SHARED CONCERN

Breaking the news to parents that their newborn child has a disability

A booklet of guidance for medical students,
doctors and health workers

To accompany the video
SHARED CONCERN

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SOPHIE
Society of Parents
Helping in Education

HEALTH EDUCATION AUTHORITY

Published for SOPHIE by the King's Fund Informal Caring Programme with financial assistance from the Department of Health and Social Security and the Health Education Council (now known as the Health Education Authority).

ISBN 0 900889 91 98

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Video

1929933866

The video is available for hire from CFL Vision, Chalfont Grove, Gerrards Cross, SL9 8TN (tel 02407 4433).

Purchase enquiries to the King's Fund Centre at the above address.

Acknowledgement of Help and Support

From KIDS (Pond St, NW3): Liz, Pauline, Dawn, Ann and Gloria.

From the Resource Team for People with a Mental Handicap: Siobhan and Sheena.

Sarah Franklin for her help in typing and proof reading.

The Co-ordinators and Management Committee of SPECTRUM, Hampstead.

Lastly, but by no means least, Martin Bould, Janice Robinson and Barbara Fretwell from the Informal Caring Support Unit at the King's Fund Centre.

Shared Concern

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Introduction

Two and a half years ago, a group of parents of children with varying disabilities, supported by Dimitri Sklavounos, a clinical psychologist, began to look at all aspects of bringing up a child with a disability and the help (or lack of it) available to them.

Over the months that followed, it became clear that most of the parents were not satisfied with many of the services. We asked the question, what can we do about it? How could we, as consumers, put forward our needs and those of our children?

We regarded the breaking of the news as the first crucial step undertaken, and the one which had the most lasting effect on our lives, and on those of our children. When we looked more closely into the subject, we found that there was very little training or guidance in the five years a medical student spent qualifying. Even though considerable progress has been made in some areas during the last decade or so, this progress has been consistent neither across the country, now even within the same hospital.

We felt it would be painful for parents to go into medical schools and talk to students on this subject, so we decided to make a film and write an accompanying booklet which would explore the issues in more depth. The Society of Parents Helping in Education (SOPHIE) was born!

We were successful in our application for backing from the King's Fund Informal Caring Programme and we contracted Picture Palace Productions Ltd to make a professional film. We would like to thank Martin Bould of the King's Fund for the enormous help and guidance he gave us, and Tim O'Mara and Vernon Layton, producer and director, for their dedicated work on the film.

Shared Concern, the video we produced, tackles the difficulties doctors experience when they face the unenviable task of informing parents that their baby or young child has a disability. SOPHIE believes this video and booklet, when used as part of student training, and followed by discussion, will help to highlight and resolve many of the uncertainties associated with this task. We would also suggest that *Shared Concern* illustrates the potential for constructive co-operation between parents and the medical profession.

Nicole Specker

SOPHIE Co-ordinator

April 1987

Reactions of Parents

Everyone reacts in his or her own individual way to highly stressful events. Although people go through broadly defined stages, it is important to remember that these are not discrete stages.

In most cases parents will experience a number of these reactions or emotions simultaneously or fluctuate from one to another and back again.

The table is not intended to be exhaustive. Rather, it is to highlight some of the more usual reactions and feelings and the phases that they constitute.

The doctor breaking the news should not assume that dealing with 'feelings' will be done by the social worker – one cannot split feelings of parents and the job of transmitting information to parents about their child. One needs to be able to recognise and assist parents in their feelings as well as passing to them the relevant information.

Some of the emotions expressed by parents to the doctor and other professionals may be difficult to cope with. There may be resentment, anger and suspicion directed against the teller of bad news because he or she will be associated with it. The parents also may feel that the child's condition was caused by the doctor, or blame him or her for not preventing it.

The doctor needs to accept these feelings without becoming resentful or punishing and may be able in time to work through them with the parents. This is again a time when the professional may particularly need support and guidance from other colleagues in the same department. If parents' feelings remain too strong and hostile, a change of doctor may be necessary.

One of the helpful ways to assist parents adjust to having a child with special needs is to support them through their differing and intense reactions. These need to be treated with respect and sympathy. Parents are often helped by knowing their reactions are perfectly normal. They also need to have allayed any inappropriate anxiety, guilt or blame – with clear explanations why these are inappropriate. Sometimes the greatest help of a professional is sharing with the parents through these early days. Even though the need to *do* something is strong, listening and being available is also of great value.

SHOCK	*EXPERIENCED AS:*
Emotional disorganisation	"Stunned" "Hit me like a bolt"
Confusion	"I didn't understand" "I couldn't grasp what you meant"
Paralysis of action	"I felt paralysed" "I felt numb"
Disbelief	"This is not happening to me" "Are you sure? "Are you sure it is my baby?"
Irrationality	"I don't want to hear any more" "I don't want to talk about my baby any more" "I want to go home now"
REACTION	
Sorrow	Silently crying, hysteria
Grief/Bereavement	Mourning the heathy baby which had been expected. Mourning the child that was, who will never be the same again.
Anxiety	"How bad is it?" "Will he/she die?"
Denial	"It can't be true" "But he/she looks so beautiful"
Guilt	"Is it because I drank" "Is it because I smoked" "If only I had..."

Failure	The mother may repeatedly apologize to her husband because she feels she has failed him by not having a perfect child.
Blame	Both parents may blame each other or one or the other.
Anger/Aggression	One or both parents may accuse the doctor of not taking enough care. Some may ask if or what went wrong during delivery, ie that it was due to neglect. Physical violence towards the doctor may also occur.
Defence	One or both parents may state: "There is nothing like that in my family".
Depression	Shattered world. "Why me?" "Why my baby?" "I will not be able to cope"
Feeling of Isolation	"Feeling as if I was the only person in the world that had a child with a handicap"
Controlling Emotions	Some parents may make supreme efforts to keep their emotions under control. Fearing that if they let go they may never recover.
Rejection of Child	One or both parents may decide that they do not want to take the child home.
ADAPTATION	When parents start to ask if anything can be done to help their child.
ORIENTATION	Parents will want to know where they can obtain help and further information.
IMMEDIATE CRISIS OVER	Contact with support services established; arrangements made for first visit or meetings with parents.

Breaking the News

No parent wants to have a child with a handicap or special need. The first news that the child has some kind of difficulty is never welcome and is often traumatic and devastating to the child's parents.

There is no 'perfect way' of breaking bad news, but there are recognised ways of doing it as carefully and sensitively as possible.

The following notes are intended as guidelines on how to break the news and support parents in the early days of knowing that their child has a handicapping condition or special need. These guidelines are applicable to most forms of disability.

This is not a blueprint for action, but is a framework for discussion and further consideration by yourself and with your colleagues.

Although the major issues are covered in the video *Shared Concern* and this accompanying booklet, each situation in real life requires individual consideration.

Preparation before Meeting the Parents

When commencing work in a paediatric or child-centred setting, it is important to find out whether guidelines are available for those breaking this kind of news, and who is most often involved.

Talking to others in your department about the breaking of bad news of children's special needs is a useful way of preparing yourself. It can be a painful and difficult task. Anyone breaking the news needs to be able to turn to other colleagues for their own support during that time. What kind of support can they offer?

Preparation can start as soon as cause for concern is established.

The informant should be a person whose experience and position carries conviction regarding the diagnosis or cause for concern. When the baby is in hospital, in most cases this will be a consultant paediatrician or senior registrar. In certain situations it may be appropriate for the GP to be involved.

There should be no more than 2 or 3 people breaking the news. It is helpful to have a senior member of the ward staff present, so that the knowledge about the cause for concern and about parents' reactions is readily available to all midwives and nurses on the ward.

When a baby or child living in the community has been identified as having a special education need or a learning difficulty by the health visitor, GP, nursing staff, teacher, psychologist or social worker, it may be appropriate to involve the GP, health visitor or other professional in the breaking of the news and in the follow-up sessions. In these cases, parental agreement should be obtained.

Parents should be told as soon as possible that there is a suspicion of handicap, even before a firm diagnosis or full details are established.

It is advisable, except under rare circumstances, to see both parents together. It may be important that a single parent has the opportunity to have another person present to support him/her, such as a friend or relative. This may be extremely difficult to carry out in practice if there is no prior knowledge of the family available.

If the family is well known to the General Practitioner, it may be appropriate for the person(s) breaking the news to speak with the GP in order to obtain a better understanding of the family. Careful consideration should be given to the needs of parents of a different ethnic, cultural or religious group. Discussion with someone (eg: race advisor) who can advise on these aspects should be undertaken, so there is an awareness of the possible implications in breaking the news and for future support.

It may be that there is a "link-worker system" (see references, Asian Mother and Baby Campaign) which can be used in an advisory capacity to the professionals and for interpretation whilst breaking the news. It is not appropriate to use a sibling as an interpreter, and care must be taken using other relatives in this way.

Initial Session

It is usually best to see both parents together in a private room. It is important to allow about ¾ hour for breaking the news, and then see the parents frequently during the next following days.

You need to remember that most parents will quickly be in a state of shock and may only take in a very limited amount of information. So the content must be kept to the most important aspects. In breaking the news, it is important to take parents through what has happened to their child, and the possible implications. Give them plenty of time to absorb the information. Take the first session slowly, and do not take it beyond the parents' own endurance.

Clear, simply stated factual information needs to be given (no medical jargon). The parent does not need to hear medical details during the first session – just the basic medical facts and some of the developmental implications. The latter needs to be very carefully stated. Repetition is helpful in enabling the parents to retain the information.

Parents frequently experience greater respect, trust and confidence when someone has been open with them. This applies equally when the professional admits to not knowing the cause of the child's difficulties.

It is very important to talk about the child as a person, who will grow and learn, have emotions and needs, and have a personality.

Parents have often commented that they do not find it useful to have their child described as a 'medical failure', where the stress is put on everything that the child will not be able to do.

Do not use denigrating terms such as 'vegetable', 'only fit for institutional care', 'cabbage', 'deformed'. These frequently disrupt bonding between parents and child, and lead to negative perceptions which deleteriously affect the interactions between parents and child.

Bland reassurances do not help a parent – saying things like "there's no need to worry", "everything may turn out OK."

Do always leave hope for the parent. Often professionals cannot predict the child's exact rate of learning from birth, and with recent kinds of educational programmes and techniques children with learning difficulties and handicaps often make more progress than is expected at the time of the first diagnosis.

Depending on the circumstances, it may be appropriate to mention briefly to the parents the other professionals, such as physiotherapists, who can help the child maximise his or her potential.

Parents may express grief in your presence. This is part of the bereavement process (for the child they have not had and the loss of their previous life which will now always be different). Parents need to be able to cry and grieve – without being rushed or made to feel uncomfortable. Recognising parents' grief and showing respect for it is often of major therapeutic significance at this stage.

Immediately after the first disclosure, parents should be seen a number of times. Parents frequently say how important it is to be able to see the relevant professionals as much as they can in the first few days. This gives parents time to absorb the informaion and ask further questions.

It is important not to assume that each parent will interpret the information in the same way. All parents react differently, and this may be the case within the the same couple.

Ideally the following sessions should be given during the next day and then a few days later by the same professional(s) who originally gave the first information. Again, visits need to give the parents time – probably another ½ to ¾ hour during each meeting. with both parents present.

Subsequent Sessions

In the subsequent sessions, it is important to ask the parents individually what they have understood. This is also a valuable way of getting to know the parents better, and to communicate in ways that are appropriate to them. During the visits that follow the first disclosure, parents may still be in a profound state of shock for a considerable period of time. They may continue not to absorb information.

Parents may need to ask the same questions over and over again – going over the bad news again and again. They require patient and sympathetic listening – empathy and support. Going over and over the news and information is part of of he process of acceptance – so it is important that professionals are ready to sympathetically go through the information many times. Doctors and other professionals should not feel useless or that they are doing the job badly, because parents may want to cover the same ground many times.

It is important not to assume medical or general knowledge on the parents' part, and not to leave out information assuming that the parents know it.

Encourage parents to write down their questions before seeing the professional, so that they can remember what they want to ask. They may helped by your writing down any advice given to them. After a few meetings, it may be advisable to write simply and clearly on a sheet for parents the medical information about their child. That way, they can go over it again later at home.

There is a greater likelihood of parents individually and collectively expressing very strong emotions during this period. These will often be complex and ambivalent. They may be feeling very unloving towards their child. It is important to listen and let parents express their own feelings without judgement by the listener. Some parents will never adjust to their child having a disability and this has to be recognised and accepted without judgement. For those who do adjust successfully, the time span can range from months to years. It is important never to take a moral approach to parents, eg that they should love their child.

They may be wondering whether or not to take the child home, or they may wish that the child was not alive. They may have had thoughts of murdering the child. They need to be able to express their feelings and to be reassured that these are 'natural' reactions and no cause for guilt.

The parents may also express great anger towards the professionals. This will often be verbal but on rare occasions may also be expressed physically. At times of physical threat, restraint should be the main response. This may well require assistance from colleagues.

In the later visits, it may be helpful to see each parent of a couple separately so that they can explore their own feelings privately.

Each partner of a couple may also take a different time in adjusting to their child and the news than the other, and this requires sensitive, flexible involvement with each partner.

It is worth remembering that diagnosis is an ongoing process and not a static one-off event. The assessment of a child's special educational needs and the implications of a medical diagnostic condition will be explored over a long period of time as the child grows and develops. Prognosis of the child's development is frequently unclear in the early days.

It is therefore advisable to avoid blunt statements like "she will be mentally handicapped" without qualification. This term does not reflect children's many differences in rate of learning and will conjure up the worst fantasies. You need to be able to communicate the current state of knowledge from where you are in the diagnostic process, but also to communicate that the process of assessment will continue over time.

In cases where the diagnosis is not confirmed, parents are most likely to respect being told this, if it is done with compassion and, where possible, with a clear commitment to pursue this.

Parents may wish to seek a confirmation of the diagnosis from other medical specialists. It is important that this is respected, even if it seems unnecessary. It is not unusual for parents to need to do this as part of their way of coming to accept the situation.

Many parents feel more secure if the professionals express their willingness to respond to any doubts or concerns after discharge. This may involve offering a period of time in the hospital for the baby, if this is thought necessary to help the family to cope.

Support Inside and Outside the Hospital

Support for the family needs to begin from the earliest days of concern about the child, whether the child is in the hospital or in their own home. It will need to continue over time, although the form of support may vary as the needs of the child and its family change.

Parents vary considerably in how they can best be helped and supported – some only want to talk to another parent, or only to a voluntary agency, or only to a doctor, or do not feel ready to talk to anyone. Sensitive work with parents requires finding out what support and help suits the particular parent best, and offering the parent the opportunity to choose where they turn to for support and assistance. The choice might include the hospital chaplain, social worker, local priest or friend.

Parents often benefit from the opportunity to meet other parents with children with special needs, through parent support link services and voluntary agencies.

It is important to avoid pressurising parents to take up services in the early stages – parents will take them up in their own time, if they are offered in a flexible way and if contact is maintained.

On many occasions parents may prefer not to have the task of telling other people. Professionals offering to do this is usually greatly appreciated.

Parents may need to be protected from too many visitors in the early period – often it is more important to have a few visitors who visit regularly (this needs multi-disciplinary coordination).

There is a need for a coordinator for the family – whoever is the most appropriate person. The doctor should never withdraw until it is ensured that co-ordination is happening by a named person. The family should also be informed of the relevant voluntary groups available. Families should never be left waiting for services – they need immediate accessible help from the beginning (see list of appropriate agencies – end of booklet).

The junior doctor can often play a role in coordinating services and liaising with professionals on behalf of the family, which can be both influential and valuable.

During these early days, parents are often assisted by giving some practical activities and advice (helping parents to do normal parenting skills, handling the child). Parents often experience a loss of confidence in handling their baby at this time. They may feel shock and that playing with and handling the baby is a waste of time. Professionals can help by giving a positive role in warm, appropriate handling with the baby and guiding parents in the handling.

It is important that parents are informed of all developments as soon as possible. This includes developments in the condition; in ascertaining diagnosis and in responses from outside agencies.

The amount of time parents need may be quite great. If the doctor's time is genuinely restricted, it is essential that the necessary assistance and support can be provided by other colleagues (eg: nurse, social worker, psychologist).

Preparing the Family for the Future

Parents, even experienced parents, are entering unchartered territory. For them it is important that they receive as much knowledge as possible about the possible difficulties in the immediate future.

The main emphasis should be on assisting the parents regain as much competence and confidence as is possible. The diagnosis should lead to prompt and positive help for the child and family. This should be done without inundating them with visitors.

Parents will need positive information about the available help and support for the child – teaching services (eg: portage home learning services, speech therapy, physiotherapy, occupational therapy), parent and child opportunity groups, nurseries, support services for parents and families (social workers, self-help parent groups, voluntary agencies).

Parents need to be linked to the appropriate personnel in the community as soon as possible – the family doctor, health visitor, home liaison teacher, social worker, so that the family do not feel isolated and abandoned.

Linking parents with other parents of children with special needs may also need to take place at this stage, if it has not happened in the hospital.

Maintaining Hospital-Community Support

Once the child and family have been linked up to community services, the role of the hospital personnel may be over. But frequently it is appropriate to maintain hospital-community links over a long period of time. Some children with special educational needs have complicated medical conditions requiring long-term paediatric monitoring and intervention. Children without a medical diagnosis often require ongoing diagnostic investigation as changes in medical knowledge and techniques may throw up new light on the child's condition. Doctors in the community and hospital medical staff often need to work closely together around children with special needs.

It is helpful to maintain regular liaison between hospital staff and professionals working with the family in the community. This may include the GP, health visitor, social worker, occupational therapist, physiotherapist, clinical and educational psychologist, nursery staff and teachers. It may also include members of voluntary agencies. All liaison and decision-making around the child and its family should actively involve the parents.

Points to consider

1 **Tell the truth**: Explain how and why to best of available knowldge

Professionals withholding information (either cause or uncertainty about cause) *confirms* that they are covering up in the eyes of the parents.

Aadmitting to not knowing the cause may initially increase parents' anger, but will ultimately bring about greater respect for the professionals.

2 **Break the news gently and sensitively**: The pain of the news is a massive enough burden for parent(s). If broken gently and with respect and concern for the parent, the parent will feel more able to ask for more information/support.

Take at at the pace of the parent(s): If the task is undertaken as soon as is practicable, then there is a greater potential for breaking the news over 2 or more sessions, as necessary.

4 **Transmit hope**: This is one of the most crucial factors. Conditions themsleves may be irreversible, but their impact on the individual's functioning often varies dramatically.

Research shows that everyone can make some progress.

5 **Avoid degrading descriptions**: 'only fit for hospital care', 'a vegetable' 's/he's handicapped'.

6 Write down the relevant information Research shows clearly that in such situations 60% of the information is frequently forgotten or not heard. The significant information may be lost.

7 Ask the parent(s) to draw up a list of questions: This can avoid unnecessary frustration on both sides, and time-wasting when parents struggle to recall questions during doctor's rounds etc.

8 Follow-up with subsequent visits: Parent(s) being left with bad news intensifies their sense of helplessness and isolation. Sharing their distress over a number of visits increases the support experienced by the parent(s).

9 Avoid 'We don't have the time' excuses: If you are *genuinely* unable to offer the necessary time, recruit the help of other professionals (eg. social worker, chaplain, parents' group).

Not having the time is *no* excuse for families needing a great deal of support.

10 Give information on local resources: Give or direct parent(s) to a place where they can obtain information on local support groups/organisations.

Waiting for parents to be ready may be unwise. Give them information which they can read whenever *they* are ready.

11 Offer to break the news to relatives: On many occasions parent(s) might prefer not to have the task of telling other people.

12 Keep parent(s) informed of all developments (in condition or ascertaining diagnosis etc.) **as soon as possible.**

13 Parents will not resolve many conflicts while in hospital: The time scale usually consists of years.

The sensitivity and amount of support offered to the family will actually help them to resolve some of these conflicts more quickly and constructively.

14 The degree of sensitivity, concern and respect for parents you manifest in this situation will greatly influence the productiveness of future working relationships between professionals and parents.

Usually first experiences have dramatic effects for both professionals and parents.

The more the parents can trust and respect the doctors, midwives and nurses etc, the more productive the starting point of working together on future occasions.

Insensitivity etc damages these working relationships, frequently throughout the lives of the family members.

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Practical Ways for Students to Increase their Awareness of Mental and Physical Handicap

If a medical student has had first-hand experience during his or her training of the long-term effects on families of bringing up a child with a disability, then he or she will be much more aware and sensitive to the implications of breaking the news to parents.
Suggestions for first-hand experience include:

- visit some of the services and find out what help is given
- visit the special schools and if you have spare time, offer to help in some activities they organise
- visit families who have children with a disability. Talk to the parents and listen to what they have to say. They have a wealth of practical experience which you will find useful
- find out if there are any ways in which you can do voluntary work with children with disabilities. Some schemes such as SPECTRUM in north-west London link medical students to a family for the period of their training. Students can help by baby-sitting, taking the child out and on organised holidays. Ask if a scheme exists in your hospital. Local volunteer bureaux are also points of contact. Other medical students may know of suitable schemes.

Students can also find out what services exist in the area where they live or study.
The following suggestions are intended to help students:

- make enquiries to find out your hospital's policy concerning breaking the news and to ascertain what support would be available
- find out if there is a community paediatrician or special team to help families with a child with a disability
- undertake a project to list all the statutory and volutary projects offering support to parents in your local community, with name, address and brief details

Outside the hospital, starting points for these enquiries may be the local disablement association, a local branch of one of the voluntary organisations listed in the section on useful addresses, or the community health council. One of them may be interested in printing a directory for parents, based on the information you gather.

The following headings are taken from a booklet for parents, 'Help Starts Here', published by the Voluntary Council for Handicapped Children. They may serve as a framework for a project looking at local information and support for parents.

Special equipment and information

health services for equipment
health visitors for advice and help
social workers to help cope with stresses and problems
Community Health Council for queries or complaints
parents groups
voluntary organisations

Financial help

attendance allowance
Family Fund for Handicapped Children
Family Income Supplement
free milk and vitamins
grants for extended education
house adaptations and equipment
housing benefit
invalid care allowance
mobility allowance and Motability
fares to hospital
severe disablement allowance
supplementary benefit
(Note: this list was drawn up in 1985. Rules on benefits change frequently, and major changes are planned in 1988. For up-to-date information, consult the Disability Rights Handbook published by the Disability Alliance ERA, 25 Denmark Street, London WC2H 8NJ. Tel: 01- 240 0806)

Holidays and Short term care

Pre-school help

Education

Leisure and recreation

Useful Addresses

Association for All Speech Impaired Children (AFASIC)
347 Central Market
Smithfield
London EC1 (01-236 3632)

Association for Spina Bifida and Hydrocephalus (ASBAH)
22 Upper Woburn Place
London WC1 (01-388 1382)

British Diabetic Association
10 Queen Anne Street
London W1M OBD (01-323 1531)

British Epilepsy Association
Crowthorne House
New Wokingham Road
Crowthorne
Berkshire (03446 3122)

British Institute of Mental Handicap
Wolverhampton Road
Kiddermister
Worcester (0562 850251)

Brittle Bones Society
112 City Road
Dundee (0382 67603)

College of Speech Therapists
Harold Poster House
Lechmere Road
London NW2 (01-459 8521)

Colostomy Welfare Group
38 Eccleston Square
London SW1 (01-828 5175)

Contact A Family
16 Strutton Ground
London SW1 (01-222 2695)

Cystic Fibrosis Research Trust
5 Blyth Road
Bromley
Kent (01-464 7211)

DHSS Leaflets Unit
Government Buildings
Honeypot Lane
Canon's Park
Stanmore
Middlesex

Disabled Living Foundation
380/384 Harrow Road
London W9 (01-289 6111)

Disability Alliance
25 Denmark Street
London WC2 (01-240 0806)

Down's Children's Association
4 Oxford Street
London W1 (01-580 0511)

Family Fund
PO Box 50
York
YO1 1UY (0904 21115)

Friedriech's Ataxia Group
Burleigh Lodge
Knowle Lane
Cranleigh
Surrey (0483 272741)

Haemophilia Society
PO Box 19
16 Trinity Street
London SE1 (01-407 1010)

Invalid Children's Aid Association
126 Buckingham Palace Road
London SW1 (01-730 9891)

Lady Hoare Trust for Physically Disabled Children
7 North Street
Midhurst
West Sussex (073 081 3696)

Leukaemia Society
45 Craigmoor Avenue
Queen's Park
Bournemouth
Dorset (0202 37459)

MIND (National Association for Mental Health)
22 Harley Street
London W1N 2ED (01-637 0741)

MENCAP (Royal Society for Mentally Handicapped Children and Adults)
123 Golden Lane
London EC1 (01-253 9433)

Multiple Sclerosis Society
286 Munster Road
Fulham
London SW6 (01-381 4022)

Muscular Dystrophy Group of Great Britain
Nattrass House
Macaulay Road
London SW4 (01-720 8055)

National Association for Deaf/Blind and Rubella Handicapped (SENSE)
311 Grays Inn Road
London WC1 (01-278 1000)

National Association for the Welfare of Children in Hospital
Argyle House
29-31 Euston Road
London NW1 (01-833 2041)

National Autistic Society
276 Willesden Lane
London NW2 (01-451 3844)

National Council for One Parent Families
255 Kentish Town Road
London NW5 (01-267 1361)

National Council for Voluntary Organisations
26 Bedford Square
London WC1 (01-636 4066)

National Deaf Children's Society
45 Hereford Road
London W2 (01-229 9272)

National Eczema Society
Mary Ward House
5-7 Tavistock Place
London WC1 (01-388 4097)

National Physically Handicapped and Able Bodied (PHAB)
42 Devonshire Street
London W1 (01-637 7575)

Partially Sighted Society
40 Wandsworth Street
Hove
Sussex (0273 736 053)

Royal Association for Disability and Rehabilitation (RADAR)
25 Mortimer Street
London W1 (01-637 5400)

Royal National Institute for the Blind (RNIB)
224 Great Portland Street
London W1 (01-388 1266)

Royal National Institute for the Deaf (RNID)
105 Gower Street
London WC1 (01-387 8033)

Scottish Information Services for the Disabled
Claremont House
18-19 Claremont Crescent
Edinburgh (0351-556 3882)

Scottish Society for the Mentally Handicapped
13 Elmbank Street
Glasgow (041-226 4541)

Shaftesbury Society
112 Regency Street
London SW1 (837 7444)

Spastics Society
12 Park Crescent
London W1 (01 636 5020)

Spinal Injuries Association
76 St James's Lane
London N10 (01-444 2121)

Tuberous Sclerosis Association of G Britain
Martell Mount
Holywell Road
Malvern Wells
Worcs (068 45 63150)

King's Fund
54001000094725

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Parent & Co-ordinator – SOPHIE

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Our thanks to the following for their participation:

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Jean and Norman Willson
Linda Sevenoaks
Kathy Murphy
Lalita Shah
Dimitri Sklavounos, clinical psychologist
Dr Naomi Dale, Director, KIDS
Dr Tony Hulse, Paediatrician
Dr Dion Smythe, Paediatrician
Alan Counsell

The nurses and staff of Queen Charlotte's Hospital
The pupils and staff of Speenhamland County Primary School, Newbury

The unseen parents without whose help this film would not have been made:

Christa, Jackie and Richard, Caroline and John, Mahnaz, Barbara, Carol, Pat, Valerie, Denise and Jenny.

Additional thanks to Jenny Craddock

Typeset and printed in England by Intertype Limited