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Discussion Paper

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Family Based Respite Care for Children with a Disability

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INTRODUCTION

A group of workers organising family-based relief care schemes has been meeting since 1980, first at Thomas Coram Foundation and then at the King's Fund Centre, when it was felt that a group would be helpful to enable people to get together to support each other and share information.

Since that time, a closed group has met on a regular basis, looking at particular aspects of respite care, and organising occasional workshops.

Although the Schemes represented within the group vary widely, features of respite care offered by families have emerged, with workers experiencing similar problems of isolation and lack of appropriate support within their own structure, their professional development sometimes overlooked.

The group has considered the range of tasks undertaken by relief care workers, and the supervision offered to them. It continues also to discuss developments in child care practice with regard to children with special needs and their families.

This collection of papers (each by a different author) has been produced by members of the group in an effort to reach a wider audience of people considering establishing a Scheme, or involved in a scheme not within the group. We hope it sparks off debate.

Group members who prepared the discussion papers came from the following agencies:

Brent Social Services
Buckinghamshire Social Services
Camden Social Services
Canterbury Social Services
Croydon Social Services
Ealing Social Services
Hammersmith Social Services
Haringey Social Services
Hounslow Social Services
Lewisham Social Services
Merton Social Services
Oxfordshire Social Services
Surrey Social Services
Sutton Social Services
Family Link, Lambeth

FAMILY BASED RESPITE CARE SCHEMES: WHAT AND WHO ARE THEY FOR?

In her research 'They Keep Going Away', Maureen Oswin expressed great concern about the way respite care is frequently arranged for children with disabilities. Maureen's concern focused on the tendency to see children with disabilities primarily as a burden, from whom parents would be simply relieved and delighted to have a break. She documented much descriptive evidence of the failure of many workers and services to take account of the complex and conflicting feelings of parents and children. In some cases respite care arrangements seemed to reflect more the feelings of workers than the needs of children and families.

Maureen Oswin's research was concerned primarily with residential respite care but included, too, some discussion and comments on the quality of family based respite care - a form of provision that has mushroomed from a handful of schemes in the mid-1970s to in excess of 100 in the mid-1980s.

Maureen expressed cautious confidence and optimism in the capacity of these schemes to meet the needs of children and families.

> 'It enables the children to have short term care in an ordinary home environment instead of in the abnormal environment of a hospital or hostel'.
>
> 'The integration of handicapped children into ordinary families reassures parents'.
>
> 'It helps to spread understanding of handicapped children amongst the neighbours and relatives of the special foster parents who, for the first time in their life, will get an opportunity to meet and know handicapped children as children instead of thinking of them as members of an amorphous shut-away group labelled mentally handicapped'.
>
> 'One of the characteristics of special fostering is the special atmosphere between the natural parents and the special fostering parents'.

It seems, then, that family based respite care, complementing rather than as an alternative to residential respite care, has much to offer. A fundamental issue that needs to be addressed in the organisation of such schemes, however, is the status of the families offering their care. Are they simply 'good neighbours' who may need some advice or back-up from time to time? Or is such an informal approach too informal when considering the vulnerability of children and the need of many parents for a reliable and secure service? How can services be organised to ensure an adequate level of safety and reliability without stifling, through organisational bureaucracy, the essential elements of care and spontaneity?

This dilemma is reflected in the variety of titles for carers. Nearly all suggest different degrees of organisational structure, but all avoid the more formal title 'foster parents'. Maureen Oswin has expressed her regret about this.

> 'It is a pity, however, that the honourable task of caring for other people's children through fostering is apparently held in such low esteem, that it has been necessary to think up new titles for the mentally handicapped children's schemes'.

Why have virtually all workers and schemes avoided the term 'fostering'? Social work practice in fostering has changed considerably over the same period as family respite care schemes have been developing. A trend in fostering practice has been towards much greater formality and the endeavour to secure children in one placement, either with their own family of origin or in a substitute placement, either foster or adoptive.

Very short periods of fostering, for children in care, are still used to assist natural parents at a time of crisis or particular stress. However, the emphasis on most workers' practice, is to endeavour to establish the viability of a child's placement with his or her natural parents and either to support parents in their parenting role or to secure alternative parent figures for the child. The situation in relation to children with handicaps is more complicated and the current 'yardsticks' of parental capacity to cope or parental failure, do not apply nearly so readily. Nevertheless, it is understandable that many workers in the field of respite care are concerned that in using the term fostering in relation to children with disabilities, the same yardsticks will be applied in a way that does not take account of the special circumstances faced by parents with a disabled child. Whilst Maureen is, therefore, right about the traditional idea of fostering, the term currently has particular connotations that many respite care workers have found crucial to avoid and may well do so for the next decade or two.

In developing practice, perhaps the most important thing is to extend to parent respite care services that reflect the special additional demands faced by parents of children with disabilities and that are sensitive to the needs of children. The concerns of mainstream child care workers that children should have security and consistency in their day-to-day care must also apply to children with handicaps. Residential and family based respite care has a crucial role to play in ensuring that parents of children with disabilities have the same opportunity for breaks and separation from their children that all parents have and need. The title given to carers is perhaps less important than ensuring that respite care schemes are now developed properly, informed by main stream child care practice but responsive to the special situations of families with disabled children. As Maureen concludes:

> 'It would seem important for the schemes to now be carefully and quickly monitored at national and local level in order to decide guidelines for those involved in their organisation and to prevent the repetition of mistakes and the likelihood of some incident occuring which might sadly discredit the services'.

That is what this series of papers hopes to contribute to.

ORGANISATION AND FINANCE

This information is based in part on a non-representative survey of twelve established schemes whose coordinators attend the group.

ORGANISATION Respite care schemes tend to have an organisational structure which has grown in answer to local conditions so it is difficult to make comparisons between schemes. The schemes in the survey are mostly based in social service offices and run by experienced social workers, senior social workers or development officers. Eleven coordinators have a social services line manager whose degree of involvement varies tremendously. Staffing of schemes ranges from 1 part-time worker to 2 part-time workers with a full-time coordinator. Most schemes have some degree of clerical support. Some coordinators also have responsibility for other work, usually fostering (see paragraph on coordinators). In a list of 18 tasks (eg. assessment of families, publicity, etc.)all the coordinators except one carried out the vast majority of tasks themselves (Appendix 1). However, some schemes do use volunteers or other workers to support the coordinator in some aspects of the work. Only 2 schemes function as voluntary organisations and only 3 schemes have parent/user advisory groups.

FINANCE Comparisons of budgets across schemes is difficult because many costs are absorbed into other budgets and schemes operate differently. However, some useful points can be noted. Eleven of the schemes are either joint-funded or were before going to Social Services Department funding. The following imaginary budget gives an idea of the range of costs in running a respite care scheme

	Pounds
COORDINATOR (incl. on costs, London)	13,000
CLERICAL/ADMIN. WORKER P/T	5,000
STATIONERY, POSTAGE ETC.	1,000
TELEPHONE	600
TRAVELLING workers & carers	600
TRAINING	500
INSURANCE	300

N.B. Other on-costs may need to be added to salary figures and schemes may need to budget for rent, rates and office costs.

PAYMENT OF CARERS. Payments to carers vary from approx. £15 to £25 for an overnight stay. Schemes allow between £300 and £800 per carer per annum, so for 30 children a budget may be: £9,000 to £24,000

Publicity budgets also vary considerably, from £500 to £2,500

When all costs are included it is obvious that family-based respite care, while not 'cheap', is very cost effective when compared to residential care.

ORGANISATION - DESIRABLE REQUIREMENTS

While taking into account the differences between areas, the Respite Care Study Group have looked at some organisational requirements which are desirable.

SCHEME

It is important for the development of a scheme that it has clear organisational status and identity. This is so respite care is not confused with other services, such as fostering and so the service is not marginalised by the organisation. The scheme should have close links with other organisations particularly parent/user groups. It should have secure and adequate funding for a realistic period. We think this should be at least three years, bearing in mind the implications for planning a service with reference to good child care practice. It should have clear guidelines of operation, with reference to child care practise and organisational constraints in particular.

COORDINATOR

The coordinator should not be expected to do other work which may conflict with respite care. Ideally they should be full-time and the complex range of tasks and responsibilities involved must be recognised in setting up supervision and management arrangements. (See appendix 1). Ad-hoc line management arrangements are not acceptable in terms of effective management or in terms of the status of the scheme. There should be adequate deputising arrangements for the coordinator (to allow participation in planning forums, support meetings etc. and to do development and review work). The coordinator must have adequate administrative and clerical support.

SUPERVISION OF RESPITE CARE WORKERS

The King's Fund Study Group ran 2 joint sessions with supervisors of schemes within the Group during 1986, to work on developing guidelines for the supervision of workers.

The following is a resume of the content and conclusions of those meetings.

Many different tasks and responsibilities of respite care workers were outlined and it was clear that:

1. The tasks and responsibilities of respite care workers are very wide and not within the usual brief of a social worker.

2. The range of tasks represented a very difficult task for supervision.

Issues of supervision

The following issues were raised within the context of three different areas of need for the worker, i.e. personal, professional and management, and with the understanding that few supervisors would be able to meet all these needs.

1. Purpose of supervision needs to be clearly defined and regularly reviewed.

2. Different tasks need different supervision/supervisor. There is a need to identify the full range of worker's needs and to jointly identify ways of meeting needs.

3. The supervisor should be in a powerful position within the organisation in order to secure resources for the Respite Care Scheme.

4. Supervision should be used to lobby support within the management structure.

5. Knowledge base of supervisors may be limited so that the supervisor may need educating.

6. Workers may need an interested group or co-worker as much as supervision.

7. Where does the responsibility lie for raising issues - with the worker or supervisor?

8. Maintaining the status of the scheme within supervision when the worker has other statutory responsibilities.

9. Lack of time for regular meetings with the supervisor.

10. Multiplicity of tasks - worker and supervisor may have different agendas for supervision - e.g. the death of a child versus monitoring statistics.

11. A worker may shield their supervisor from painful aspects of their work - i.e. not discussing the death of a child or a particular disability, if likely to distress the supervisor.

12. Workers can be difficult to supervise - reluctance to let go of the scheme that has been developed, a tendency to hang on to autonomy.

13. Scheme can become personalised - the worker becoming the sole focus of the scheme.

14. The worker may be managing other staff - social worker or clerical.

15. Variety of social work levels/statuses in the appointments of Respite Care workers.

16. Saying 'no' to parents may be especially difficult for Respite Care workers - having tried to develop a user sensitive-service.

17. Holding the anxiety of time-limited schemes of a project nature.

18. Managing the tension of specialism within a generic structure of service provision.

The issues and conclusions may be summed up as follows:

1. Tasks and responsibilities of respite care workers are wide ranging. Some workers have additional responsibilities (e.g. fostering). Workers may be isolated and measuring workload is difficult.

2. Workers hold different positions within the organisational structure of various agencies; likewise supervisors who also frequently hold a multiplicity of roles.

3. The nature of the respite care task may present difficulties for supervision. No one supervisor is likely to be able to meet all needs.

4. Worker and supervisor should develop a supervision contract plus support network to help meet needs not covered by supervisor. Possibilities of group support/supervision (work team/advisory group) or buying in appropriate supervision might be appropriate.

5. The development of advisory groups were seen as valuable. Interest in the service and worker would not only then rest on the individual supervisor. However this should not exclude or be in conflict with individual supervision. It is important to be directly accountable to someone.

6. Newly launched services seen as projects may be of special interest and appealing to supervisors. As projects develop into services, management interest may decline.

7. A conflict may exist with the service wanting to be part of the agency but a separate specialist service.

WORKING WITH FAMILIES USING THE SCHEME

The aim of the work with families is to develop a scheme which meets the needs of local families and is accessible to them and to ensure that using the scheme is a positive experience for the disabled child and their family. At the same time it should be recognised that families may need additional or alternative services. There should be a choice. Other services might be: residential care, relief care in a residential unit, specialist child minding, holiday play schemes, care in the home, home helps, incontinence service, behaviour therapy, counselling.

Working with parents as colleagues

To establish and develop the service in line with need, through discussion with local parents. In some schemes parents are represented on the management committee and some schemes are managed by parents. Many schemes involve parents in the preparation of Relief Carers and most recognise the crucial role parents have in passing on information about the care and day-to-day management of their child.

Publicising the Scheme

Parents need to be informed about the scheme - at the outset and periodically. Through letters, leaflets, talks, newsletters to individual parents, PTA meetings, Voluntary Associations. Special efforts must be made to include ethnic minorities, using ethnic minority workers where available.

Preparation

To enable family to use the scheme - to what extent should families be persuaded to use the scheme? Families need information about the mechanic of the scheme including who they should contact if they need further clarification or are dissatisfied with the service. Need to build up trust, acknowledge feelings of guilt, ambivalence about using scheme - affirm right of rest of family to have space for themselves, need to talk through possible feelings on initial separation, important to see father and siblings as well as mother, and to work with child with regard to their feelings about the scheme.

Some initial work can be done around problems which might arise later, clarifying the workers supportive role. Value of worker who knows the family, where use of scheme is one aspect of work with them: the scheme is not a panacea for all problems.

Do all families need this level of preparation? Discussion with scheme co-ordinator, parent already using the scheme or relief carer may be sufficient to build up confidence, reinforce right to break and positive aspects for child. Similarly, contact with participants in scheme at social gatherings.

Work with family once linked

Parents may be unprepared for inability to benefit from breaks because of anxiety/guilt. Where life has revolved around disabled child, there may be a loss of purpose - some one else can cope. A delicate balance in the family may have shifted. Parents may be unprepared for the strong attachment which develops between their child and the relief carers. Again, what are the child's feelings. Are the family getting less support than the Relief Carers?

Monitoring of Links

This is necessary because families' needs change: relief carers' circumstances change. Are needs being met? Are relief carers being over-burdened? There may have been unspoken expectations on the part of parents or relief parents, e.g., child would be taken out more or that families would become close friends, differences may arise as to how the child's handicap or behaviour should be coped with. Under-use of scheme - is this due to unresolved feelings or wrong choice of relief carers. How much choice do parents themselves get? Over-use of scheme - what is happening in family? Is long term care appropriate?

Review

Is six monthly review a minimum? This can take the form of worker checking out situation with both parties or could be meeting of all those involved in parents or relief carer's home.

Ways of organising Support/Monitoring

Coordinator works with Relief Parent, specialist or generic Social Worker works with family. The workers liase.

Link worker appointed to each link, e.g. Co-ordinator, Specialist Social Worker, parent, role to monitor link and deal with problems relating to scheme - refer to Social Worker where appropriate, Link workers meet regularly.

Additional support can be provided by:-

Relief Carers - they can encourage use of scheme and open discussion of problems relating to care of child.

Groups for parents.

Joint workshops with Relief Carers.

Social gatherings.

Newsheets.

Support also needs to be extended to families on waiting list for scheme or where link has broken down.

In some areas these standards seem impossible to achieve

Do coordinators then have a responsibility not to continue to expand the scheme? It may be inapproprate to link some families unless social worker continues to be involved.

RECRUITMENT OF CARERS

A Before planning methods of recruitment, decisions need to be made about what sort of Scheme is needed. This may be determined by:

1) **The present needs of parents of children with a disability and what services are already provided** eg quanity and quality of residential care and what parents themselves want. An open meeting or questionnaire are useful ways of finding out parents' views.

2) **What is possible?** What resources are given to set up the Scheme, eg finance and staff time.

3) **How the Scheme is defined?** e.g, is it for physically or mentally disabled children or both; what is the age range of the children; how is disability defined? Is the respite care to be in the child's home, carer's home or both? How much will carers be paid?

B **Who does the recruitment?**

This may be: professionals, scheme coordinator, social workers, teachers, relief carers or the parents themselves may find their own relief family.

C **What sort of people are needed?**

Can anyone help or are particular people needed?

Is experience necessary?

Are families, couples or single people wanted?

What age (maximum/minimum)?

How much time are they expected to give?

When is time most needed (i.e. after school/weekends)?

Are there accommodation requirements such as a spare bedroom, downstairs toilet?

Should they live in a particular area? How important is geography and understanding of local community culture?

Should they have transport?

Do they need a telephone?

Is specific cultural understanding necessary? (services of an interpreter might be required in recruiting).

Are people wanted from particular ethnic backgrounds?

Are people needed who can cope with particular disabilities.

D Methods of recruitment

It is important that publicity should not stigmatize the scheme or the users.

General Approach

1) Press Release.

2) Advertisements in newspapers.

3) Posters and leaflets on public noticeboards, libraries, swimming pools, General Practitioners' Surgeries, clinics, hospitals, dentists, Churches, CAB, Volunteer Bureaux and voluntary Associations such as MENCAP.

4) Radio and TV slots.

5) Talks to groups of people.

6) Open evenings to the public.

7) Caravan, stall, mobile publicity board.

8) Video

9) Accounts in church magazines, residents's associations and other organisations' newsletters eg National Childbirth Trust.

10) Postcards in shop windows.

Individual Approach

1) Personal contact with those involved in the Scheme - parents, carers, professionals and existing social networks.

2) Meetings with Health Visitors, individually and in small groups.

3) Discussion with teachers in special schools and units.

4) Personal approach to childminders and foster parents, individually and at their general meetings.

5) Publicity and information given to colleagues to distribute and disseminate where appropriate.

Different methods of recruitment work in different areas and experience has shown that it is more successful when the potential applicant has heard about the Scheme from several different sources.

PREPARATION OF CARERS

Preparation may be a better word than training, as 'training' assumes that during this process, people will learn to do the job required and are trained at the end of the course. It is important to emphasise that the initial preparation is just the first stage in a much longer process.

Aims of the preparation course

1) To develop an understanding of the needs of disabled children and their families.

2) To provide practical information for carers - e.g. management of fits.

3) To give information about other services available which could be useful for future advice.

4) To explain the operation of the Respite Care Scheme and how caring families fit into this.

People Used in Preparation Sessions

1) Experienced carers already approved.

2) Parents using the scheme.

3) Social workers involved with families of disabled children, eg hospital social workers or community mental handicap team workers.

4) Teachers.

5) Social workers in the Respite Care Scheme.

Organisation of the Preparation Sessions

1) Discussion groups.

2) Talks on specific subjects

3) Role play.

4) Task orientated sessions

5) Individual preparation.

6) Involvement of other agencies, eg MENCAP.

PREPARATION OF CARERS: MODEL 1

Our local 'handicap grapevine' tends to supply us with more applicants keen to help on our Scheme than one worker on a part-time basis can cope with. Because we have not needed to advertise since our circulation across the Borough at the outset, people apply when they feel ready to help - so there are usually one or two applicants each month.

Nearly all our applicants come from within the Borough disability networks, and usually know several people involved with the Scheme. The majority are already involved with children or adults with a disability, and many work as home helps, dinner ladies, club leaders etc. This means that although we take up five references on each applicant, more information is often readily available to me - and to the children's parents.

Ours is a 'count me in Scheme'. We felt that the service should be easily available to children's families and carers. We feel that with our widely differing population we will need a very varied group of support parents: carers from different ethnic groups, religions, language groups, ages, attitudes and backgrounds. We cannot expect them all to conform to ideas and beliefs, nor share our views on disability and for this reason we feel we must provide a highly individual preparation for each household. We feel that most people can help a child with a disability, and so we try to include as many people as possible - but some people may have to wait some time for linking with an appropriate child.

In the past we ran two courses of preparation sessions, but now feel that these did not equip families to care for the children. Instead we have a system of combining getting to know applicants and their households with teaching them about the needs of some of the children on the scheme, and introducing applications to new ideas and thoughts on disability.

Our view is that it is the parents who are best able to teach people about their child, helped by us. We feel that offering an overall training programme highlights disability and problems, over and above personality and potential. For this reason we are keen to teach people about specific children, and encourage applicants to go elsewhere for general training on disability.

We try not to impose fostering-type standards, and see ourselves as recommending a support family as having clear references, and in our view being an appropriate link. Approval is really by the child's parents.

When people apply to become carers, I try to visit them at home as soon as possible - ideally within a week. The first contact is to tell them about the Scheme face to face - rather than sending out information. This session is to give them factual information about the Scheme, and take time to outline various issues. If people want to help, they may fill out an application form then - the majority do as they have already previously heard of the Scheme.

During the next two sessions, I try to get to know the applicants and their lifestyle. I need to know them well enough to know what child to link with them, and some of their strengths and weaknesses. They need to know me, trust me and understand the workings of the Scheme. I stress permanently that the Scheme only works if people are honest, and so they must question anything that worries them. Some people will need to be taken on visits to schools, or to children's clubs if they are anxious about their ability to cope - this is particularly useful when one partner only of a couple has experience of disability.

I usually visit applicants three times - unless I already know people well in their work setting. I do a safety check on their accommodation and take up references on all applicants - even if the two households have known each other for many years. When references are through, I visit to discuss with the support parent children available for linking. As I believe that respite care should be a pleasurable experience for all concerned - and we pay so badly - I always try to offer support parents a choice of children: usually two or three. I give a very brief sketch of each child, always starting with the 'problem areas' first - e.g. 'he's eight, wheelchairbound, with limited use of one hand only, no community skills and very prone to moaning when not kept occupied'. If people look shocked, I pass quickly on to describing the next child. If they look interested, I talk about the child's personality. (In matching, I believe in stressing difficulties first, rewards later).

After I have outlined all children I think possible for a support parent, I invite them to decide which child they would like to consider. (99% of the time support parents decide on the child I would expect them to enjoy most). At this point I talk about the child or young person and its family in depth, going through our 'portrait form' in detail and giving as much information as possible. I stress possible areas of difficulty, but also the emotional rewards. I try not to be too enthusiastic about any child, but we are most fortunate in having children on the Scheme with attractive personalities.

When a support parent has decided on a particular child or young adult, I discuss their interest with the child's parents, and with the child if appropriate - again being as honest as possible. We would advise a child's family of major problem areas in a support parent's references, eg a relevant conviction. Respite care is a partnership between the child and its family with the support parents, and I regard myself as a broker who needs to communicate as much information as possible.

If the child and family like the sound of a support family, I seek an introduction. At first, we arranged all introductions at school or day care unit, but I now feel that the venue of the original session needs careful consideration. There are clear advantages of linking in school first: both families are away from home, while the child feels secure, and they can be taken out of the introduction by a staff member so as not to hear discussions about it. Most children's behaviour is so much worse at home that it is often appropriate to show prospective carers the naughty side first - again stressing personality over disability. If carers are not deterred, further visits are arranged. Parents may agree that it is best to start off in the child's home, but very anxious parents may want to visit the support parents home first.

Introductions begin in a tense way, but usually a child breaks the ice. Small-talk stops and families begin in earnest to get to know each other. I do insist that children's parents talk about their child in depth, and am always pleased at how they stress the positives in their child, and often their feelings of attachment to him or her. This enables us all to look at relationships together. I do push people to go through the portrait form together with me; it really is impossible to have a cool relationship with anyone after they have heard so much about the child as a personality. Often support parents and children 'click' on first meeting and we can look at the emotional commitment both families have in respite care.

Our view is that it is the parents' responsibility, helped by us, to train support parents about their child. We will, in fact, go over the information several times in different settings.

I feel that a total of three introductory sessions are necessary for a child as a minimum - except when a 'sitting service' is offered. Three venues are usually necessary: child's home, support parents' home, and school. It does not seem to matter in which order these are visited, but omitting any of them has not proved successful. An extra visit may be necessary: usually to cover behavioural programmes or particular feeding problems. (I find parents can teach most things, but programmes may be complicated to explain and some mothers find it distressing to demonstrate feeding children with severe tongue thrust, when most of the food comes back out). Extra visits can be arranged to look at issues with school nurses, teachers, therapists etc. such as coping with incontinence, management of fits, etc. I try to provide support parents (and often families, too) with appropriate leaflets, and sometimes reading lists.

On the visits to support families' homes, I find it helpful if both households can be present in total. The child with a disability's siblings will be less anxious if they know where he is going, and support parents own children tend to be more accommodating if they have seen the child in its own environment, and played with its toys. To some extent these visits can be seen as educating whole families about the needs of a child.

I am present on all introductory visits. I find it vital to continue to talk to support parents throughout these sessions about the child and its needs, and the different needs of its parents. We cover important areas during these sessions, usually with the child's parents bringing up the topic, which we may continue to discuss when no longer in the company of the child's family.

I have found it better to look at issues with support parents regarding specific children they have met, than in training sessions in a theoretical way.

Each introduction is totally different. Each household will receive a mass of information over a period of time about the other, and will slowly build up trust in one another. Often both are very mervous initially and covering information about the child several times is helpful to everyone.

On the last session if all feels well, the child's parents sign a casualty consent form and we give them their books of vouchers. I remind both households at this time of our monthly groups, which are open to children's parents, support parents and professionals and look at issues regarding disability in an informal environment, so the opportunity of training continues.

Clearly our method of introducing carers to the Scheme is different from some other respite care schemes. It would not suit everyone, but it works well for us. Several schemes work to this model - e.g. Brent and Haringey.

PREPARATION OF CARERS - MODEL 2

All respite care schemes offer some degree of preparation to prospective carers. Many carers already have experience of children with disabilities, through teaching or nursing. Other carers may have had knowledge of people with some degree of disability either through family or friends. Some carers have no experience of working with children with disabilities.

The preparation course gives carers the opportunity to find out as much information as possible about caring for children with needs over and above those of any child. On the basis of the information given, carers who feel the scheme is not for them can withdraw before starting the reference or assessment procedure: An outline of the preparation course shows the programme of 6 sessions currently in use: small group discussions are incorporated to help everyone participate.

1. Introductions - the department, the scheme, the participants. Short video of a neighbouring borough's scheme.

2. Video - 'A Handicap to Love' - small group discussion on issues affecting parents.

3. Four parents talk about their own children and small group discussions focus on the emotional needs of parents and children.

4. What it's like to be a carer - the viewpoint of experienced carers.

5. Physical care - the management of different needs, i.e. epilepsy, incontinence etc. - session led by a school nurse, includes some video aids.

6. How the scheme works? Administration, evaluation of the course.

Issues around the emotional needs of parents and children, and people's feelings about disability predominate. Included within the course is reference to the needs of children from different racial groups and the need for carers to offer their services to all families regardless of ethnic or cultural background. The sessions are led by a coordinator and two specialist social workers, with the administrative assistant attending when necessary.

The courses do involve a considerable amount of work. Feedback from participants is positive in the main and the courses have been amended to take into account their suggestion on improving some sessions.

One of the main issues around the preparation course is that people can either feel they need more information than necessary or that they are fully equipped to do the job. The real training is done with the parents of the child and/or those directly involved on a professional level. As the care needs of each child are so individual, the preparation course is an introduction to the process of work with the parents and in getting to know the child.

In the preparation course stress is placed on the needs and responses of any child who is looked after in someone else's home, but many carers do not feel confident without an input of information on different disabilities. Care has to be taken that people see the child first and the disabilities second.

Some positive aspects of the course are:-

a) providing sufficient information and understanding of the task involved, so carers can think about the kind of child they could care for.

b) providing opportunities for carers to raise anxieties and discuss areas of concern or interest.

c) providing a setting where some element of group support and sharing may be built up.

d) providing prospective carers with direct access to parents and experienced carers.

Some negative aspects of the course:

a) The considerable amount of time spent on what can only be a general introduction to the task.

b) The possibility that some black participants may withdraw from a course, particularly if no black workers are present.

c) The difficulty in helping carers concentrate on the task of caring for someone else's child, when the main concerns expressed are to do with disability.

PREPARATION OF CARERS - MODEL 3

Our preparation is composed of 3 areas:

a) An informal introductory course.

b) Visits to our clubs and activity sessions.

c) Specific preparation when Link Family is approved and matched to an appropriate child.

A) The Preparation Course is concerned with the following:

1. The development and importance of the Link Family Scheme and relationship with other services. The general operation of the Scheme and practical points such as insurance and payment.

2. Understanding the practical and emotional aspects of having a disabled member within the family.

3. Understanding the needs of the children. An Introduction to the main disabilities (eg Cerebral Palsy, Downs Syndrome, Spina Bifida etc.), related medical aspects and management techniques (eg management of epileptic fits).

4. Understanding the importance of developing the child's full potential. The role of special education, the significance of play and development of independence skills. Basic practical information on aspects such as sign language and behaviour modification.

5. Opportunity to consider the Link Family role and to meet and explore issues with Link Families and parents of disabled children participating in the Scheme.

The course is composed of 4 sessions which take place at the following venues:

The Disabled Centre (Voluntary agency); Mary Sheridan Centre (Health Service); St. Nicholas Special School (Education); the Family Support Unit (Social Services).

It is particularly useful to hold preparation sessions at these venues as participants can see around Centres, meet staff and find out about their service. All disciplines are represented and we aim to work closely with all services involved with the children.

A specialist doctor, special education teachers, special Residential social workers, parents and experienced Link Families help lead sessions together with the Link Family Organiser. Facilities such as video, slides and tapes are utilised. Both partners and older children are encouraged to attend the course and 'preparation' opportunities.

B) Visits to our Link Family activities are arranged for new recruits. These are excellent opportunities for children to mix and to allow applicants to gain experience and dispel anxieties. Our Link Family activities are for the children, their brothers and sisters, parents and Link Families and so enable applicants to meet local families and individuals participating in the service and to find out what it's really about! These activities also provide an opportunity for informal introductions to take place and, on occasions, for 'matching' to naturally occur. Activities include 3 local activity clubs; regular 'Bounce' sessions at the Sports Centre, plus numerous outings and meetings. They have proved an excellent asset to the preparation of Link Families.

C) The final 'preparation' of each Link Family is organised when the introduction to the selected child has occurred. This involves very specific information and experience relevant to the individual child and his parents, teacher, therapist and medical specialist will be utilised as appropriate. It will be important that the Link Family has full understanding of the child's disability and has made appropriate visits (eg to see child at school, or the Centre). A daily details form covering all details of the child's care, interests and specific needs (eg medication) is completed jointly by the parents and Link Family. This, together with a check list, helps the Organiser to cover all areas to ensure the Link family is fully 'prepared' in order to offer the child the best care possible.

Using volunteers

The recruitment of volunteers initially came about in order to enable individuals to participate who had something to offer but were unable to fulfil the commitment of a Link Family. Volunteers have to complete a short form, references are taken up and preparation sessions attended. The applicant may then, if suitable, be registered with a recommendation of the sort of work he or she is most suited to. Volunteers are able to offer a valuable service and back-up to the Link Family Scheme in a variety of ways, depending on time availability, interests and abilities of the individual volunteer. These may include the following:

1) Befriending an individual child (who is carefully matched to them). This could be for short day's visits (i.e. not overnight) such as specific outings, helping him/her pursue a special interest such as swimming, or just a regular get-together.

2) A 'sitting service' to enable parents to go out for an evening, sitting with a child whilst mum goes to the doctor, or joining a parent or Link Family if they wish to take a child somewhere and need an extra pair of hands.

3) Helping with our Link Circle Clubs and activities such as the Bounce sessions at the Sports Centre.

4) Helping with publicity, newsletters, looking after our toys, parties etc. There is no end to what volunteers might do!

Insurance cover is offered to volunteers. Payment will be made when a volunteer cares for a child (such as an evening sit) and travelling expenses can be met.

Careful matching of volunteers to suitable activities is made - ie some volunteers may need full supervision and will, therefore, be limited to certain activities.

The use of activities

The Canterbury, Whitstable and Herne Bay localities have each developed 'Link Circles'. These local ventures are primarily concerned with

a) The development of leisure and social opportunities for children and

b) The development of supportive networks of families and individuals within each locality.

Each area runs an activity club for disabled children, together with their brothers and sisters and the children of the Link Family (caring family). Each club aims to offer a high level of supervision and a wider range of interesting activities - art, crafts, music, outings and cooking (especially popular at the eating stage!).

Sessions held at Canterbury Sports Centre, known as 'Link Bounces', are also a regular feature particularly during school holidays and half-terms. These are always well attended. Parents and Link Families bring, and usually remain, at the Centre with their children. The children of all ages and abilities enjoy a range of activities such as trampolining, badminton, ropes, soft play. It is also an excellent opportunity for parents, and Link Families and Volunteers, to meet and for new interested people (adults and children) to find out more about the Link Family Scheme and to gain experience of children with special needs in an unthreatening and enjoyable setting.

The Link Circle also aims to develop contacts with local groups and organisations (eg guides, judo groups etc.) in order to participate as fully as possible in local community life and to make full use of community resources and facilities (such as the Sports Centre).

The Link Circle activities are organised with the assistance of local parents, Link Families and Volunteers and have proved very successful. Friendships between children and parents have developed and opportunities for members to help each other and to share experiences are always encouraged. An informal, supportive local network has undoubtedly developed and continues to do so. Our Link Circle's aim of developing the acceptance and integration of the disabled child into the community is making definite progress.

SELECTION AND APPROVAL PROCESS

The purpose of selection

Why is selection needed?

Who is it to protect - the children and their families, relief carers, or the organisers?

Is it mainly to determine what is realistic for a carer to offer and therefore provide information used in the linking/matching process?

The selection process has some implications for how the scheme is seen by both parents and professionals.

Who makes the selection?

This is mainly seen as the responsibility of the professionals, although in some cases parents may have pre-selected a carer, who then needs to be endorsed by the professional staff.

The final decision for approval rests either with individual staff at senior level in statutory organisations, or with a panel. There may be some parent representation on some panels.

Once the approval process is completed for the scheme, it is then necessary for the family using the carer to make their own specific approval of that person. It is stressed that children are not received into care, linking arrangements only continue if all parties are happy - the child, the parents and the carers.

What is the selection process?

Selection has been based on various models:-

1. An in-depth assessment based on that used for foster parents, but adapted to take into account some of the different tasks of being a carer.

2. An assessment based on that frequently used for child minders.

3. Self-selection, often prior to assessment, through the experience of attending preparation courses or other groups.

Many schemes combine preparation with selection and for some this is on an individual basis with no involvement in groups.

References

Most schemes take up some of the following:

Police - in the case of a local authority there is a duty to take up police references;
Personal references;
GP - self questionnaire;
Medicals;
Health Visitor;
Local Authority;
NSPCC;
Probation;
Housing;
Education Welfare.

Approval

Counselling-out may be necessary

The approval process is as careful as can be but final responsibility for confirming the link lies with the parents.

MATCHING/MANAGING INTRODUCTIONS

Introduction

How are families with disabled children linked to Relief Carers? Do they get together by some kind of self-selection process or are they "matched" by some third party, e.g., the scheme organiser? These notes are some ideas on the nature of this matching process and some consideration in enabling families to form a supportive link.

The Matching Task

This task is about:

Attempting to find a relief carer that will be "acceptable" to parents, and
Attempting to find a relief carer whose motivation would be rewarded.

What Makes a Relief Carer Acceptable to Parents?

They must meet the needs/expectations of parents:

(a) Most commonly these needs/expectations will simply be the creation of the same opportunities for the disabled child to visit friends, be accepted, experience independence, give parents space, as exists for their other children; but

(b) The needs of parents might be quite different from (a) above - the primary need may be mainly for acknowledgement of the parents position/problems/isolation/inter-dependence with their child; in these circumstances, 'relief care', provided on its own, may not be relief at all but may be stressful and painful.

(c) The parents primary need may be for proof of their child's acceptability to the world - the existence and availability of the relief family is enough in itself without the child ever actually having to visit the relief family.

(d) Some parents may need to feel Relief Carers will take the child in a crisis, at anytime.

What About the Relief Carers Needs and Motivation?

(a) Moral values: offering help in order to keep the handicapped child's family together/enable them to continue caring for their handicapped child. The way the parents actually use the break they are given by the relief family may be very important. The relief family may consider that there are justified uses for the break they give parents, e.g. parents going out together, taking children out etc., and unjustified uses, e.g. a single parent going out with a boy or girl friend, going to work.

It may be important to relief carers that the parents needs are special and not simply the same as any parents needs for a break from their child(ren). Some Relief Carers can feel undervalued if there are too many 'other' helpers, e.g. in the extended family.

b) Maternal/protective instinct. The Relief Carers need to care for children. Sometimes rivalry arises between the two families and children become almost in the middle of a 'tug of love'?

c) Assuage guilt at not having a disabled child - 'we feel so grateful that our own children have all been healthy'. Relief families may react strongly to parents who make more demands than they can meet because this reinforces their guilt?

d) Many families have a strong religious motivation for offering to look after a handicapped child.

So the task of matching is about trying to find a link where the needs of both families are met. One is trying to take account of many different aspects. Some of these might be:

Tangible	Feeling
Relief families capabilities/ child's management needs.	Class, race, culture
Geographical location/transport	Attitude of children in Relief Family/over identification of adolescent with disabled child.
Amount of time needed/available.	Inter-action of parents.
Practical Accessibility of Carers Home/degree or disability	Handicapped child's needs/behaviour.

It seems very difficult sometimes to take account of even these basic areas let alone to take account of the deeper needs/expectations of the two families.

Managing Introductions

Some important elements in establishing a link between two families are these:

Matching - thinking about the issues identified above/trying to match the needs of the child's family and the relief carers/trying to take account of the worker's own bias/preconceptions; - the importance for the worker undertaking the matching task, to distance themselves from the pressure to 'offer' a Relief Carer to parents who seem desperate.

Preparation - discussing with parents their expectations/past experiences of receiving help;

- parents experience of their child being cared for by someone else eg in hospital/by a relative; what they liked/disliked; how they coped with separation; rivalry;

- different attitudes towards respite care between the mother and father and how this is to be resolved;

- parents experiences of looking after someone else's child;

- talking with a Relief Carer about their experiences of caring for other children - their own children being cared for by someone else; building on discussion of these kind of experiences and feelings in any training/preparation programme;

- talking to each of the Relief Carers caring for any child, getting each person to share their views/feelings - how will their lives/routines be disrupted by having a disabled child visit?

- how much to tell the Relief Carers about the child's parents/family dynamics?

- enabling less experienced Relief Carers to gain awareness or degrees of disability by visiting Special Schools, Clubs, etc.

Details

- getting correct and full information about the child; information needs to be comprehensive and detailed as apparently trivial things to one family can be extremely important to the other.

Introductions - at whose house? Should both families be present or just parents to begin with? Making sure there is enough structure to reduce anxiety, to give both the families an opportunity to acknowledge doubts, but not so much structure that difficult and unexpected feelings that arise cannot be shared.

What the Relief Carer can offer/what the parents need is likely to change with time but changes should be made in a planned way rather than by default. After the first introductory meeting, both families should be given time to reflect and decide whether the link seems 'good enough' to try one or two initial short visits from the child. When the Relief Family have got to know the child better it often seems helpful to establish some kind of contract so that expectations on both sides are as clear as possible.

Contract

Establishing clear expectations; what the Relief Family can offer/what parents would like even though this would probably need to be changed as the link develops; how problems are to be tackled if a link goes ahead ie the role of the support worker to the link.

PREPARATION OF THE CHILD FOR RESPITE CARE

One member of the King's Fund Group has looked at techniques used in adoption and fostering to prepare children to move into families. The techniques have been adapted for use in preparing children with disabilities to stay with respite carers.

Preparation

This area of work can be overlooked and it is clearly in the interests of the child that someone should enable the parents to undertake it. It may be the family's social worker, a key worker for the family/child or the scheme's organiser.

The following gives an outline of the content and method:

Aims: a) simple; b) easy to repeat; c) involve the child, e.g. looking at a photograph, even if the child is disabled and can only look, they are still being involved in the process

Methods: a) doll play - two families; b) glove puppets; c) photographs; d) bed clothes; e) favourite toys; f) charts.

Rehearse and repeat separation acts to provide security for the child. Talk through with the child, using dolls to represent the people involved. A photograph album, with pictures of the child's family, the carer's family, pets, familiar furniture etc. can be very helpful. The child's favourite toys and even bedding should go with the child. A chart illustrating the journey between the child's home and the carer's home can be an effective technique, especially if 'teddy went too'. 'A Who Cares Chart' illustrating all the significant people in the child's life can be another method.

Rituals: Use the same suitcase, toys, drinks etc. and have them waiting when the child arrives, or have objects from the carer's family placed with the child in his own home so that the carer's family stays alive in the child's mind when away from them. With the profoundly disabled, touch, taste and smell are very important - having things that are links and evoke these sensations are important. Security comes also from physical handling - parents must show carers the best ways for their child. This is particularly so for children who are sensorily impaired, so that washing, feeding and changing are replicated as far as possible.

Anxiety and Testing

Anxiety and Testing: Look for signs that can be pointers to the child's anxiety when separated from his family, e.g. sickness, diarrhoea, withdrawal etc. Grief at separation may be expressed by the following:

1. Purposeful physical activity (searching behaviour - seeking their mother and father).
2. Apparently purposeless physical activity (bewilderment behaviour, milling aimlessly around etc.)
3. Clinging to people (comfort seeking behaviour - holding on to carer).
4. Asking questions (reassurance behaviour - repeatedly asking anxious questions, such as 'mummy come?' etc.).
5. Quarrelsomeness (protest behaviour) - competing for attention.
6. Withdrawn (mourning) behaviour - silent crying, rejection of food and/or drink.
7. Loss of ability (characteristic of anxiety and grief), loss of verbal ability etc.

Some reactions of children after returning home:

Withdrawn behaviour

Anxiety behaviour

Loss of skills

Every child, including children with disabilities, has a way of testing out - parents can share this with carers. A deaf child may shut his eyes and turn off - respite carers need to know his particular way of testing.

Cover stories: particularly with the physically disabled - how can parents tell children about visits to carers without appearing negative? By explaining why different people in families do different things, e.g. your brother or sister may go and stay with friends etc. If the parent feels guilty - the child will pick it up. It is important to develop a story that is confident, positive and honest.

Holidays: Should be positive events - the idea of making it a special time and enjoying it because parents own sense of enjoyment will transmit to the child.

Anger: You can make some of the biggest moves with children when anger, temper or tears come out in uncomfortable situations. This could be seen as a positive step in a child's first experience of gaining some degree of independence from the family, which is common to all children.

Conclusion:

It has been the experience of organisers of respite care services that the preparation of a child for respite care is not always easy and assumptions are made that parents know how to do it.

Parents often need support to do this as the consequences of omission can be very hard on the child.

Further information can be found in Maureen Oswin's book **They Keep Going Away** (published by King Edward's Hospital Fund 1984).

SUPPORT FOR CARERS

A wide range of support for relief carers is offered by different agencies which include:

1. Group Support - sharing the demands and satisfactions of the task, support and training may be combined in groups. Carers may use group as campaigning forum - on behalf of individual families or the respite service. Some problems of mixing carers of different backgrounds in a group. Not all carers find group support helpful; leaders need to keep the purpose of the group clear.

2. Social Groups - several schemes organised social events, e.g. regular outings, parties, picnics etc. Carers may feel isolated and want to meet up on a social basis rather than for more formalised support sessions.

3. Individual visits - by scheme organiser, or user family's social workers. Specialist staff may be available to relief carers on an emergency or non-emergency basis.

4. Newsletters - seem to be widely used and appreciated by carers. Why?

5. Insurance Schemes - some agencies cover extra premiums or make ex-gratia payments.

6. Legal - some agencies use a reception into care when the user family is thought to be at risk of disappearing, or for other reasons. Some agencies issue guidelines for parents and relief carers spelling out where responsibilities lie. Contracts may be used in respite services.

7. Child Abuse - carers will need specific information and advice about dealing with suspected abuse (including sexual abuse). Carers will need advice about the procedures that will be followed if they are accused or suspected of abuse themselves.

8. Emergency Support - relief carers may be able to call on social worker, organiser or out-of-hours service in an emergency.

9. Bereavement - carers should have access to specialist counselling when caring for a terminally ill child, and after the death of the child.

10. Finance - Are parents more likely to use the service if relief carers are paid? Payments may enable some people to take on a caring task. Telephone installation or rental may be considered by some agencies.

11. Equipment - from relief care budget or occupational therapist, trusts, health services.

12. Transport - relief carers or parents may be reimbursed. Community transport and Dial-a-Ride may be used. School transport and volunteers also provide transport back-up to some schemes. Disabled parking stickers may be available in some areas.

Some general issues in providing support for relief carers

a. Should support structures be developed for carers - this may result in de-normalising the service. How do users of the services view the support given to the relief carers? Parents may themselves play an important role in supporting the relief carers. Carers may have existing support networks.

b. There are problems in identifying what relief carers need - carers may well perceive themselves as coping and competent, making it difficult for them to ask for or receive help in their own right.

c. Long standing relief carers have different support needs compared with new relief carers - can their different needs be met using a group model?

d. Caring families may become possessive about 'their family'. This may militate against the use of back-up relief and other sources of help.

e. Support models tend to mirror methods of support developed for helping foster parents. This probably reflects the fact that many schemes have been developed by workers from this background. Alternative models of support may be more appropriate for respite schemes, e.g. co-counselling, social activities etc.

LIAISON WITH OTHER AGENCIES

Confidentiality v Need to Know

All families value their privacy. For families with disabled children this right is perhaps even more cherished because their child's medical condition may require detailed and frequent sharing of family information, and the opening up of their homes to a succession of Health, Educational and Social Service professionals.

Many parents feel that in asking for respite care for their disabled child, their needs are essentially the same as other families who make use of baby sitters and friends. Parents may feel that applying for relief care from an agency, voluntary, health or local authority, offers some guarantee of competence and professional backing to meet the special needs of their child. They may find it less stressful to learn that care is provided as a regular service, not as a favour to be requested of friends and family, only when the siuation is really desperate.

Baby sitters do not normally share information about their clients - is there any reason for sharing of information between organisations offering relief care to parents with disabled children? Confidentiality is highly respected as crucial to the protection of the relationship between doctor and patient, social worker/client and the maintenace of trust and confidence.

It would seem to be desirable therefore that agencies and families should have clear guidelines about what information will be shared and when. Voluntary agencies value their independence from statutory agencies, and the bureaucratic procedures that these employ. The guidelines may need to reflect the differences between respite care and other forms of care - for example, foster care.

Possible Justifications for Liaison

(1) Choice of Relief Care Provision

Some areas of the country have no choice about relief care provision, or no provision at all. Other areas, however, have a variety of respite care services ranging from Health, Social Services and Voluntary provisions, offering residential, family-based, and sitting-in services. Some children and their families will be using more than one of these services, some nearly all.

(2) Treatment Plans

Children need a consistent approach to their behaviour/learning, in order to develop their full potential, and with some handicapped children responses need to be particularly clear, and routines maintained. It may be vital that carers and parents share information, keep records to ensure optimum treatment, and amend treatment plans if appropriate.

(3) Development of skills for Carers/Agencies

Sharing of information is clearly vital for development of service provision, maintaining and raising standards. Obviously this may not necessarily impinge on individual privacy, but clearly some discussion of individual situations may arise. Group support is however much valued by organisers, carers and families who can feel very isolated. Liaison may be needed where carers are offering a service to different agencies, e.g. respite carers who are also child minders. There may be organisational blocks to liaison. Some schemes have found it helpful to establish a forum/advisory group/committee etc. to improve liaison. Liaison therefore needs to be at 2 levels - the individual practical level but also at the more general conceptual level.

APPENDIX 1

List of Tasks Undertaken by Respite Care Scheme Coordinators

Recruitment of carers
Training and preparation of carers
Assessment of carers
Approval of carers
Publicising the scheme
Assessment of user familes
Matching
Introductions
Support of links
Liaison with other agencies
Development of scheme
Formulating guidelines
Administration of scheme
Clerical work
Securing funding
Day-to-day financial control
Scheme budget control
Group activities, (e.g. clubs, support groups)

APPENDIX 2

Film list and references

Films

National Children's Bureau; MENCAP; Spastics Society;

all produce excellent listings of currently available films covering many aspects of disability.

It makes all the difference - Cheshire Foundation Family Support services - 1981 - Concord Film Council - Telephone: 0473 - 76012.
2

With a little help - Yorkshire Television - 1977 Concord Film Council - Telephone 0473 - 76012.
2

A handicap to love - Man Alive Film - 1980. Concord Film Council Telephone 0473 76012
2

Sharing care - Barnardo's shared care scheme - 1981. Barnardo's Film Library - Telephone 01 550 8822.

Young children in brief separation - Robertson films - 5 films 1967-1976. Concord Film Council - Telephone 0473 76012.
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