KING'S FUND CENTRE

REPORT

CHILDREN FIRST?
FAMILY BASED RESPITE CARE AND THE CHILDREN BILL

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CHILDREN FIRST? FAMILY BASED RESPITE CARE AND THE CHILDREN BILL

CONFERENCE REPORT - 21st NOVEMBER, 1989

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FAMILY SUPPORT AND RESPITE CARE - SOME ISSUES FOR DISCUSSION

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Introduction

'Respite Care' as a service figures predominantly in any study of parents' perceptions of good support services and shared care when there is a disabled child in the family. But 'respite care' has many definitions (ranging from an hour's sitting service to virtually full-time residential care). Respite care may be a 'top-up' service to residential schools, when a child is spending little time with any permanent family. It may be part of a network of services offered to families to choose from at their own discretion. It may (or may not) be available for all children with disabilities. There is increasing concern that many parents with children with severe behaviour or physical disabilities may be excluded. Increasingly there is also significant concern about the quality of child care provided, and the need to see respite care not as isolated 'emergency' provision, but as an important component in local authority child care policy and practice.

The Office of Population and Census Survey Reports (1989) on the lives of disabled children and their families give important information on the lives of disabled children and their families. Of the 360,000 disabled children in the United Kingdom, 355,000 live at home. Of the 5000 living away from home, 33% had significant health or behaviour problems which had led to natural or foster family breakdown. The exact nature of such 'problems' is not specified. But it seems reasonable to assume that better support services could have contributed to children remaining in families. Only 4% of the families interviewed received respite care. 60% did not know of the existence of such a service. Only 12% of parents with children living at home had a social worker. Only 72% of the foster parents had a social worker, despite caring for children with significant special needs. The most frequent source of information and advice was a doctor (either the GP or a paediatrician) and only 38% of parents belonged to a voluntary organisation. Again over 60% did not know of the existence of any independent advice or support through the voluntary sector.

The parents were, however, very clear about what they wanted. 23% of parents of 0-4s wanted domiciliary services to avoid disruption to family life. 28% of the parents felt they had less time for their non-disabled children. Finding out about local services (which often existed, even if parents failed to use them) must have been influenced by the fact that 75% of single parents in the

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An independently elected council established under the aegis of National Children's Bureau

study relied wholly on state benefits, with 48% of the men having lower equivalent income than counterparts in the wider community. Hence families had less time, energy or even income (for travel or sitters) to get out and make local connections which would lead to respite care and other support services. Overall, therefore, the OPCS studies tell us that parents have a wider range of unmet needs - and that many of these needs are not met because parents do not have the opportunity to identify local services. The small numbers of families with regular social work support must give rise to the greatest concern (a) because of the local authority case management implications of the White Paper on Community Care and (b) because access to respite care would be most likely through a social services contact. Similarly the small number of parents knowing of local voluntary organisations means that unmet needs may not percolate through to local authority planners - and important support services may be apparently underused.

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SHORT-TERM OR RESPITE CARE - SOME ISSUES FOR CHILDREN'S SERVICES

Respite or short-term care families with a handicapped child has developed historically as an emergency service - frequently providing short-term care within a long-stay hospital or other institution in order to meet a family crisis. Traditionally respite care was offered in 'block' bookings for summer holidays or similar periods and was usually distant from the family home and local services. However, in the last decade there has been a general commitment to flexible family support services, which include respite care as one of a range of options for individual families and children. This shift in thinking towards seeing respite care as part of an integrated service and not a special one-off intervention was based upon Maureen Oswin's principle that 'short term care should be regarded as a very specialist service needing clearly defined aims based on principles of child care practice and requiring continuous monitoring of standards with an emphasis on how it might be affecting individual children'.

In the past decade there has been growing concern to provide flexible short-term care which offers:

a) A local service, where the child can continue to attend school as if he or she were living at home;

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b) Good quality child care which ensures that the child is not treated as a sick patient, but as any child who happens to have a disability;

c) Availability on demand. Research into different models of respite care has clearly indicated the importance of parents choosing patterns of use and being able to use a service flexibly. There is good evidence that many families prefer to use respite care services for short periods of time (sometimes during the day only) rather than in longer-term block bookings.

d) A service which meets the needs of all children. Concern has been expressed about the lack of respite care for children with the greatest need, e.g. emotional and behaviour difficulties or complex medical problems.

e) Age-appropriate care - so that young children and adolescents are given relevant care and occupation.

f) An integrated programme of family support which sees respite care as part of a wider range of professional support services to meet family needs. Escalating use of respite care may indicate a need for preventive services to prevent some children slipping into long-term care.

Respite or short-term care is available in a number of forms. Some children still receive such care in long-stay mental handicap hospitals.

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The most recent DHSS statistics show over 11,000 annual short-stay admissions to long stay mental handicap hospitals. This group of hospital users represent the multiple and severe behaviour difficulties which many local authorities are currently unable to place.

A particular problem in some respite care schemes has been apparent under-use, despite parental appreciation of the availability of such a service. The Honeylands evaluation (1987) and the DHSS Social Work Inspectorate study of respite fostering in Norfolk and Oxfordshire (1984) both identified a number of families who emphasised the importance of guaranteed availability of respite care in enabling them to maintain severely handicapped children at home. Two families in the Honeylands study (Brimblecombe and Russell, 1987) actually claimed they had used emergency short-term care when in fact they had never done so. But so real was their perception of the service offered that they felt secure enough to feel that they had used it and found it a critical factor in continuing family care.

The non-take-up of precious and expensive beds (or substitute families) can be a problematic issue for service providers and planners. The National Development Team (1985) in its annual report noted that: 'anxieties about occupancy rates and the cost of the establishment deter management from being willing to risk places being unused for a time.

The need to book short-term care as much as a year in advance discourages parents from requesting help and a vicious circle develops of cutting places because demand appears low'. Studies of short-term care in the

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Preston Skreens Family Support Unit in Kent (Pahl, 1981), Honeylands (Brimblecombe and Russell, 1987) and Avon (Robinson, 1987) have all found very varied patterns of use amongst families if services are used in ways and at times appropriate to individual family needs. The Preston Skreens study, for example, found that out of 21 families using the unit for respite care, 38 at one end of the scale had only once stayed overnight (day-time respite care becoming an increasingly popular option for many parents) whilst three children had made over 50 visits respectively. The majority of families using both Preston Skreens and Honeylands were light users, with respite care complementing a range of other services. The Avon research (1987) emphasises the fallacy of assuming that respite care is a universal panacea for all family problems. This study found that 'many of the user families had unmet needs as did many of the non-user families ... in both groups there was a call for more home-based services such as sitters, helpers to assist mothers etc. It is evident that the respite care service alone cannot meet the needs of all families with a handicapped child ... it is important to provide a range of services for these families'.

Evidence about the ability of short-term respite care to alleviate family stress is inevitably subjective. The Honeylands evaluation suggests that many families may in fact need relief, but will still only use respite services on an occasional basis. Hence family relief may not be instantaneous and, indeed, measurements of stress levels in families in the Honeylands studies suggested that some families were actually more stressed at the start of using a service than before they did so. Overall stress levels were clearly significantly reduced after a period of time.

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But the stresses associated with letting a child go to another family or unit for the first time are frequently under-estimated. The DHSS Inspectorate Report (1984) in Oxfordshire made a similar point, noting the stages through which parents needed to go in becoming positive utilisers of respite services. This study identified three hurdles for potential users to overcome, namely using the service chosen for the first time; leaving the child overnight and placing a child for a longer period while the parents went away on their own.

Although there has been no comparative research into parental satisfaction with different models of respite care, it seems that parents are more likely to be satisfied if a service is clearly linked to a voluntary organisation, school or a wider service like Honeylands or Preston Skreens in order to put the service in context and to ensure that respite care is a rewarding experience for the child. Additionally families cannot make coherent use of a respite care service if they do not know of its existence. 47% of families interviewed for the OPCS Survey (1989) had no knowledge of such provision - although 48% of parents find it difficult to make friends because of difficulties in getting out or finding time for personal relationships.

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SUMMARY

"Practice Issues in Family Based Respite Care"

C Robinson

As this is a very broad topic, a number of key areas of practice have been selected for inclusion:

1. Access to services
2. Preparation of a) Children and families
   b) Carers
3. The Matching Process
4. Co-ordination
5. Support
6. Effectiveness

These are explained below:

ACCESS

Three issues have arisen during our research work.

i) Services are not equally accessible to all groups. Two have already emerged as less likely to use family based respite care - black and ethnic minorities and those families in social classes IV and V on the Registrar General's Scale. In both cases they were more likely to be using institutional care than family based respite care.

This suggests a need to:

a) Make information about services available through many media including word of mouth and ensure it is translated into the appropriate languages.

b) Make services acceptable to other groups by asking what they need/want and trying to be flexible, eg Asian carers where appropriate or a carer who will provide transport if the family has none.

c) If families find it difficult to negotiate respite stays with another family, provide support and, if necessary, an intermediary.

ii) Currently family based respite care has little social stigma associated with it because it is an entirely voluntary arrangement and is quite informal but some families nonetheless think it implies either an abdication of parental responsibility or failure to cope.

This raises two points:

- the need to retain the non-bureaucratic approach which currently exists under the Children Act
- the need to increase public awareness about the need for respite care and to establish respite care as an acceptable service like child-minding.

iii) Access to services depends also on adequate resources.

It is not possible to broaden out services to make them more accessible to current non users without money or people to:

- advertise
- recruit suitable carers
- support links

Therefore securing an adequate budget must take priority.

PREPARATION

There is evidence that some children are placed in family based respite care without adequate preparation. Lack of preparation may lead to the child's behaviour deteriorating which may either cause parents to stop using the service or to want more help because they find the child more difficult to cope with. Ultimately, the child may be rejected and enter long term care.

In terms of practice therefore there is a need to:

1. Provide slow, careful introductions.
2. Make parents, carers and other professionals aware of the symptoms of homesickness.
3. Offer adequate training and support to ensure families know how to prepare children and how to deal with homesickness.
4. Ensure good communication and feedback so that any problems are openly discussed and addressed.

Preparation of Carers

British and American studies show that some parents think carers are inadequately prepared especially around practical/medical issues and the management of challenging behaviour.

So in terms of practice we need:

- Adequate training at both an individual and group level which involves parents and which is on offer on a "pre-service and in-service basis".
- Advice and support when needed from "experts" (could be parents).
- Contact numbers for "on-line" help.

MATCHING

Research indicates that occasionally this is more a matter of "trial and error" than systematic matching.

Often social workers say they use an element of intuition to match carers. This may lead to a high number of unsuccessful links (we are aware of a case where five had occurred) or families withdrawing because of one bad experience.

What is required:

- consultation about needs and preferences on the carer's side (these are likely to change so this should happen every time a link is proposed)
- ask parents what is most important
- work through a checklist.

CO-ORDINATION

Our research shows that between 18 and 21% of all respite care users in three local authority areas are using two or more types of respite service.

A small minority use three or more.

This is particularly problematic when children are away from home most of the time.

Often one service does not know what other help has been made available to the family.

Suggestions for practice are therefore:

1. Panels to include representatives of Social Services, Education and Health Authorities who act as gate keepers to services to discuss:

    - the allocation of places
    - more consistent placements
    - to ensure the welfare of the child

2. Co-ordinators for respite care to document usage and to visit families to make suggestions for alternative preferable arrangements.

Lack of co-ordination also means that services may be duplicated and there are gaps in provision.

Panels could also make recommendations for complementary/coordinated services.

SUPPORT

Lack of support may mean:

- Losing carers
- Families failing to report problems so use services less or withdraw altogether.
- Children drifting into long term care.

The amount of support provided by different agencies is very variable.

In terms of practice we need:

- to monitor usage
- to provide group support for carers and ideally users
- to visit families
- to carry out reviews at least annually and ideally more often.

EFFECTIVENESS

Requires:

- SERVICES TO BE RELIABLE - may be improved by asking CARERS to make a commitment for a specified time - could introduce contracts and a minimum period of notice to withdraw.

- Securing enough money to last out to end of financial year.

COMPREHENSIVENESS

Requires:

- adequate advertising
- complementary services
- flexibility
- resources

APPROPRIATENESS

Requires:

- assessments of users prior to placement
- reviews including users and carers
- being able to offer alternatives

QUALITY OF CARE

Needs:

- proper training
- thorough assessments of carers
- adequate support including practical help, eg equipment
- good communication between all parties
- reviews
- evaluation of satisfaction and standards

TIMELINESS

Requires that services are offered:

- When they are needed - not delayed
- So that the child's welfare is paramount - ie not at a time when the child is already coping with other major changes - new school, new baby, etc.
- Ideally, do not use in an emergency if an alternative can be found, eg care at home.

INTEGRATION AND CREATING A POSITIVE EXPERIENCE FOR THE INDIVIDUAL

- do not use respite as a purely custodial arrangement
- do not forget to consult children if at all possible
- find out what child enjoys and build into respite stays if you can
- use community facilities - libraries, swimming pools, youth clubs etc.

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THE CHILDREN ACT AND CHILDREN WITH DISABILITIES

PETER SMITH

During the days and weeks of debate on the Children Bill, there was no debate on the wisdom of including children with disabilities along with other children 'in need'.

As well as being remarkable in itself for such a major change, this presented me with a problem as I could not check my understanding of the Bill against the report of parliamentary debate in Hansard.

However, I have checked with Notes on Clauses.....and a senior official at the DH to make sure that I have got it right.

Children with disabilities in need of services will be treated in the same legislative framework as other children in need of services. The new provision will apply to all children in need including those who are disabled or handicapped within the meaning of section 29 of the National Assistance Act 1948. Let's look at some definitions.

A child is 'in need' (Section 17(10) if

a) he is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services;

b) his health or development is likely to be significantly impaired, or further impaired without the provision of services; or

c) he is disabled.

(11) 'For the purposes of this Part, a child is disabled if he is blind, deaf or dumb or suffers from a mental disorder of any kind or is substantially or permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.'

The Lord Chancellor in Committee in the House of Lords said:

> 'The definition in the Act is taken from Section 29(1) of the National Assistance Act 1948 which currently applies the provisions of that Act and other welfare legislation to both disabled children and disabled adults. The 1948 Act is to be modified by amendment .... to limit its provision to disabled adults, local authorities' responsibilities to disabled children being placed with their responsibilities to other children in need in this Bill. Therefore, we are taking the children content out of that Act and putting it in this Bill.'

The White Paper, the Law on Child Care and Family Services, signalled the direction of the Government's thinking. Services, including the provision of accommodation, should be provided on a voluntary basis in partnership with parents. 'Such a service should', in the words of the White Paper, 'be seen as a positive response to the needs of families and not as a mark of failure......' The Children Act aims to put into practice this way of thinking. David Mellor, then Minister of Health, said in Standing Committee:

> Arrangements for children who need to live away from home should be seen as a service used on the basis of partnership and cooperation, and not as a mark of personal failure' (Hansard, Col 156 18.5.89)

These new, entirely voluntary and cooperative arrangements will replace the existing concept of 'voluntary care'; this phrase should fall into disuse.

The aim is to provide a service free of stigma. Before I go into detail of the nature of the new arrangements, it is essential to look at at the overall intentions and some key messages of the Act.

1. READ THE ACT AS A WHOLE

The Act has a structure and a logical sequence. It consists of 12 parts, probably 15 schedules and 108 Sections. Despite its length the Lord Chancellor advised repeatedly that the Act must be read as a whole. To dip into the Act selectively, he warned, without starting with the principles in Part I, or reference to the first important introductory sections, for example 17(1), would be to risk misunderstanding and giving misleading advice.

2. SCOPE

When the Lord Chancellor introduced the Children Bill into the House of Lords in December 1988 he said,

> 'The Bill in my view represents the most comprehensive and far reaching reform of child law which has come before Parliament in living memory.'

The Children Act 1989 is not just another piece of children's legislation. A cursory glance at the list of Acts to be repealed, in part or in their entirety shows the wide scope of the Children Act. Repealed in full are the Guardianship of Minors Act 1971; the Nurseries and Childminders Regulation Act 1948; the Guardianship Act 1973; the Children Act 1975; the Child Care Act 1980; the Foster Children Act 1980. Also repealed are large sections of The Children and Young Persons Acts 1963 and 1969, The Adoption Act 1976 and The Health and Social Services and Social Security Adjudications Act 1983. The Act is a large, comprehensive, consolidated piece of legislation covering both public and private law dealing not only with child care legislation, where parents and the local authorities may be in dispute, but also with the private law including guardianship, custody and other matters related to family proceedings.

The scope of the legislation is wider than anything before; it is literally unprecedented.

As well as overhauling such wide areas of legislation, the Children Act also changes the court structures within which cases can be heard by introducing concurrent jurisdictions. This means that care cases will be allocated to magistrates' courts (to be renamed family proceedings courts) county courts, or the High Court, depending on the degree of complexity.

3. ACCESSIBILITY

The Children Act replaces the present legislative framework for children which David Mellor, described as 'confusing, piecemeal, outdated, often unfair and, in important respects, ineffective.'

The House of Commons Social Services Select Committee Report (1984) called for 'the production of a simplified and coherent body of law comprehensible, not only to those operating it but also to those affected by its operation'. The Children Act 1989 is the Government's response. The Lord Chancellor was able to say to the House of Lords that 'by far the greater part of statute law will be here in a form which is simpler, more accessible to those who work it and more comprehensible'. The law is consolidated and this improvement should help challenge the perception of law as daunting and hostile, which is commonly held by social workers and other human service professions.

4. BALANCE BETWEEN PROTECTING CHILDREN AND HAVING PROCEDURES WHICH ARE FAIR TO PARENTS

The Children Act and the preceeding consultation exercise evolved simultaneously to, and partly as a reaction to, well publicised child abuse tragedies. Responsibility for the distressing events leading to the deaths of Jasmine Beckford, Kimberley Carlile, Tyra Henry and Doreen Mason, was laid at the door of inadequate child protection law and social work practice. To the pressure to tighten up the law on child protection was added, after Cleveland, the pressure to ensure that parents have the right to challenge quickly in court the decisions of the local authority. At Second Reading in the Commons David Mellor described what the Government sees as a 'better balance ...... between the need to protect children and the need to enable parents to challenge intervention in the upbringing of their children'. This new balance can be illustrated by the better protection which should be available to children as a result of the new grounds for emergency protection orders containing a predictive, forward-looking element, 'likelihood of harm', while the parent's position is improved by having a right to apply for variation of such an order after 72 hours.

5. CHILD PROTECTION - A PRIORITY

While the Act was progressing through Parliament it became increasingly evident that if the Government had to disturb the balance discussed above, it would come down on the side of child protection. At Report Stage in the Commons the emphasis on child protection was sealed by the introduction of both a child assessment order and a lower threshold for granting an emergency protection order.

6. PARAMOUNTCY PRINCIPLE

The first principle of the Act is that the child's welfare must be the paramount consideration of the court. In Mr. Mellor's words:

> 'there is an improved statement of the welfare principle governing court decisions in respect of children; that is, the child's welfare must be the paramount consideration. All courts in reaching all decisions about the care and upbringing of children must do what is best for the child.'

The principle of paramountcy, which is the headline in Section 1(1) of the Act and applies throughout, supersedes the differing standards and principles which currently operate. Subsection (2) presents a checklist of factors which courts must consider before reaching a decision about a child. The item first on the checklist, and therefore by implication, the most important, is the duty to ascertain the wishes and feelings of the child. The duty to find out the wishes and feelings of the child is just as clearly emphasised under the duties of the local authority in respect of children they are looking after. A patronising 'we know what is best for the children attitude' will not be lawful.

7. PARENTAL RESPONSIBILITY

The second principle of the Act is that the upbringing of children is primarily the responsibility of parents. The concept of parental responsibility is introduced which, it is hoped, will replace the concept of parental rights. This shift in terminology aims to encourage a change in perception. The notion of parent's rights over children, as if they were property, is overtaken by the concept of parental responsibility, with its associations of parental duty and obligation towards children. Parental responsibility can be shared between a number of people. Both parents retain parental responsibility after divorce, and when their child is being looked after under a voluntary arrangement with the local authority.

8. NON-INTERVENTION IN FAMILY LIFE UNLESS NECESSARY

The welfare of children is primarily the parent's responsibility and the State should help parents discharge their parental responsibilities when necessary, but otherwise not intervene. Thus for example, a court order should not automatically be made if the conditions for the order are proved, but in addition it must be shown that making an order is better for the child than not making an order. Equally in the public domain, the State should only intervene in cases where the children are 'in need'. The definition of 'in need' is open to quite broad interpretation but it is nevertheless intended to limit the remit for State intervention in family life.

9. PARTNERSHIP WITH PARENTS

It is an important principle of the Act that services provided to families with children in need should be provided in partnership with parents. There will be duties for the local authority to find out the views of parents and give them due consideration. The local authority will also be required to maintain the child in his own home where possible and, if not, to promote contact between the child and his family. Creating partnerships with parents will take time and require skill in negotiation but partnership is to be required by law, not left to good practice.

10. DISTINCTION BETWEEN STATUTORY CARE AND VOLUNTARY ARRANGEMENTS

The Act makes a clear distinction between children in care, which means as a result of care proceedings, and children who are being looked after by the local authority under a voluntary arrangement with parents.

The phrase 'in voluntary care' should fall into disuse because it perpetuates the confusion between voluntary and compulsory arrangements. In order to encourage parents to use services to prevent family breakdown and to reduce the stigma associated with them, any element of compulsion has been removed.

The requirement for parents to give 28 days notice of their wish to remove a child from voluntary care will be abolished. So also will be the procedure whereby the local authority assumes parental rights. Under the Bill parental responsibility can only be transferred to the local authority as a result of court proceedings, where parents and child will have full party status and representation. The helping professions will have to be far more aware of the children's legal status.

Strenuous efforts by lobbying organisations to include a notice requirement to terminate a voluntary arrangement were firmly rejected by the Government on the grounds that compulsory notice would be incompatible with the essential voluntary nature of the arrangements.

11. A CONSUMER LED SERVICE?

The duties to find out the views of children, parents, and other significant people in a child's life, and to give those views due consideration could lead to more of a consumer led service. It could reduce the degree of unchecked administrative power of the local authority. The service providers will be more accountable to service users especially in view of the introduction of mandatory complaints procedures which will have an independent element. The details of the complaints procedures are left to regulation, but Section 26 specifically allows complaints from the child, a parent or other significant adult. Complaints can be heard about all services under Part III including provision of accommodation.

12. MULTIDISCIPLINARY AND INTER-AGENCY COOPERATION

This theme runs throughout the Act, which attempts to rectify some of the deficiences in cooperation which have been identified by enquiries and reports. At the end of this paper I will identify some particular areas in which inter-agency cooperation will be required.

PART III Local Authority Support for Children and Families

1) Duty in 17(1)

'It shall be the general duty of every local authority -

(a) to safeguard and promote the welfare of children within their area who are in need; and

(b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.'

2) Section 17(5) contains a duty to facilitate the provision of services by others, including in particular voluntary organisations. This is obviously consistent with the philosophy of the White Paper 'Caring for People'.

3) Section 20 deals with the provision of accommodation - Sub-section (4) states:

A local authority may provide accommodation for any child .... (even though a person who has parental responsibility is able to provide him with accommodation) if they consider that to do so would safeguard or promote the child's welfare.

Sub-section (8) states:

Any person who has parental responsibility for a child may at any time remove the child from accommodation provided by or on behalf of the local authority under this section.

Thus, the local authority cannot provide accommodaton for a child if a person with parental responsibility objects. Nor can it prevent the removal of a child from accommodaton by a person with parental responsibility.

4) In providing accommodation the local authority must ascertain the wishes and feelings of the child 'so far as is reasonably practicable and consistent with the child's welfare', and give due consideration to these wishes and feelings

The local authority must take into consideration not only the wishes and feelings of the child but also the parents when making decisions.

5) 22(6) and (7)

'Where a local authority provide accommodation for a child they shall so far as is reasonably practicable and consistent with his welfare, secure that the accommodation is near his home';

and

'Where a local authority provide accommodation for a child.... who is disabled, they shall, so far as is reasonably practicable, secure that the accommodation is not unsuitable to his particular needs.'

These duties regarding provision of accommodation bring into question at least the lawfulness of indiscriminate transporting of children to far-flung residential homes for respite or indeed long-term care.

6) A further consideration in law relating to child care for the first time is the duty to give due consideration to the child's 'racial origin and cultural and linguistic background.'

The duties of Section 17 are expanded in Schedule 2 Part I, which is a very important part of the Act. (Schedules have equal force in law to the main body of the Act and the Lord Chancellor emphasised that schedule should not be seen as secondary to the rest of the Act.)

<u>Identification of children in need and provision of information</u>

1. (1) Every local authority shall take reasonable steps to identify the extent to which there are children in need within their area. Every local authority shall publish information about services provided by them ..... and take such steps as are reasonably practicable to ensure that those who might benefit from the services receive the information relevant to them.

Maintenance of register of disabled children

2. (1) Every local authority shall open and maintain a register of disabled children within their area.

Assessments

3. Where it appears to a local authority that a child within their area is in need, the authority may assess his needs for the purposes of this Act at the same time as any assessment of his needs is made under -

(a) the Chronically Sick and Disabled Persons Act 1970;
(b) the Education Act 1981;
(c) The Disabled Persons Act 1986; or
(d) any other enactment.

Provision for disabled children

5. Every local authority shall provide services designed -

(a) to minimise the effect on disabled children within their area of their disabilities; and
(b) to give such children the opportunity to lead lives which are as normal as possible.

Provision for children living with their families

6. Every local authority shall make such provision as they consider appropriate for the following services to be available with respect to children in need within their area while they are living with their families -

   (a) advice, guidance and counselling;
   (b) occupational, social, cultural or recreational activities;
   (c) home help (which may include laundry facilities);
   (d) facilities for, or assistance with travelling to and from home for the purpose of taking advantage of any other service provided under this Act or of any similar service;
   (e) assistance to enable the child concerned and his family to have a holiday.

Maintenance of the Family Home

9. Every local authority shall take such steps as are reasonably practicable, where any child within their area who is in need and whom they are not looking after is living apart from his family -

(a) to enable him to live with his family; or

(b) to promote contact between him and his family, if, in their opinion, it is necessary to do so in order to safeguard or promote his welfare.

Charging for services

Parents of children with disabilities may be charged for any services received under S17 (and Schedule 2) except advice and counselling (see Section 29(6). The local authority will have a duty to consider whether they should charge parents if they are looking after a child, but they may only recover contributions if they consider it is reasonable to do so. (See Schedule 2, Part III, Para. 19). Vigorous efforts to remove this duty to consider charging parents from the Bill were unsuccessful.
So if a child with disabilities is provided with respite care in a hospital there will be no charge (unless the introduction of charges are signalled in today's Queen's Speech) and yet if the local authority provide care in the community there may be a fee. As I understand it, the local authority are only under a duty to consider charging; and having considered, and seen that there would be no charge for the child if he or she were in hospital, the local authority would be bound to conclude it is not reasonable to charge under these circumstances. However, local authorities will interpret these sections differently.

Inter-agency Co-operation

The Children Act is a clear attempt to draw services for children more closely together, especially health, education and social services to provide a more effective safety net.

Section 27 Imposes a duty to cooperate on social services, housing, education and health authorities in order to help a child in need.

Sections 85 and 86 require education and health authorities who have looked after a child for a consecutive period of more than three months to notify the local authority. The local authority must then take steps to ensure that the welfare of the child is adequately safeguarded.

This measure is to avoid overlong use of respite care and tackle the problems of some young people with disabilities who are shuttled between different services year round with nowhere which is effectively home.

Section 87 requires proprietors of independent boarding schools to safeguard and promote the welfare of children in their schools. The local authority will have to inspect to ensure that the children's welfare is safeguarded.

CONCLUSION

I think it is a good piece of legislation; how it will apply in practice is of course not all clear - it requires training, changes in attitudes and availability of resources. It could be a valuable charter to improve services for all children, including children with disabilities. Keep in mind Para 5, Schedule 2, give it a high profile to increase the chances of resources becoming available to implement the good intentions of the legislation.

PMS/VB/PS88

4

WORKSHOP REPORTS

1)	The Implications of the Bill for Children in Residential Schools and Local Authority Care.	S. K. Trickett
2)	Respite Care and Welfare Rights	Roland Farley
3)	Raising the Profile of Family Based Respite Care	Geoff Green
4)	Organisational location of Respite Care	Julian Hillman
5)	Implications for the Legal Protection of the child	Phillada Ware
6)	Parents' Viewpoint	Jo Cameron

WORKSHOP REPORT - 1)

THE IMPLICATIONS OF THE BILL FOR CHILDREN IN RESIDENTIAL SCHOOLS AND LOCAL AUTHORITY CARE

S. K. TRICKETT

There are many children in boarding schools who probably should not be there, but have been thus placed because there are insufficient community resources in the way of respite care, fostering schemes, family support etc., to enable them to live a life of quality at home, whilst attending special day schools.

Section 15 of the Children Bill states that it is the duty of every local authority to provide services for children in need, as much as possible within the family. The Bill explains "A child should be taken to be in need if....he is disabled". Schedule 2 of the Bill elaborates: "Every local authority shall provide services designed (a) to minimalise the effect on disabled children within their area of their disabilities; and (b) to give such children the opportunity to lead lives which are as normal as possible."

During the Report Stage of the Children Bill in October, David Mellor moved an amendment to allow councils to give financial support to parents of handicapped children who want to send them to "an establishment outside England and Wales which specialises in providing for children with special needs". He had in mind here the Peto Institute in Budapest and other similar establishments. Will such monies be readily available to parents who need help in caring for their disabled child nearer to home? There are enormous resource implications in this Bill which have not yet been addressed, and unless extra money comes from Central Government Grant (or the poll tax), local authorities may still be in a situation of having to send children with more complex needs to boarding schools.

For those children who are in care whilst attending boarding school, the Bill has altered the concept of "in care" to that of "being looked after" by the local authority; this could take the form of respite care, or shared care, with decisions as to the child's welfare being made jointly by both parents and local authorities. Will this partnership in decision-making be sufficient to prevent a child from drifting between life in boarding school and a series of carers in Homes or Hostels in the holidays? Social workers will need to be able to recognise such a situation, and thus help parents come to a decision regarding their child's current and future welfare; this obviously has implications for social work training.

WORKSHOP REPORT - 1A)

CHILDREN FIRST ? FAMILY BASED RESPITE CARE AND THE CHILDREN.

TUESDAY 21st NOVEMBER 1989.

KING'S FUND CENTRE

WORKSHOP A.

THE IMPLICATIONS OF THE BILL FOR CHILDREN IN RESIDENTIAL SCHOOOLS AND LOCAL AUTHORITY CARE.

WORKSHOP LEADER - SUE TRICKETT

SOCIAL WORKER (SPECIAL NEEDS) ILEA

Issues and questions were raised as follows -

1) GENERAL OBSERVATIONS.

At present, residential school placements are often set up because there is no appropriate alternative resource that would offer care. ie. placements are not always made to meet specific educational needs.

The new legislation will enable parents to ask for funding of placements outside England and Wales for children with more complex needs. (eg. The Peto Institute.)

Resource implications are enormous - and no additional funding will be available other than for training.

School placements are sometimes chosen by parents because they are less stigmatising than L.A. "In Care " status. New legislation might be helpful here as care should be possible without stigma.

Proposals contained in "Caring For People " white paper will mean centrally funded , locally managed budgets with an unrealistic upper limit. Concern was expressed that financial considerations will again outweigh service and good practice considerations.

The 1989 Act makes **child's** interests paramount. The present practice of offering emergency hospital beds to meet **parent** needs often leads to loss of plans for child. Some areas report a shift from care in special hospitals to periods of " assessment " on paediatric wards - especially for children with chronic health problems, /challenging behaviour / or complex disabilities.

Problem of referral to Social Services Departments that often have first contact with a child as he/she reaches adulthood at 18 or school leaving age via C.M.H.T.S.

CONT..................

2) TRAINING

Funds will be available from Central Government only for training. All other costs of implementing the Act will be the responsibility of Local Authorities at a time when most face cuts because of the introduction of Poll Tax.

The Association of Directors stressed the financial implications contained in the Act but failed to win extra resources. The comparatively small fund available will have to be shared by Social Services Departments via Local Authorities, and by the Legal system via the Home Office. (£4 million over the next 2 years)

Implications for working more productively together with other services on training issue. eg.- pastoral staff / Education - Paediatric Services / Health Visitors. However,- will some Departments be tempted to use the funds to cover other training deficits ?

(See new publication -

"Training Together " - available from London Boroughs Training Committee - written by a consortium which included the LBTC and National Childrens Bureau)

3) INSPECTION/MONITORING OF ESTABLISHMENTS.

Many children are currently not in L.A. care but are placed under other legislation eg. National Health Services Act 1977. This has created difficulties in making satisfactory plans for these children.

Concerns expressed by childrens Legal Service about placement of children in private boarding schools and nursing homes, and the apparent abandonment of children in such establishments when their parents are living outside the country. Children in this position will be better served.
Establishments with more than 3 children will now have to register as Residential Homes. (From Oct 1991) The L.A. will have the right to inspect.

Establishments with 3 or less children will be foster homes and registered as such.

DES has already got powers to inspect premises providing education and to decide on efficiency but the new Act gives L.A.'s the duty to inspect **care** for the first time.

4) CHILDREN USING SEVERAL PLACEMENTS

Some children in residential schools use a variety of " respite care " placements during every school holiday. Others are in 52 week educational placements.
Such children are experiencing very little parenting.

Health and Education placements providing consecutive care for 3 months will now have a duty to inform LA. The LA then has a duty to decide how best to provide for the child.

5) LOCAL SERVICE PROVISION / WORKING TOGETHER.

L.A.'s must now provide services as close as possible to child's home. Multi- Agency Panels will consider whether a child has to go outside local community to a placement able to meet needs.

CONT.......

All agencies will be looking at budgets,- which will usually favour local provision.

Agencies will need to work much more closely together .
Informal networking / structures should mean these children are given higher priority.

Disabled Person's Act and assessments at school leaving age- a further forum for co-operation.

Concern expressed about group of children who have pattern of respite care that builds up into longer, more frequent periods away from home, especially around age 10/12 or adolescence. (sometimes presenting challenging behaviour.) How to provide **local** services ?.

6) FAMILY BASED SCHEMES.

Many budgets cease at age 18 or school leaving age.

After age 16/18 if young person has been resident in a LA or private establishment for longer than 3 months he/she will be eligible for leaving care assistance.

Questions Raised.-

A) Will the Act promote the good practice necessary to avoid extended /unco-ordinated periods of "respite care " for some children.

B) There are huge implications for more resources. Services will need to work much more closely together.

There will be a need to develop Joint Planning Teams for children's services.

Georgina Hockaday
Workshop A
23.11.1989.

Children First?
Family Based Respite Care and the Children Bill

Respite Care and Welfare Rights

To charge or not to charge. Whilst the Children Bill does not it seems introduce means testing for respite care services it re-emphasises the discretionary powers of local authorities to waive or levy a charge.

"We believe that many people see making contributions towards the maintenance of their children as tangible evidence of shared responsibility for their children while they are living away from home. The power to charge is drafted with a view to ensuring that no person will be required to pay more than they can reasonably afford." David Mellor, September 1989.

An alternative view may be that many families needing this type of service are likely to be in receipt of Income Support or on low fixed incomes. Whilst the intention of the Bill shall be to promote reasonableness, is their a risk that many families will be deterred from using this kind of support if they are concerned they may not be able to afford it?

To confuse or enlighten. There has been much uncertainty regarding eligibility for continued payment of Attendance Allowance when using respite care provision. The Social Security (Attendance Allowance) Amendment (No 3) Regulations 1983 state that Attendance Allowance shall not be suspended in respect of a person under 18 years who is provided with respite care in a private dwelling in pursuance of section 21 (1)(b) of, and paragraph 2 of schedule 8 to the National Health Service Act 1977.

The Department of Social Security has indicated it is their intention to retain this within the Children Act, though it had initially been overlooked. However, will the cut off point continue to be aged 16, or 18 years?

The Independent Living Fund may help. A Government sponsored charity, the Independent Living Fund may give a grant either on a one-off basis, or to fund ongoing respite care. However, the impression is they perceive their role as being to supplement existing respite care services, rather than be an alternative to them. For example they may assist by providing top up funds when the scope of a respite care scheme is not adequate to meet the needs of the user. To be eligible the applicant must be in receipt of Income Support, or have a low fixed income.

However, who knows what the impact of the White Paper on Community Care will be on the future funding of respite care?

Roland Farley **November 1989**

WORKSHOP REPORT - 3)

Raising the Profile of Family Based Respite Care.

INTRODUCTION TO WORKSHOP

Family Based Respite Care Schemes are relatively new in social work terms. They serve a group of clients who have in the past been regarded as the Cinderellas of the statutory services and development has been piecemeal rather than as a result of a major report or specific legislation. This has resulted in a wide range of different schemes, having comparatively few resources with the service as a whole having a low profile.

But there are good and bad sides to every situation. In the case of family based respite care development,free from a tight legislative framework has resulted in innovation and variety. Clients, carers and future customers have been much involved in the development of their service and the service has been spread through voluntary and statutory agencies.

On the downside, financial resources have always been an issue if a scheme is to develop beyond a certain point.

Equally the question of minimum standards of service loom large when comparing the quality ofdifferent schemes often in neighbouring areas.

To get resources and maintain high standards invariably means influencing those with the power to effect descisions. To acheive this aim the profile of family based respite care must be raised and this brings into focus the kind of strategies that are needed.It seems that both local and national initiatives are called for.

The competition for attention and resources is going to be fierce but the struggle cannot be delayed.

Now is the time to coordinate policy.

WORKSHOP DISCUSSION

Members of workshop introduced themselves and described their schemes in terms of their state of development, their current profile, and location within their departments.

Workshop then brainstormed advantages and disadvantages of having a LOW PROFILE.

Advantages

You can work within the resources you have
No danger of creating great expectations
Saving of money
Not too many people come forward requesting respite care

Disadvantages.

Low profile means unequal access to service. People don't find out about schemes
The lower the profile, the less the resources, which may even be cut if not all used
Difficulty in finding a voice, spokesperson
Problem in getting resources
There is no way of discovering the real need.
Low public awareness therefore no one comes forward to offer care.
Less effective pressure group. for family based respite care.

The workshop then reorganised into pairs. each of which looked at : **Two aspects of respite care which would be useful to highlight in promoting such care.**

Two strategies to promote the take up of respite care
On coming together the group came up with the following ideas.

THINGS TO HIGHLIGHT ABOUT RESPITE CARE.

Flexible, cheap, home based, local, provides continuity of care, geared to needs of individuals and famiiles, integrates people into the wider community, high quality, accepatable to parents.

IDEAS USEFUL FOR PROMOTION OF RESPITE CARE.

Use statisitics to highlight effectiveness, Use Mencap to publicise schemes, have a named publicity/spokesperson, Use the media. Think about programmes like 40 minutes,.National Association should have a key role in publicity. Evaluation of individual schemes to prove their worth. Individual stories the human interest . Education of voluntary groups

Local, cheap, flexible, home based

Geoff Green

WORKSHOP REPORT - 4)

ORGANISATIONAL LOCATION OF RESPITE CARE

JULIAN HILLMAN

Julian Hillman introduced the workshop by giving a short explanation of his own position in relation to the service being operated in Hammersmith & Fulham. He was the Area Manager based in one of the four Area Teams and he acted as Chairperson to the coordinating Group of Family Link, responsible for the day-to-day management of the service. He had also acted as Chairperson to the Advisory Panel, wbhich was a group of professionals in the department, professionals in the Health Service and voluntary organisations who referred families for the service, plus carers and families and a councillor representative from the Social Services Committee. In recent months, mainly due to the expansion of the service, some consideration had been given as to whether its location in the local Area Team was the most appropriate and what alternatives might exist within the Department. No solution had been reached.

In order to assist the group in coming to their own conclusions about the advantages and disadvantages of a variety of settings, Julian had provided a "grid to assist in the decision making". (A copy of this is attached.) The purpose of the grid was to point out the positives and negatives involved in a variety of different choices about location, all of which were listed. Each choice had implications for different interests involved, ie families, carers, staff, funding and liaison with other agencies. The group were given some time to work on their own choices considering the attractiveness of certain settings to different groups of people. Feedback took time to try to work out whether specific settings had considerable advantages over others and what those might be. The 18 people in the group thought that location was extremely important and although there were no obvious front runners in terms of where services should be within the organisational structure, there were certain settings that commanded more support than others. The advantages and disadvantages of those raised during the workshop are listed on the attached sheet. In thinking about the significant issues in location, what emerged as most important was that the service could so easily be marginalised in the way that people with disabilities were marginalised in society. Any service should be placed in a setting where this was least likely to happen. Services needed access to higher management, to resources, to adequte support for workers, and most important was the need to promote the rights of any family with a disabled child. The guilt so often experienced by these families led to a relunctance in taking up whatever services existed and work was needed to facilitate the use of family-based respite care.

To some extent, the debate centred around specialism versus the generic approach and whether families were best served by having a family placement location or a disability location. In the end, would the Children Act be the decider? Questions taken for discussion at the plenary session were: What are the implications for location of services post the Children Act?

What are the implications of the Griffiths White Paper?

2 attachments

Decision making about the most appropriate setting for family- based respite care

Setting	Advantages	Disadvantages
NHS		
Paediatric Dept./ Child Development	Secure funding Training/support to carers Good parental access	Against principle of normalisation; therefore unhelpful to parents
GP attached	Easy parental access	Against normalisation principle Liaison problematic Encourage carers to be over-concerned with medical model rather than normal child care principles Difficult for staff to liaise and find resources for all of their work
Community Health	Secure funding	Medical model approach, removed from child care policy
Other - CMHT	For adult services secure funding Training/support to carers Specialist could militate against normalisation	Limited work resources
VOLUNTARY		
National	Secure funding Good facilities for staff Good support to families	Mainstream informed child care practice less accessible
Local	Service responsive to local needs Good potential involvement of parents	Insecure funding Liaison variable with other agencies Lack of contact with main child care practice

Other

SOCIAL SERVICES

Central Family Placements	Location in mainstream child care resources Secure funding Good staff supervision Training/support to carers	Familes experience stigma of using Social Services. Difficulty in involving parents Possible privatisation of respite care
Disability Team	Secure funding Good parental access Appropriateness for adult services	Limited staff supervision on child care issues Against normalisation
Local - Hospital	???	An institution No local base Funding insecure No staff support
Area Team	Local base Potential to involve parents Potential for good liaison Accessibility for carers	Variable supervision Stigma for families using the service
Other - Resource Centre	Good staff supervision on child care issues Training/support to carers Good parental access Good liaison	Insecure funding

GRID TO ASSIST DECISION MAKING ABOUT THE MOST APPROPRIATE SETTING FOR FAMILY BASED RESPITE CARE

Please put a tick in the box if you consider any option very positive and a cross if you consider any option negative. Leave a blank if a particular option seems middle of the road.

Viewpoint Setting -------> NHS	Families	Carers	Staff	Funding	Liaison	Total	
						✓	x
Paediatric Dept./ Child Development							
G.P. Attached							
Community Health							
Other: CMHT							
VOLUNTARY							
National							
Local Only							
Other							
SOCIAL SERVICES							
Central - Family Placements							
Disability Team							
Local - Hospital							
Area Team							
Other							

NOTES: For families and carers the image of, or stigma attached to, certain settings may be very important. This could also be true for staff. Supervision and support would be important, presumably for all those involved. Money may be more easy to attract to the voluntary sector, or liaison may be easier in a specialist disability team who know the right people to contact. These kinds of arguments and many more would affect how you filled in the above grid.

WORKSHOP REPORT - 5)

WORKSHOP ON THE IMPLICATIONS FOR THE LEGAL PROTECTION OF THE CHILD OF THE CHILDREN BILL

PHILLADA WARE

These are some of the issues which arise from my own interpretation of the bill. The first six concern children with disabilities, the last three are relevant to all children. The group may wish to choose which topics are of most interest.

1. Respite Care will cease to be provided under the National Health Service Act of 1977 and be provided by Local Authorities as part of their duty to "safeguard and promote the welfare of children within their area who are in need" (Section 15). It will be part of the provision of "accommodation for any child in need" (Section 18) and the legal distinction between respite care and voluntary care (under Section 2 of the Child Care Act 1980) will disappear.

   Is this change likely to affect the <u>take up</u> of the service?

2. If respite care is part of the general duty to provide accommodation it would appear that respite care provision will come within the remit of the <u>Boarding Out regulations,</u> (section 20) or such revised regulations as may be brought out after the bill is made law.

   <u>What implications will this have for practice?</u>

3. A recurring theme in the Bill is that decision-making, reviews and complaints procedures should include, where possible, the child, his parents, anyone having parental responsiblity for him, and any other person considered relevant.

   Are there ways of making this provision more useful to children with disabilities?

4. Another recurring theme is the requirement for <u>information sharing</u> between local authorities, <u>health, education and housing departments</u> and the obligation to give help if it is "compatible with their own statutory or other duties and obligations and does not unduly prejudice the discharge of any of their functions".

   Is this likely to make any difference in practice?

5. Section 26 provides for the local authority to make reasonable <u>charges</u> for services except where parents are in receipt of income support or family credit.

   If local authorities do charge <u>will it be a disincentive</u> to families?

   What is the experience of authorities which charge for respite care already?

6. Later sections of the bill give power to the local authority to satisfy themselves about the arrangements in their area for the care of children in voluntary homes, private children's homes and independent schools. The Secretary of State has power to inspect any of these establishments and also any residential care home, nursing home or mental nursing home used to accommodate children.

What sort of priority are local authorities going to give to this aspect of their work. In what ways are children in residential homes, boarding schools and hospitals vulnerable?

7. Legal protection for children in general

The new basis for care orders will be that the court is satisfied:

(a) that the child concerned has suffered significant harm or is likely to suffer such harm, and

(b) that the harm or likelihood of harm is attributable to

i. the standard of care given to the child, or likely to be given to the child if the order were not made, being below that which it would be reasonable to expect the parent of a similar child to give to him, or

ii. the child's being beyond parental control.

Is it possible that these grounds could discriminate against either parents or children who are disabled?

8. Emergency protection orders will replace Place of Safety Orders. They will last for 7 days and can be challenged by parents in court after 72 hours. Child assessment orders and emergency orders excluding a member from the household can also be obtained. If a child is of "sufficient understanding to make an informed decision he may refuse to submit to a medical or psychiatric examination or other assessment.

In what circumstances will these new provisions be useful?

9. "Any person who has parental responsibility for a child may at any time remove the child from accommodation provided by or on behalf of the local authority under this section" (section 18 (8)).

In what circumstances may this cause problems?

The implications for the Legal Protection of the Child under the Children Act

1) Boarding Out Regulations

Under the Children Act respite care will in all probability be covered by a revision of the 1988 Boarding Out Regulations. Respite care services will therefore need to give consideration to bringing their procedures and practices into line with those of other forms of accommodation provided by the Local Authority. Here, revising assessment and review procedures will be important.

Consideration of these issues led into a discussion of whether these changes will have the effect of applying good child care practices to children with disabilities or lead to a 'bureaucratisation' of respite care and a reduction in the flexibility and informality of these services.

2) Panels

Consideration of the appropriateness of panels and the most suitable form of panel arises in part from anticipating the application of the Boarding Out Regulations. There followed an unresolved discussion on whether panels integrating respite care and foster care, or separate panels, respresent the best way forward.

The use of both panels and the Boarding Out Regulations will add consierably to the costs of respite care - both aspects have considerable administrative as well as social worker costs.

Concerns surfaced about whether these changes would make the process of offering and arranging respite care slower and in other ways less attractive to user families.

3) Partnership with parents under the Act

The paramouncy of the child's welfare may reduce the potential for conflict between children's rights and parent's rights. However, the partnership principle seems to involve giving due consideration to the wishes of parents in respect of the type of respite care provided. There may always be some parents who prefer residential to family-based forms of respite care. Residential respite care may continue to be more acceptable to the relatives and friends of some user families. These issues represent a considerable educational challenge to workers in this field in relation to both prospective users and the general public.

WORKSHOP REPORT - 6)

THE CHILDREN ACT 1989: From the Parents' Point of View

JO CAMERON

> *From the Parents' Point of View- Jo Cameron*
>
> *Asking for help from an outside agency because you, as a parent or family, are in need of a break from the every day pressures of supporting a child with special needs, can be very painful and difficult. It can conflict deeply with your own desire to care, to love and to protect, and there can be a real sense of failure. This need for respite care, unless handled with the utmost sensitivity and flexibility, can become destructive to the family as a whole.*
>
> *In the case of my own family, this need occurred when Tom was 18 months. At that time an all-or-nothing solution was offered - full-time placement in a nursery. We opted for a child minder's support for half a day, which then extended to one day a week. When he was eight, we realised we needed a Family Link for the occasional day, or at the weekend. That stage of recognising our need as a family, and going to ask for help, was unbelievably distressing. Through the process of my involvement as a parent representative on a Family Link Scheme, where partnership with parents was considered crucial and invaluable, the co-ordinator had become a friend. His sensitivity and understanding of our dilemma, and the careful matching with another family, has enabled us to choose. We choose infrequently, compared to other families whose needs are 'greater' than ours, but those breaks have been of immeasurable support. If there had been any thought of Tom going into "care" - this would never have occurred. I believe that if payment was part of the package - our other financial commitments may well have taken priority.*

I think it is fair to say that as a parent and a professional I feel confused about the Act. At this moment in time, not much information has been disseminated, or written in every day terminology so that the Act is accessible to parents and professionals alike.

The "Highlight" from the National Bureau has been most useful.

ASPECTS THAT ARE IMPORTANT FOR PARENTS:

1. Very encouraged that children with disabilities have been included under the heading "Children in Need". For far too long children and their families have been segregated from the mainstream, given different opportunities, and their needs considered separately from other children often under the umbrella of Mental Handicap teams which have included adults.

2. The description of children with disabilities (Section 17 (ii)) has the same meaning as the National Assistance Act 1948. The terminology is outdated and perpetuates the medical model surrounding disability. Obviously it is important to establish which group of disabled children you are referring to for particular purposes, but it is notable that other children in need have not been so precisely labelled.

3. **Schedule 2 para 6**

"Services must be provided to minimise the effect on disabled children in the area of their disabilities and to give such children the chance to lead lives which are as normal as possible".

This is a very positive inclusion, but does it give a legal standing for parents to choose and demand integrated provision.

In terms of respite care, this should mean that Family Link Schemes should be given priority within a flexible provision. Families in certain areas are desperate for respite care. Will this duty now ensure tjhat those local authorities who are providing no opportunities, or merely a minimal amount of respite care, can be challenged. It also suggests that the childminding service should be made available to families of children with special needs. This has training implications.

4. Parents will be very reassured that their child will not be "taken into care" in order for them to receive respite care.

Parents have been very resentful that their child, because of disability, needs to be associated with the stigma attached to other child care orders. It is for this reason that Family Respite Care services have been so valued by parents.

5. The fact that Local Authorities are empowered to charge for services provided, is an extremely worrying aspect.

For many parents their child's disability is low on the agenda of social need. Many in need of this service are already receiving income support or are on low fixed incomes. If means testing takes place this may prevent families from taking up the services offered. The preventative intervention of Respite Care Services will be lost, and the situation will revert back to many more parents needing crisis intervention and their children taken into care. This has obvious resource implications, especially when Family Respite Care Services are recognised as being a most cost effective way of supporting families.

6. There are other worrying aspects of this Bill which parents in need of respite care will need to address, either as individuals or as a group, if they are given enough information and opportunities for partnership.

THESE ARE:

a. A major piece of legislation, but how are parents going to learn about their parental responsibilities and their children's rights within the Act.

Recommendation - A parents' guide.

b. How will it be a consumer-led service unless parents or carers are involved at all levels.

Recommendation - Parent representation at all levels

c. How will parents use the Mandatory Complaints service unless they know it exists.

How will they know what they can complain about unless they know their children's rights.

d. Who will be involved in setting-up this service? Will there be parental and voluntary representation.

e. What is meant by Local Authorities under the Act listening and taking into account what services are needed from the consumers' point of view? Procedures in order to ensure that this occurs need to be specifically laid down.

It must be recognised that:

Partnership with parents in some areas is non-existent.

Participation and evaluation from parents is a key factor. Parental forums attached to Education have worked successfully in some appropriate support in some areas. This example should be followed by social services.

f. There has been no concrete discussion of resources: this is particularly worrying for children with disabilities as one needs to question who will prioritise the service need.

Will children with disabilities get an equal resource share - or will services to support their needs continue to be underprioritorised?

Most Acts surrounding Disabilities have an opting-out clause; . i.e., 1981 Education Act "Efficient Use of Resources". UN Declaration on Children's Rights "according to available resources.

7. The National Association for Family Based Respite Care must become a strong voice for parents under the Children Act. This will be essential in order to ensure that Families and their child with special needs receive adequate respite care, most especially in those areas where none or very little exists.

5

THE NATIONAL ASSOCIATION OF FAMILY BASED RESPITE CARE

PEGGY MAXWELL

Family Based Respite Care has expanded rapidly in recent years as a flexible response to the needs of those caring for a disabled child or adult at home. Workers in this field are in a unique situation - accountable to their 'clients' for the quality of their work. Family Based Respite Care is founded on the basis of the expressed needs and preferences of permanent carers, rather than being a solution created by professionals.

Workers in this field began meeting with others, first locally and then regionally to support one another, debate important issues and develop a Code of Practice. The National Association has grown out of these regional gorups and the first General Meeting of the National Association was held on October 16th 1989, following a Press Launch. The National Association has grown out of an awareness of the need to comment in an informed and effective way on government policies and proposed legislation.

One of the first tasks of the National Association was to seek funding for a National Development Worker - this has been achieved by Christopher Orlik's appointment - with a brief to collate information and to develop a profile of Family Based Respite Care throughout the UK. The other tasks for the Development Worker are to organise a conference and to produce a report to include proposals on the way forward for the Association.

Family Based Respite Care has always been a close partnership between the users of services and workers, and the National Association aims to develop the direct involvement of all participants. It is, however, essential to monitor and evaluate the quality of the provision and ensure that in future developments, flexibility and informality are balanced against clear accountability to the users of respite services.