to challenge the social exclusion, devaluation and dehumanisation routinely experienced by disabled children and adults.'

Although there were some positives to be taken from the accounts of those who participated in this research, in terms of their interaction and communication with professionals, there were many areas of concern which appear to be as relevant today; the failure to meet need and the necessity to fight for services being just two.

Indeed, according to Read (*ibid.*, p.62):

> '...contact with those [professionals] ostensibly there to help and support, can make mothers feel worse. Across almost two decades, a wide range of literature and official reports record considerable levels of unmet need for quite basic services. There is also substantial dissatisfaction with many aspects of the services that exist, the ways they are delivered and the contact between families and providers.'

Although Summers and Jenkins (2001, p.57) note that '...Families undertake a vital role in supporting their children and adult family members with learning disability...' it would appear that there is little wider acknowledgement of that contribution. In spite of the fact that historically, parents have made clear what they need to enable them to care effectively for their children, the service response to those needs has been less than satisfactory. Indeed, the following Social Services Inspectorate report provides an illustration of the difficulty parents face in accessing services:

> 'Families of disabled children still face many barriers when they try to access social services. It is difficult for them to find out what services are available and support may only be offered when a situation has reached crisis point.'
>
> (DoH 1998, p.1)

A more recent Inspection of Services for Disabled Children in Wales (SSIW, 2004, p.3) highlights the considerable disparity in parents' experiences of service provision:

> 'Some parents and carers were extremely pleased and positive about the services they receive...Some parents felt they really had to fight for services. The experience of some others was poor. They expressed anger and frustration.'

This need to fight for services was also clearly an issue for the parents who participated in the research reported here. It is sobering to note that the situation appears to have changed so little over recent years.

As already noted, parents with children with disabilities are more likely to experience financial hardship through their inability to fully engage in the employment market, than those with non-disabled children. Although financial issues were not explored in the research reported here, it is important that attention is drawn to them in any wider analysis as they present as further evidence of the inequality experienced by these families.

Key findings from the OPCS survey of 1989 illustrate that:

- At the time the survey was undertaken there were 327,000 children in England and Wales under the age of 16 who had one or more disabilities. The majority of those children (91.2%) lived with their families.

- Seventy five percent of parents with a child with a disability expressed concern that they did not have enough money to care for their child.

- Research indicates that those mothers who have children with disabilities who are able to enter employment experience lower levels of stress as a result of their improved financial situation. Notwithstanding this, such mothers are less likely to be in employment than other mothers.

- There are twice as many disabled children in those households in Social Class V as there are in Social Class I. The relationship between household income and disability has been confirmed by the 1991 Census.

- Parents who are black and those who are single are least likely to be in receipt of respite care for their children, in spite of the fact that they are often most in need (Beresford 1994)

According to Dolan and Dowling (2001, p.21):

> 'Families with children with disabilities experience a range of inequalities that families with children without disabilities do not suffer.'

In expanding on their point, the authors assert that:

> 'In the same way that lack of funding, inflexible care arrangements and the prejudices of others disable those with impairments, it causes stress to those who are caring for disabled children and has an adverse effect on family welfare. This often leads to unequal opportunities and outcomes – in work, leisure, finance and quality of family life...it is not only disabled children that suffer as a result of social organisation that fails to take account of difference, but the whole family unit. The lives of these families are different from other families. They are not different but equal – they are different and unequal.'(p.24)

Undoubtedly, definitions of disability are crucial in that they play such a significant part in the way people with disabilities experience life. Spastic, invalid, cripple, retarded, handicapped are labels which have all been used at differing stages in the history of disability, and indeed are still used today by some. Such labels function only to fuel negative perceptions, implying worthlessness and further promoting marginalisation.

In considering definitions, Ryan and Thomas (1980, p.13) purport that they:

> '...have always been conceived by others, never are they the expression of a group of people finding their own identity, their own history.'

It would appear that the emphasis placed on the power held by particular groups allows them to make such definitions. For Barton (1996, p.9):

> '...the outcome of...interventions by professionals has been one of disempowerment, marginalisation and dependency.'

The research study reported here provides an illustration of Handy's (1985) sources of power, in particular, resource power, position power and expert power. The FST were in an extremely powerful position by virtue of the fact that they were 'gate-keepers' to a valuable resource: a much-needed support service for children and families. As already noted, some families were denied that service. The team's position as professionals who were deemed 'experts' in their field, also afforded them considerable power. Indeed, the study attests to the way in which a group of professionals worked to safeguard that power, and protect their professional interests while jostling for position with other professionals who were perceived to be predatory in nature. Indeed, the theme is very much one of maintaining control of service users and also of scarce resources.

Highlighted above, have been some of the problems which the families with children with learning disabilities who participated in this study faced, and which other families with children with learning disabilities continue to face on a daily basis today. Clearly, at the time this research was undertaken there was considerable scope for improvement. The FST had the potential, and indeed, the opportunity to contribute to that improvement. However, the team was unable, for a range of reasons, to grasp that opportunity. Moreover, the first 12 months of the team's life was spent grappling with internal and external obstacles to their development; these barriers to development will be considered next.

The FST – identifying the barriers to development

Given all the problems encountered by parents who participated in this research prior to the establishment of the FST, there was considerable potential for the team to redress the balance in families' favour. Instead, what emerged was evidence of a range of problems which proved detrimental to the team's development, and also significantly impacted upon the quality of the service provided to families.

The problems experienced by the FST during their first year in existence proved a considerable barrier to supporting families with the care of their child(ren). It was the case that the failure to resolve these problems served to further marginalize, exclude and isolate parents, for in some cases they were denied access to a service intended to provide them with much needed additional support. Organisational and professional boundary problems contributed to the role confusion experienced by team members, while the apparent lack of preparatory planning and 'marketing' work left the team isolated and perceived as a threat by other agencies. Lack of effective management arrangements meant that a range of problems, including accommodation issues, remained unresolved for a considerable period, undermining both the morale and effectiveness of the team.

Within the team itself, there was a great deal of role confusion. This contributed to a lack of clearly identified aims and objectives which could be linked to agreed ways of working. At the same time, an over-arching concern with professional 'standing' and etiquette contributed to several problems: first, it hindered the resolution of issues relating to multi-disciplinary team working, in particular the geographical boundary problem; second, it created difficulties in working with non-professionals; and third, it reinforced the existing power imbalance between providers and users by undermining the validity of families' perceptions.

The difficulties associated with multi-disciplinary teamworking identified in the research reported here appear to be as relevant today. For, in a 2002 National Assembly for Wales conference on 'Inter-Agency Working with Disabled Children and Young People', the difficulties encountered in such working were made clear. In a contribution focusing on multi-agency working in the early years, much of the attention was upon the barriers to such working and the means by which these could be overcome. The following were identified as barriers to effective working:

- a lack of understanding of others' roles
- language
- professional jealousies
- a lack of clarity in terms of one's own role
- differing goals

It appears from the above that very little has changed in terms of multi-disciplinary working in Wales since this research study was undertaken.

Parents' anger at the lack of support offered to them in caring for their child, coupled with their perception that no-one seemed to understand the task they faced in caring led to the undertaking of the Mencap study (2004) already referred to. The resulting report:

> '...demonstrates that there is a mismatch between what families need and what services deliver. The very real anger, fear and desperation that many feel is apparent.' (p.2).

A number of key messages emerged from that research: namely, the need to listen to parents and understand their situation; to work in partnership; to respect parents' expertise with regard to their children; and to deliver services which are responsive to need. One of the parents who participated in the Mencap study posed the following question:

> 'We live in a society that sees people like my daughter as worthless. Why, then, would it be one that delivers high quality services?'

It would appear that the above quotation goes some way to answering the questions posed at the beginning of this Chapter, for, at the very heart of disability issues lies the notion of the perceived worth of an individual to society. Given this, one could question the extent to which the FST's inability to resolve the problems they faced was a reflection of a lack of professional commitment to that particular group of service users. Perhaps, the fact that children with learning disabilities are not seen as a priority group provides some explanation for the apparent ineffectiveness of the management structure. The manner in which professional theorising on disability focuses on the pathological model, and the 'handicapped family' model has already been noted. Does such predominantly negative theorising, either explicitly or implicitly, form the basis of working with families? It appears most likely that all of these factors taken together result in ineffective service provision.

What is clear, is that it was not sufficient to set up the FST and then deny it access to an effective management structure and support mechanism. Problems became evident in the very early stages of the team's life and these problems should have been addressed as a matter of urgency. They were not addressed, however, and internal and external issues were allowed to escalate to a point where they militated against effective team working. In the final analysis, the FST was allowed to flounder in the midst of professional rivalries and hostilities. Commitment had been needed from all parties – team members and management - if the team was to succeed. Unfortunately, that sense of commitment appeared to be lacking and thus, some families suffered the consequences.

Middleton (1999, p.35) notes that:

> '...disability has become a medical issue first and foremost. It is commonly defined, diagnosed, and conceptualised as tragic: a mother giving birth to a child with an obvious impairment will probably be moved to a side ward.'

Children with learning disabilities are not amenable to a 'cure' and thus have an anomalous role in society. They are pushed aside because they are different; this is allowed to happen because they are perceived to make no meaningful contribution during their life. The FST represented a response to identified need. The idea of the team was welcomed by the majority of families who anticipated that team members would act as a point of contact for them, and provide them with a sense of continuity where that had previously been lacking; essentially they would be someone to turn to. Yet, the outcome was that some families in a particular geographical area were denied access to much needed support.

There is evidence that little has improved for families with children with learning disabilities since the research reported here was undertaken. Certainly, in spite of attempts to further 'Ordinary Life' principles, it is the case that these families continue to live extraordinary lives and to face extraordinary constraints, be they structural or attitudinal.

One cannot deny the emergence of a plethora of policy and legislative initiatives in recent years. However, one has to question their meaning, and also the extent to which they have been implemented, as the evidence indicates that parents appear to be making the same pleas in 2004 as they were some years ago. This reflects the existence of deeply embedded discriminatory attitudes which emanate from a medical model of disability; the result is the equating of disability with worthlessness.

What next then, for learning disability services? It is clear from the scant progress made since the research reported here was undertaken that policy makers and practitioners have a considerable task ahead of them in addressing the issues raised. In spite of the progress made in some areas, in an attitudinal sense there is still much to be achieved. Indeed, there can be no room for complacency:

> 'We might like to believe that the task of de-institutionalising the care of people with a learning disability is now complete. Nearly all the long stay hospitals are now closed. Many rights are now enshrined in the Disability Discrimination Act. But the reality is that many people are still denied many things that most people take for granted, such as a decent income, somewhere appropriate to live, the chance to work, leisure opportunities, and choices in education. Today's services aim to enable people and promote equal treatment and inclusion. This brings new challenges and responsibilities, the greatest of which is to change public attitudes towards people with a learning disability and raise understanding.'
>
> (Mencap 2004)

Among the concerns expressed by social and health care professionals regarding the provision of health services to children with disabilities and their families include the inadequate and unfair distribution of resources; the low priority accorded to community as opposed to hospital care; the focus on child protection rather than family support; and the difficulties experienced in working across agency boundaries (Middleton 1999). Such difficulties, when taken together with the obviously discriminatory attitudes which pervade thinking about disability, appear considerable; they are not, however, insurmountable.

The predominance of the medical model in terms of learning disability cannot be discounted, for it continues to play an influential role in both professional theorising and popular thinking. Yet in spite of this, it is not impossible to provide effective services for children with learning disabilities. What is needed, however, is leadership, drive, and the vision to initiate change. These elements appeared to be lacking in the FST. Thus, in the face of a range of difficulties the team was unable to function effectively.

The research study reported here provides an illustration of the obstacles to multi-disciplinary teamworking. Unfortunately, one of the only positives to emerge from the study was parents' optimism at the setting up of the FST. The former were hopeful that the team would address the problems they had experienced for so long. At the time the research was undertaken parents' contact with the team had been minimal, however, and it is to be hoped that their optimism was later rewarded.

A number of questions remain, then: namely, how could the FST have overcome the obstacles it faced and thus make a significant contribution to change? Moreover, what are the lessons to be learnt from this?

- First, many of the external problems encountered during the team's development could have been avoided by ensuring that from the very start, the service was properly planned, adequately managed and forcefully marketed to other agencies. Internal problems could have been at least mitigated by ensuring that robust, ongoing team building programmes were integrated with the team's chronological development. Had these things been done, the FST would have been far more effective in helping to ensure that families did not become 'pawns' in a set of organisational tensions which served to deprive many of them of a much-needed service.

- Second, one of the team's roles included the development of community groups; the team could have used such groups to advantage. The latter could have become 'lobbying' agents in the search for additional resources such as speech therapy, for example, which in a historical and contemporary sense has proved so scarce. The Children's Sub-Group could have been similarly mobilised by the team. By working together, it is possible that parents and the FST could have made significant progress.

- Third, as already, noted one of the predominant features of the team's relationships with other professionals appeared to be the latter's uncertainty as to the team's value. Had the team been given a budget to provide services which could only have been accessed through them, for example, respite care, then, this would have placed them in a powerful position vis a vis other agencies, and the first twelve moths of the team's life might have been entirely more positive.

- Finally, Scope's Right from the Start project (2000) points to increased levels of satisfaction on the part of parents where disclosure is made by a professional

> who is sympathetic, understanding and approachable; who is direct and communicates well; and who imparts sufficient information, and allows parents the opportunity to ask questions. None of the above require financial investment. Rather, they require investment in terms of individual attitude and approach on the part of professionals.

Clearly, the Government has made inclusion a central theme of policy and practice for children with learning disability. Yet as Utting, in the Foreword to 'Progress on safeguards for children living away from home' (2004, p.vii) notes:

> '... centrally driven policies depend for their success on the motivation, skills and attitudes of thousands of front-line staff...'

If we are to see real improvements in learning disability services, those front-line staff need to be motivated to confront their own attitudes; to challenge popular deeply embedded attitudes; and to act as change agents in the provision of services.

APPENDICES

Contents:

- *Covering letter inviting families to participate*
- *Reminder letter*
- *Interview guide for use with families*
- *Interview guide for use with Family Support Team* members

FAMILY SUPPORT TEAM

OUR REF:

Dear

Health Authority has recently appointed an independent researcher, ..., who is funded by the Welsh Office, to evaluate the work of the Family Support Team. Part of the research project involves interviewing a number of families who either use the service, or have been contacted by the Team, in order to find out whether or not their wants and needs are being met by the Family Support Team.

Should you be willing to take part in the research study, could you please fill in the slip below and return in the stamped addressed envelope. .... will then contact you to arrange a convenient time to visit.

If you have any questions, please do not hesitate to contact me at the address and telephone number given at the top of this letter.

Yours sincerely

Co-ordinator Family Support Team

REPLY SLIP:- (*Please delete as appropriate)

* I do wish to take part in the research study.

* I do not wish to take part in the research study.

NAME: ______________________ **DATE:** ______________

ADDRESS: ______________________________________

______________________ **TEL NO:** ______________

FAMILY SUPPORT TEAM

OUR REF:

Dear

You may remember I wrote to you a few weeks ago, to ask if you would be willing to take part in a research project which involves evaluating the work of the Family Support Team. .... is carrying out the research. She is an independent researcher, employed by the Health Authority but funded by the Welsh Office.

Part of the project involves interviewing a number of families who either use the service or have been contacted by the Team, in order to find out whether or not their wants and needs are being met by the Family Support Team.

It would be very helpful if .... could speak to you. Should you therefore be willing to take part in the research study, could you please fill in the slip below and return in the stamped addressed envelope. .... will then contact you to arrange a convenient time to visit.

If you have any questions, please do not hesitate to contact me at the address and telephone number given at the top of this letter.

Yours sincerely

Co-ordinator Family Support Team

REPLY SLIP:- (*Please delete as appropriate)

* I do wish to take part in the research study.

* I do not wish to take part in the research study.

NAME: ______________________ **DATE:** ______________________

ADDRESS: ____

______________________________ **TEL NO:** ______________________

INTERVIEW GUIDE FOR USE WITH FAMILIES

Section 1 – Family life; wants and needs

- 'Map' of family life:

Regular contact with?
Help from? Including professionals and non-professionals

- Developmental history:

Moment of diagnosis
Early counselling
Child's relationship with siblings
Child's relationship with friends/extended family
Critical periods:

    Milestones – talking/walking
    School
    Adolescence

School – any advice as to where child is to be 'placed' – mainstream or Special Unit?
Social relationships - parents

- Behaviour of child/ren:

Attitude of family to such
Does family need help with behaviour problems?
Does family need more respite?

- Other needs:

Financial needs?
Problems with transport?
Access to facilities?

- Visits from professionals:

e.g. Health visitors. Are such visits useful?

- Decision-making:

Are families involved enough in this process?

Section 2 – Family Support Team

- Extent of contact with FST?
- What is FST providing at the moment?

INTERVIEW GUIDE FOR USE WITH FAMILY SUPPORT TEAM MEMBERS

At Interview 1, all team members to provide information on the following:

- Their role
- The number of families on their caseload
- The process of adapting to the concept of multi-disciplinary teamwork
- Geographical boundary difficulties

At Interview 2, all team members to provide information on the following:

- The team's progress to date
- Issues relating to multi-disciplinary teamwork
- Whether original aims and objectives have been achieved
- The team's links with other agencies; has the FST been 'accepted' by other agencies?
- Issues relating to management support
- Accommodation issues

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