File: Respite Care G:

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Discussion
Notes

KFC 85/84

Relief care for families with handicapped children

King's Fund Centre
126 Albert Street
London NW1 7NF
Telephone 01-267 6111

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RELIEF CARE SUPPORT GROUP

The group first met in December 1980 when there were a number of workers involved in London relief care schemes.

It was felt that a group would be helpful as it would enable people to get together more formally and spend time sharing and learning from each other.

The group was started as a support group for the workers already involved in existing schemes, and not for workers who were setting them up. New members have joined once their schemes are set up.

The small group met four times a year at Thomas Coram, and in 1981 some of the members helped organise a successful workshop at the National Childrens Bureau for parents, carers and professionals involved in similar schemes.

Following this it was decided that the group needed to meet more frequently, and for members to commit themselves to attendance if the group was to serve a useful purpose.

Since then the group has met monthly at the King's Fund.

These four papers are the result of the groups discussion during this period, and were used as a basis for small groups at a study day held at King's Fund in November 1983.

The day was opened by Maureen Oswin and participants were invited to attend two of the four groups.

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
Dr Barnardos Southwark

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 handicapped 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 outset - 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 mechanics 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 handicapped child, there may be a loss of purpose - some one else can cope. A delicate balance in the family may have been shifted. Parents may be unprepared for the strong attachment which develops between their child and the relief carers. Again what are the childs feelings? Are the family getting less support that 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 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 carers' home.

Ways of organising Support/Monitoring

Co-ordinator works with Relief Parent, Specialist or generic Social Worker works with family. The workers liaise.

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.

Newssheets.

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 Co-ordinators then have a responsibility not to continue to expand the scheme? It may be inappropriate to link some families unless social worker continues to be involved.

RECRUITMENT AND SELECTION

Before planning the methods of recruitment and selection thought should be given to decide what sort of scheme is needed. This may be determined by:

1. The present needs of parents of handicapped children and what services are already provided.

2. What is possible. What resources are given to set up a scheme, i.e. finance and staff time.

3. The organisors background is likely to influence the scheme. For instance the scheme may develop differently if the post holder is based in an adoption and fostering section to the way it would if the post was based in a residential section or a special school.

4. Is relief to be given in child's home or carer's home, or both.

Who does the recruitment

This may be:

Professionals Social Workers Teachers Parents Relief Carers

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. school holidays)
Are there accommodation needs such as a spare bedroom or a downstairs toilet?
Should they live in a particular area?
Should they have transport?
Do they need to have a telephone?
Is specific cultural understanding necessary?
Are people wanted from particular ethnic backgrounds?

Method of recruiting and general publicity of the scheme

1. General approach

   Press release
   Advertisements in papers
   Posters and leaflets on public notice boards, libraries, swimming baths, shops, schools, clinics, G.P.s, dentists, hospitals, churches, C.A.B., volunteer bureaux, voluntary organisations such as Mencap.
   Radio and T.V.
   Talks to groups of people
   Open evenings to the public
   Caravan, stall, mobile publicity board
   Articles in magazines and other peoples leaflets
   Video

2. Individual approach

Personal contacts of anyone involved in the scheme.
Teachers in special schools and units.
Parents and relief carers.
Foster parents and child minders.

Content of publicity

Should the publicity be factual or emotive?
What should be highlighted? for instance "Help a person develop" "Give a family a break" "Work in your own home".

Can an advertisement be for a particular child? parents could write a profile.

Selection

Why is selection needed? Is it to protect handicapped children and their families, relief carers, or the organisors of the scheme? Is it to control the scheme and its development in certin directions?
Is it to assist in the linking process, therefore information about relief carers is needed.

Who selects

Professionals see it as their responsibility. Who has the final decision for approval? Is there a panel, are parents represented?
Do parents select a particular relief carer for their child?
Since children are not received into care the arrangements only go ahead if all parties are happy, that is relief carers, parents, and child.

What sort of selection

1. Traditional vetting of fosterparents which includes an indepth life history.

2. Self selection through attending groups.

Most schemes seem to combine selection with a training group.

References

Most schemes take up some of the following:
Personal references
NSPCC
Probation
Health visitor
Police
Medicals, self questionnaire, GP questionnaire, BAAF medicals
Housing departments
Education welfare

What is the criteria for acceptance

Are people counselled out?

There seems to be more general acceptance for inclusion into a scheme, but narrower acceptance for a particular child.

TRAINING POTENTIAL CARING FAMILIES

The following are some issues which may serve as a starting point for discussion.

Not all schemes provide specific 'training', it may be necessary to ask if training is desirable or necessary.

1) WHY TRAINING?

Some aims are:

- To provide carers with information about and experience of handicapped children and their families - a kind of 'baseline' for understanding the tasks involved and thinking about the kind of child they could care for.

- To provide opportunities (in group or individual settings) for carers to raise anxieties and discuss areas of concern or interest.

- To provide a setting where some element of group support and sharing may be built up.

- Carers and organiser/social worker/parents have opportunities to get to know each other (important too if any assessment is made).

- Training is often part of a selection process (by applicant and/or organiser).

Some issues raised by the training process:

- Use of the word 'training' tends to assume that during this process people will learn to do the job required and are 'trained' at some stage. Important to see it as the first stage in a much longer process, and to ensure that carers are aware of this.

- Carers may be aware/assume that approval follows training. Unless we are clear about our expectations this can cause anxiety.

- 'Training' assumes a level of knowledge and expertise on the part of the teachers! For this reason some agencies prefer to use the term preparation.

2) WHO IS INVOLVED IN TRAINING?

- Are parents consulted - are they involved in the sessions.

- Others involved existing carers - professionals or specialists e.g. Doctors, Nurses, School Social Workers, OTs, Speech Therapists, Specialist Social Workers for any particular handicap, specialists from the voluntary sector.

3) HOW DO WE TRAIN OUR CARERS?

A. Group Sessions:

- Group sessions seem to be common and enjoyed by most participants. Obviously format and content will vary a lot and success will vary a lot and success will vary with different groups.

- Difficulties encountered with such sessions are:

  Attendance - some people are deterred by group meetings or just can't come - or are afraid of 'learning'. Can discriminate against black families and other groups.

  Group dynamics - we need to be able to understand what happens in groups and to enable them to be communicative. Some groups get stuck or dominated.

  Differing levels of experience - some carers may be acutely aware of knowing less. Ways of relating information to common experiences can be helpful.

- What should the content reflect? Some areas commonly covered are kinds of handicap, needs of handicapped children, play, typical practical problems, families' need for relief, issues involved in letting their child be cared for by someone else, practical help and aids, and visits to educational/residential establishments.

- Does training offer a good balance of information/experience and are meetings the best way to achieve this? What are individual experiences of different methods?

- Individual contact can build on the impact of sessions, visits etc.

B. Some agencies prefer to prepare and train their relief carers on an individual basis.

4) FEEDBACK FROM CARERS

- Do we know what our carers feel about the experience individually/ as a group?

- Does this colour their views on the value of ongoing group support?

- Are their views taken into account in modifying future group meetings/other preparation?

- Are any carers involved in training 'new recruits'?

- Do organisers/social workers get opportunities to evaluate their preparation of carers?

MATCHING/MANAGING INTRODUCTIONS

Introduction

How are families with handicapped 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 handicapped 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 that 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.

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 breaks 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 girlfriend, 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).

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 handicapped 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

Relief families capabilities/ child's management needs.
Geographical location.
Amount of time needed/available.

Feeling

Social/cultural matching.
Attitude of children in Relief Family/over identification of adolescent with handicapped child.
Inter-action of parents.
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 e.g. 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 handicapped child visit?
-how much to tell the Relief Carers about the child's parents/family dynamics?

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 i.e. the role of the support worker to the link.

SUPPORT FOR THE RELIEF CARERS

A wide range of support for relief carers are 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 levels of sophistication in a group. Not all carers find group support helpful.

2. Individual Visits - by scheme organiser, or user families' social workers. Specialist staff may be available to relief carers on an emergency or non-emergency basis.

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

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

5. 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 do not seem to be used in respite services.

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

7. Finance - the amounts paid and the thinking behind these amounts paid vary greatly. Some schemes make no payments. Voucher systems are common. 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.

8. Equipment - from relief care budget or occupational therapist, trusts, health service etc.

9. Transport - relief carers or parents may be reimbursed. Dial-a-Ride, GLC Taxi Scheme 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.

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. Carers may feel isolated, and want to meet up on a social basis with other relief carers, rather than for more formalised support sessions.

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

e. Caring families may become possessive about "their family", this may militate against the use of back-up relief, and other sources of help.

f. Support models tend to rely on the involvement of professionals, there is relatively little evidence of relief carers supporting one another, beyond the level of sharing of information.

g. 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. Organisationally, several schemes have links with fostering sections. Alternative models of support may be more appropriate for respite schemes e.g. co-counselling.

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