

# **North Western Regional Health Authority**

## **Breaking the News**

A Resource for Developing Guidelines for Good Practice,  
Procedures and Training in Informing Parents of Diagnosis of a  
Child's Impairment

**Regional Advisory Group on  
Learning Disability Services**

# Breaking the News

A Resource for Developing Guidelines for Good Practice,  
Procedures and Training in Informing Parents of Diagnosis of a  
Child's Impairment

Price £7

Further copies may be  
ordered from:

NWTDT  
Calderstones  
Whalley  
Blackburn BB7 9PE

NW Regional Advisory Group on Learning Disability Services  
1992

This document may be freely photocopied.

## Contents

Foreword	
Introduction .....	1
Policy .....	2
Antenatal Diagnosis.....	3
The Unexpected Event: Impairment Found At Birth.....	4
Impairment Identified Later in Childhood .....	6
Follow-up Letters .....	8
Early Counselling .....	10
Roles in Early Counselling .....	13
Training for Staff.....	17
Liaison and Communications Among Professionals.....	21
Resources .....	22
Monitoring, Evaluation and Review.....	23
Appendix 1: Checklist .....	24
Appendix 2: Learning from Experience.....	25
Appendix 3: Working Group Membership.....	28

## Acknowledgements

In the preparation of this report, the Working Group drew on the work of Dr Corine Weaver, Consultant Paediatrician at Caerphilly Miners' Hospital and Mike Bray, Manager of Rhymney Valley Children's Centre, to whom we make grateful acknowledgement.

Acknowledgements are also due to all who have helped with comment, discussion and feedback on earlier drafts.

## Foreword

Pregnancy, birth and bringing up a child are anxious times for all parents but usually all is well. However, at every contact between a parent and a health professional there lies the unspoken question "is everything alright?"

One of the most challenging psychological emergencies that can face a health professional, junior or senior, beginner or experienced, is thus the sudden realisation that evidence is before one that all is **not** well. One's body language of concern is all too likely to be picked up by the parent and within a few seconds may come the explicit question "is there anything wrong?"

As individuals we can only handle this situation effectively if we have thought about it and been trained to cope with it beforehand. As professional teams the same applies. It is also important that we use the new opportunities provided by Audit to learn increasingly effectively from the strengths and weaknesses of our current practice. As in most other fields of clinical work there is no proven 'best practice' in this field and not every professional, including myself, would agree with every suggestion in this useful document. Nevertheless, I am very happy to commend it to you as a further helpful step along the road towards treatment of children with disabilities and their families as integrated members of society and towards reduction of their isolation. If implemented, it will help to reduce the not infrequent feeling amongst the families that professionals and the rest of society could have done better. I commend it to you as a basis for discussion and thought in your own practice and that of your team.

Robert D H Boyd  
Professor of Paediatrics  
Manchester University

## Introduction

These notes concern significant neurological impairment which would be likely to lead to learning disability, but will have relevance to other disorders too. They have been collated for use by local working groups on early counselling which are developing locally agreed procedures.

There are several reasons why early counselling is important:

- Distress to parents can be alleviated by the way it is done.
- Parents will have to break the news to family, friends and others and the way they are told will provide a model to help them.
- The attachment of parent and child, subsequent interrelationships and nurturing may be influenced.
- Family relationships and contact with extended social networks may be affected.
- Relationships with professionals and use of services may be affected.

The notes have been prepared by a Regional Working Group (see Appendix 3 for list of members). The Working Party was commissioned in 1990 by the Children's Sub-group of the Mental Handicap Advisory Group (now the Advisory Group on Learning Disability). The report was supported by the Regional Medical Committee at its meeting of 19 November 1992.

The pattern of provision is different in each district and these notes are offered as a resource to be adapted for local use as appropriate. They are based on both research and practical experience. They represent what health professionals, including consultant paediatricians and obstetricians, believe is helpful. Such procedures should be reviewed and improved in the light of experience.

## Policy

It may be helpful early on to identify one main medical and one main liaison person (who could be midwife, health visitor or social worker) so that parents are not bombarded by too many people.

1. All staff should be aware of the policy and procedures and have opportunities for discussing implications for their work and their own training.
2. A team approach will be followed whether the event is anticipated or unexpected and clear lines of communication will be written and placed in strategic places e.g. delivery rooms, outpatient clinic, radiology department, etc.
3. The agreed written procedure will be used as the basis of the audit cycle and updated according to feedback at audit meetings, which will act as the forum for mutual education. Parents' views will be included in monitoring procedures.
4. All medical and nursing staff must be aware of the procedure at the discovery of abnormality. This includes radiologists and radiographers who may be the first to detect antenatal abnormality.
5. Wherever possible, senior medical staff will undertake the main counselling, but all staff involved with the child and family must develop sensitive communication skills. The family should have direct and open access to an identified key person.
6. Each paediatric and obstetric unit and child development centre will undertake the training of staff appropriate to their role in the management and counselling of such families.<sup>1</sup>

---

<sup>1</sup> See section on training below.

## Antenatal Diagnosis

Parents should be informed at all times of 'what will happen next', given the necessary delay when the obstetrician and/or GP need to be contacted, before the discussion with the parents takes place.

If available the consultant will attend the scan department to see parents together.

The clinical geneticist may sometimes discuss findings with parents with (or possibly without) the obstetrician.

This may only involve obstetrician and paediatrician.

The G.P. will often play an important role subsequently in the life of the child and the family. S/he should be involved actively as early as possible.

1. At the first suspicion of a significant abnormality the consultant obstetrician should be informed and the evidence discussed in private.
  2. The radiologist/radiographer/sonographer/junior doctor should express concern to parents<sup>2</sup> avoiding detailed discussion at the first suspicion and be prepared as to how to react if questioned. Generally the message should be of the need to discuss findings with the obstetrician who will see parents as quickly as possible afterwards.
  3. Call the ante-natal clinic and inform patient's consultant.
  4. Obstetrician and radiologist meet with paediatrician (and paediatric surgeon where appropriate) for sharing of medical and social information.
  5. Parents to be seen by the obstetrician with or without paediatric colleagues and other counselling to be arranged as appropriate. Results should preferably be discussed at a venue outside the ante-natal clinic.
  6. There should be no assumption that there will be an abortion because of possible impairment, or pressure on parents for abortion. Parents may need non-judgmental support in considering this issue.
  7. A small informal discussion to be arranged when convenient to plan:
    - the management of the pregnancy.
    - management of delivery - including the place.
    - management of neonatal period.
- Other professionals involved as appropriate - G.P., midwife, health visitor et al.
8. Mother's case record to contain notes of 7 and clear instructions to staff who may not be familiar with the case.
  9. Paediatrician to be present at delivery, depending on the severity and type of abnormality.
  10. The case to be discussed at the regular perinatal Audit meeting.
  11. Staff in training to attend seminars.

---

<sup>2</sup> Whilst it is recognised that fathers won't always be available or involved, for ease of exposition we refer to parents in the plural.

## The Unexpected Event: Impairment Found At Birth

### Phase 1: In the Delivery Room

There may be a difference in response where a baby has an obvious malformation which parents can see, compared with an impairment which is not so obvious. This can be discussed in training.

If the baby has Down's Syndrome and the birth is during the night the consultant paediatrician can be notified at 9 am next day.

The single room should not be used as a way of isolating the mother and avoiding contact with her.

1. Deal with immediate resuscitation as usual.
2. Keep close communication with parents - relate the positive findings before any negative if possible, e.g. "..... a little girl ..... crying well ..... opening her eyes ....." etc. Then indicate concern if all is not well. Indicate calling senior colleague (paediatrician).
3. Ensure parents see the baby and hold if possible even if a malformation has to be covered and not revealed at first.
4. If emergency treatment is needed (example preterm baby) transfer to SCBU and inform senior. Otherwise:
5. Inform the on-call consultant paediatrician (or deputy, if not available) immediately. The senior paediatrician will direct the next move and should try to see the family in the delivery suite, otherwise as quickly as possible.
6. Inform the consultant obstetrician and nursing officer.
7. Offer option of single room and strike a balance of giving privacy whilst remaining in touch.
8. Please note - fathers often telephone the family immediately - ask them to wait until the baby has been checked

The memories of these early hours can be devastating; be sensitive and supportive; avoid hurtful terms such as "he looks a little funny" etc.

**Phase 2:**

Too many people can be overwhelming to parents and frightening. Two is enough unless parents ask for others. They must feel in control of what happens to their child.

This might be limited to say consultant paediatrician and midwife manager with dissemination of decisions to relevant people especially G.P. Occasionally it may be appropriate to involve a wider group eg: consultant paediatrician/senior registrar, the particular midwife manager/clinical specialist, the particular health visitor, social worker and member of the Child Development Unit team, the parents' community midwife, and G.P.. However, it could be overwhelming to many parents to include them with such a group.

Parents should feel in control of what happens. They should know of agencies and services available.

The G.P. will often play an important role subsequently in the life of the child and the family. S/he should be involved actively as early as possible.

A file of information on services, parent groups etc should be kept up to date at the hospital to be readily available when needed.

**Phase 3:**

1. Senior paediatrician to see parents together with one other (e.g. midwife, nurse, health visitor, social worker or G.P.). Baby should normally be present at the telling.
  2. Small, informal discussion to be convened within 24 hours of the birth, or as appropriate if the abnormality is detected in the antenatal period, but definitely before discharge. This meeting should plan the discharge and follow up arrangements. The main counsellor should see the parents again within 24 hours of the initial disclosure.
  3. Unit staff to be informed of position - close communication needed between medical, nursing and allied staff, including non-professionals.
  4. Paediatrician to inform parents of the small discussion and its purpose.
  5. Paediatrician to discuss with parents whether other agencies should be involved personally with them at this stage.
  6. Paediatrician to inform G.P. by phone and give opportunity to G.P. to meet paediatrician and parents.
  7. Brief written information on the condition, relevant community groups and services, including the name and telephone number of the key worker, should be given before discharge but only as part of counselling.
  8. Paediatrician with midwife to ensure follow up and domiciliary arrangements.
  9. Midwife or nurse manager/consultants debrief and bring up to date staff and junior doctors who were involved at the very early stages.
1. Ensure good documentation.
  2. Ensure the case is brought to Audit at the next opportunity and progress report on the family given at later Audit as appropriate.

## Impairment Identified Later in Childhood

The child may have been born with no indication of impairment. Later, possibly months or years later, it may become apparent either to the parents or to professionals that there is an impairment. This may be noticed when a child is slow to develop. Impairment may be picked up during routine surveillance. It may be identified following an event in childhood (e.g. accident, illness, abuse causing head injury, or neglect). Some medical conditions which may have been present from birth may not become manifested in identifiable impairment until later in childhood.

This is a time of uncertainty. Parents tend to experience relief when a firm diagnosis is made. Some of the uncertainty is reduced. It also helps them to be able to say to other people that their child has \_\_\_\_\_ Syndrome.

Parents sometimes complain that their observations have been dismissed by professionals and then turn out to have been justified.

If this is not done the child may miss out on much needed help.

Parents and professionals may agree there is a problem but there is delay in getting an accurate, firm diagnosis (e.g. autism). With rare or complex disorders test results can take longer.

Good medical care is not enough. There has to be acknowledgement of the social consequences for the child and the family.

Parents need someone to talk to about their concerns.

1. When the diagnosis is not clear parents need support. When a diagnosis has been made it should be communicated to the parents.
2. When professionals feel that parental concerns are unfounded, parents should be made aware that they can have a second opinion. GP's should feel free to refer children to paediatricians and child development centres.
3. When professionals identify some abnormality or developmental delay but parents are not prepared to acknowledge a problem, relevant professionals should be designated to continue to make themselves available.
4. Whilst waiting to establish a diagnosis, which may take considerable time, services needed by child and family should be made available.
5. When a child experiences an accident or illness which is likely to lead to disability there should be automatic referral to the health visitor<sup>1</sup> and hospital social worker (if the child is seen at hospital). The child and family can then be linked to relevant support services and networks. In the absence of a hospital social worker, some other link with community provision should be identified. If the child is in hospital for more than 12 weeks the Children Act 1989 requires notification to the Social Services Department.

---

<sup>1</sup> A requirement of The *Patient's Charter* is for a named qualified nurse, midwife or health visitor to be identified for each patient. See *Implementing the Patient's Charter*, 1992, HSG (92)4. Available from DoH Store, Health Publications Unit, No 2 Site, Manchester Road, Heywood, Lancs, OL10 2PZ.

A pre-discharge planning meeting should be called by the consultant or SCMO to include the family and representatives of all services likely to be required from Health, Education, Social Services and Housing to facilitate a smooth transition from hospital to home (Children Act 1989). This helps parents to relinquish dependence on the hospital team as the child moves back into the community.

Keeping a balance between conveying the likely severity of a disability, and giving parents hope is not easy. Vague terms like *special needs* and *developmental delay* are sometimes used to avoid more familiar but less acceptable terms such as mental handicap. Terms may have different implications for professionals and parents who may not understand what they are being told.

A professional may assume that parents have been told about the diagnosis when they haven't. Parents may be hearing the news for the first time from someone who doesn't realise the impact of what is being said.

Parents need access to services, support and information which would help them adjust and cope with their child's disability

This will enable sufficient time to be arranged. If a child is seen at a busy out patient paediatric clinic which is not very flexible, there may not be sufficient time to start the process of breaking the news and early counselling to do it justice. Organising a more appropriate appointment can take time.

6. In order to check understanding it may be helpful to ask parents to explain in their own words what they understand the disability to be. Any misunderstandings are likely to become apparent, which can then be corrected.

7. There should be a library of resources, kept up to date, readily available to parents and widely known. It should include:• leaflets on specific conditions• information on parent self-help organisations including local groups, regional and national organisations• books, magazines, journals, newsletters• videos•information on local services• information on welfare benefits

8. GP referrals to paediatric clinics should indicate if the reason for the referral is a suspicion of impairment.

## Follow-up Letters<sup>2</sup>

Sensitive letters following hospital consultations have not only been very much appreciated by parents, but they have also been a source of back-up information. This is extremely helpful to them and also supportive to the extended family and friends.

Professionals should be aware of how devastating, negative and 'damning' words can be when written on paper. They are there for life. The need for sensitivity, honesty and careful use of language, together with constructive statements about the future, cannot be over emphasised.

Dr David Hall, consultant paediatrician at St George's Hospital points out in *The child with a handicap* (Blackwell Scientific Publications, 1984) that:

1. With practice, this type of letter can be dictated in about 10 minutes. It is time consuming for the medical secretary, but it avoids the need for numerous letters to different professionals, except in the occasional case where a brief covering note is needed to fill in technical data or delicate family problems.
2. There is no doubt that such letters are very much appreciated by parents.
3. It is imperative to exercise care in the selection of vocabulary, both non-medical and technical. The social class and educational background of the parents must be considered.
4. The letter should only include information previously discussed; it must not be used to make up for deficiencies or omission of important information at the actual consultation.
5. As far as possible, the letter should always contain some optimistic points in the history and prognosis. Emphasise what can be done to help the child as well as the extent of the problem.

### Ideas for Inclusion in the Letter

1. **Give a summary of the discussion:** this is important to help the parent focus back on the meeting and to recap what was said.

---

<sup>2</sup> This section is taken from *Ordinary Everyday Families* by Cameron, J., and Sturge-Moore, L., 1990, Mencap Interlink Under Fives Project: London.

2. **Mention the baby or child in a 'positive way':** the child is an individual in his or her own right and has potential, which needs to be encouraged in every possible way. If the time seems right, suggest a book or two, but make sure the contents are constructive.
3. **Discuss medical implications:** use everyday language, watch carefully not to use long, medical jargon. Try not to 'label', but use terminology which is acceptable to modern parents in these very early stages.
4. **Propose an early support programme,** such as physio/occupational/speech therapy or an early intervention programme: parents do need to know there is support available for their child. Provide a chart to record the child's progress.
5. **Refer to community support:** attach - where, as hopefully, it exists - an information leaflet, appropriate to the feelings and needs of parents at this vulnerable stage, which will direct parents to both statutory and voluntary organisations. If this is not available, include the name of local voluntary groups or of a parent contact, in case this parent is isolated. Direct them to mainstream facilities, and in particular to a local integrated opportunity play group.
6. **Give encouragement, without being patronising:** help the parents believe in their child's potential, however small and delayed the progress may be. Remember to celebrate all successes.
7. **Leave the door open for contact,** either to yourself or to a member of your team.

## Early Counselling

A lot is known about what helps parents to adjust to the news that their child has a disabling condition. The following notes highlight some of the points concerning the face to face contact. These notes should not be used rigidly as a blue print but interpreted in the light of individual circumstances. They are not enough on their own and need to be used in the context of planned training with opportunities for discussion with experienced practitioners.

### Guidelines<sup>3</sup>

Parents may lose trust if they feel something has been held back from them.

There may be times when a delay of a day or two whilst waiting for test results may be justified to avoid what may turn out to be unnecessary anxiety.

If you tell one parent then he or she has the responsibility of telling the other. Both parents should have the opportunity of asking questions of a professional who is competent to answer them or to share uncertainty when this is present, which it often is.

It is disrespectful to convey sensitive information in public. Parents need to be able to express emotion freely.

An audience would be likely to inhibit parents.

For continuity it would be particularly helpful if this person is to be the key worker for the parents.

Time is needed to cope with the shock, so that emotions can be expressed, and questions asked without pressure.

1. Tell parents as soon as possible unless there are reasons not to, e.g.,
  - poor health of mother following birth
  - difficulties in arranging to see parents together at a suitable time.

If there is uncertainty then this generally should be acknowledged openly and parents kept informed of any steps taken to reduce the uncertainty.

2. Both parents to be told together, if possible. If the father is not available, arrangements should be made for him to be seen by a professional, with the mother, when he is available so that the mother is not left to break the news by herself.
3. In a private place without interruptions.
4. Without an audience of staff. However, it is a good idea to have someone, (e.g., social worker, health visitor, midwife or nurse) sitting in with the paediatrician, to take notes, or write up notes afterwards, which can form the basis of a written report to the parents. This other professional can be available for further discussion and follow-up with parents. For training, it may be appropriate for one junior doctor to be present who is already known to the family.
5. Schedule enough time (up to an hour).

---

<sup>3</sup> See also appendix 1.

Treating the baby warmly demonstrates acceptance to the parents.

Keeping a balance between being positive and being realistic is needed. If you are too indirect parents may not understand clearly what you are telling them. Because of segregation, many parents know only the myths and assumptions surrounding disability.

If your manner is too distant and professional you are likely to be seen as cold and inhuman at a time of stress which can make it difficult for parents to ask questions.

To avoid overloading parents with too much information. When the news is first given the shock usually means that parents don't take in much of the rest of what is said at that session. They need to get over the initial shock in order to begin to think more clearly.

Parents will want to learn about their child's condition. Having leaflets which answer many of their questions will help them learn at their own pace and when they are ready.

Another parent can provide consolation and a demonstration of coping in ways that professionals cannot. This can also provide a link to a parent self-help group. Parent counsellors need to be carefully selected and prepared for this role. It may be difficult to find suitable parents of children with very rare disorders.

Having to break the news to others can be difficult for parents. They may appreciate help.

Parents need to be able to comfort each other and begin to explore questions together without others present.

Parents need to know what provision is available so that they can use it when needed.

6. Baby to be present and treated as welcome e.g., being picked up. It may or may not be appropriate for an older child to be present, depending on the child's level of understanding.
7. Tell honestly and directly with no hedging or beating about the bush. Be cautious in making negative long term predictions. Explanations should be as clear as possible and not overly technical.
8. Convey warmth, understanding and respect.
9. Parents to meet with a professional over a number of interviews after the initial contact to ask and think about questions and the information given.
10. Provide brief, written, easily understood information about the child's condition. Written information does not reduce the need of the professional involvement to go over things with parents.
11. Offer to introduce a parent who has lived through a similar experience, and been selected and trained for this task. Some parents may not wish to take up this offer and they should not be made to feel that they should. Don't assume, however, that new parents won't be ready to speak to parents who have had some experience.
12. Raise the issue of parents breaking the news to family and friends and ask whether they would like help from a professional to do this e.g. to be present when parents do it.
13. Parents to have privacy with each other after the initial interview.
14. Provide written information on community services and support including details of parent groups and genetic counselling, if relevant. If the news is broken whilst mother is in hospital, this information should be provided before leaving hospital.

Interpreting may be needed for people whose first language is not English and also for deaf people. It can be very difficult establishing what the language of parents is. Interpreters (including husbands) may not always communicate as requested.

In the past parents have been lead to expect segregated education for their disabled child from the very earliest stage.

15. Arrange for an interpreter to be present if English is not well understood by the parents.

16. If anything needs to be said about future schooling, parents should be encouraged to expect their child will attend mainstream school with the support that might be needed.

## Roles in Early Counselling

As roles will vary, these notes may need substantial adaptation, depending on local practice. They are offered as a basis for discussion.

Unconditional acceptance of mother and baby and avoidance of rejection by all staff is vital.

### Midwife/Neonatal Nurse

With discretion. This may be interpreted by parents as patronising.

#### *Immediate Action*

1. To support both parents and encourage handling of baby as soon as possible after delivery to avoid rejection.
2. To encourage and make reference to positive findings before negative if possible.
3. To allow parents time on their own with baby, if baby's condition warrants.
4. To be sympathetic yet honest to parents.
5. To contact medical staff (unless present).
6. Discuss options for stay (e.g. single room, special care).
7. To avoid separation of mother and baby if at all possible.

#### *Secondary Action*

1. To give an explanation of baby's needs in relation to the understanding of both parents.
2. To contact supervisor of midwives.
3. To encourage parents to inform other family members: siblings, grandparents et al., and to offer help in informing others.
4. To listen to, take note of, and respect, parents' wishes.

#### *Third Action*

1. To inform community midwife and health visitor.
2. To ensure that the general practitioner has been informed by phone.
3. To attend pre-discharge discussion as per item 2, page 4 (phase 2).

4. To inform parents of availability of social worker and/or specialist health visitor to support parents if appropriate.

**Supervisor of Midwives**

1. To support midwife.
2. To support parents.
3. To discuss ways of improving the service offered or carried out.
4. To take part in audit.

**Health Visitor**

1. To participate in the initial multi-disciplinary planning meeting and review meetings thereafter.
2. As with every new birth, to offer to families a function which centres on child and family health care and health promotion. Work in close liaison with other professionals. In particular, acting in partnership with the specialist social worker.
3. To be easily accessible to the family, exploring with them their particular health needs, providing assistance and support in attempting to meet such needs.
4. To provide a link where necessary between general practitioner, hospital, family and others.
5. To be available to the family in translating and explaining health problems and services available.

**Liaison Health Visitor**

1. To identify any children aged 0-5 years in hospital who may have a disability and notify relevant local health visitors and other community services.
2. To gather information from the local health visitor about a child with a disability in order to brief the paediatrician.
3. To support local health visitors, e.g., providing information about medical conditions and syndromes.
4. To organise a discharge planning meeting for children leaving hospital likely to need long term care and community resources.

**Specialist Health Visitor**

1. To liaise with a wide range of professionals providing services to children with special needs and their families, including health, social services, education.
2. To advise regular health visitors on a range of services and help available to the family of a child with special needs.
3. To participate in multi-disciplinary planning for families of a child with special needs.

4. To act as advocate for the family of a child with special needs and provide support and information as required.

### **Hospital Social Worker**

1. Wherever possible to be available at the initial consultation as the 'third ear' for both parents and medical colleagues/ward staff.
2. To support medical colleagues who have the difficult task of breaking the news. It can be useful to take notes of the consultation (in agreement with all parties) to be given to parents once checked for medical accuracy by consultant.
3. To act as 'translator', if necessary, between medical staff and parents, when medical terminology may block clear communication. To ensure that wherever necessary an independent interpreter is available for parents whose primary language is not English.
4. To see parents, preferably in their own home, to follow up after the consultation and facilitate discussion between parents of their understanding of the news and, if necessary, request further contact with consultant. To be available, if required when the news is given to the extended family.
5. To use individual skills in counselling and supporting families, and to provide appropriate information re: services and resources for parents in their changed circumstances.
6. To link with the community health and social services staff and voluntary agencies who will provide local services for the family to facilitate continuity and communication between hospital and home and vice versa.
7. To facilitate contact between 'new' parents and more experienced ones when appropriate and requested. (Parent to parent befriending).

### **Others Who Might be Involved**

A wide range of professionals can be involved in breaking the news and early counselling. Probability of a handicapping condition may have been identified before birth, at or soon after birth. Developmental delay may become apparent at any time in the first three or four years. Those involved may include genetic counsellor, radiographer, ultrasonographer, radiologist, hospital midwife, community midwife, obstetrician, paediatrician, paediatric nurse, hospital social worker, field social worker, GP, health visitor, junior doctor, clergy, other parent, community medical officer, clinical psychologist, play therapist, educational psychologist, teacher, nursery nurse, community mental handicap nurse, school nurse, speech therapist, physiotherapist, portage home visitor, and others.

A local working group will need to ensure that people who fulfil these roles and functions have opportunities to participate in discussions about their own roles in disclosure, and their training needs.

## Training for Staff

The local early counselling working group will need to review what training is available, what is needed, what the gaps are and how to develop and provide training.

Following is a list of topics which need to be covered in training. This outline is provided to help those concerned:

- plan training provision
- evaluate available training
- assess each person's training needs
- plan individual training requirements.

Training is needed at different levels, from basic professional training, through post-basic to continuing in-service training.

Regular in-service seminars will be needed, with multi-professional and parent input, at which counselling skills and our own coping skills can be developed. Encourage more inter-professional team work. Include radiologists, surgeons and GPs. in these and also parents.

Training seminars should help all professionals to achieve heightened awareness of the far reaching effects of the first few hours and to develop more supportive relationships with families.

### Topics for Training

- Reasons why it is important to break the news well.
- Societal attitudes towards disabilities:
  - likely influence on parents
  - likely influence on staff
  - importance of staff acting as role models to challenge negative attitudes
- Reviewing our own difficulties in breaking bad news:
  - understanding our own feelings and defences
  - reviewing our own views about disability
  - reviewing our own expectations of subsequent opportunities
    - school, employment, leisure, a place to live
  - coping with distress of parents

- support mechanisms for staff - supervision, staff meetings, etc.
- Understanding parents:
  - reactions and phases of adjustment following receiving the news
  - current emotional state
  - understanding of language used, information given
  - expectations
- First session:
  - setting the scene
    - where and when
    - who breaks the news
    - who is present
  - what to say
  - how to say it - balance between emphasis on positives and acknowledgement of disability
  - encouraging questions.
- Subsequent sessions.
  - pacing, judging the pace appropriate for each parent so that they don't feel pressured
- Counselling:
  - principles and practice as they relate to breaking the news
  - non-verbal communication
  - listening skills
  - improving parents'
    - understanding of what you say
    - retention of what you say.
- Roles of different workers in breaking the news:
  - what is expected of you
  - what is expected of others.

- Communication procedures between staff:
  - within unit or team
  - between unit or team and others.
- Family interactions:
  - husband - wife
  - grandparents
  - siblings of baby or child
  - helping parents explain to other people
  - individual support for affected older child.
- Cultural and religious implications, especially those relating to ethnic minorities, e.g. use of interpreters.
- Introduction to services and resources available:
  - involvement of an experienced parent in counselling new parents
  - parent self-help groups
  - leaflets and books relevant
  - key worker
  - knowledge of developments in services which will be available for later phases of child's life e.g., inclusive education, supported employment, leisure opportunities, a place to live in adulthood.
- Policy and procedures - formation, maintenance, monitoring, evaluating and review (see appendix 2).
- Consumer liaison and consumer groups.

## Resources

Jupp, S., 1992, *Making the Right Start: A practical manual to help break the news to families when their baby has been born with a disability*, Opened Eye Publications: Hyde, Cheshire.

SCOVO, 1989 *Parents Deserve Better: A Review Report on Early Counselling in Wales* Available from: SCOVO, 5 Dock Chambers, Bute Street, Cardiff CF1 6AG, tel 0222 492443.

*Shared Concern: Breaking the News to Parents That Their Child Has a Disability*. Available from: Book Sales Department, King's Fund Centre, 126 Albert Street, London NW1 7NF. Tel: 071-267 6111.

The video is not intended to present, in the dramatic sequences, how disclosure should be done correctly. However, some viewers are likely to interpret it in that way if they don't have the opportunity for discussion. For this reason the video should only be shown with an experienced practitioner available afterwards for discussion. Viewers should be given a copy of the associated leaflet *Shared Concern* noted above.

Video *Shared Concern* Available for hire or sale from: Bailey Distribution Ltd., Dept KFP, Learoyd Road, Mountfield Industrial Estate, New Romney, Kent TN28 8XU.

Courses: eg counselling.

Dr Sheila Jupp, Consultant Clinical Psychologist at Stockport and co-author with Cliff Cunningham of the literature review in the SCOVO report noted above, is available to advise on training and other aspects of early counselling. Dr Jupp, Clinical Psychology Service, Offerton House, Marple Road, Stockport, SK2 5ER.

## Liaison and Communications Among Professionals

Good workable systems of liaison and communication are needed especially between local and regional services (e.g., Royal Manchester Children's Hospital, Booth Hall, Withington, Preston, St Mary's and Alder Hey). There can be delays in communications and lack of agreed or recognised procedures which can lead to problems

A child seen at a regional service may not be known to local services.

Health visitors sometimes are not notified of relevant medical information. Links with surgical wards need special attention.

This will save parents and children unnecessary travel to regional services when relevant services are available locally.

1. Paediatrician at regional service to notify GP by letter with copies to local hospital paediatrician and SCMO/community paediatrician and health visitor after first contact with child.
2. Hospital liaison health visitor to notify health visitor of child's involvement with regional service.
3. Local paediatrician in conjunction with regional service paediatrician to involve local services as soon as possible where needed, (physiotherapy, speech therapy, occupational therapy, health visitor, social worker, Portage worker, clinical psychologist, senior clinical medical officer). Guidance of local workers to be provided by regional specialists at the earliest opportunity.
4. Implications of the Children Act 1989 need to be considered by local working groups.<sup>1</sup>

---

<sup>1</sup> Department of Health, 1991, *The Children Act 1989, Guidance & Regulations, Vol 6, Children With Disabilities*, HMSO: London. See especially chapter 4 *Coordinating Services* on collaborative working and the requirement for education, health and social services to liaise in maintaining a register of children with disabilities in their area.

## Resources

Purchasers and providers will need to identify resource implications of procedures they agree e.g:

Counselling takes time and cannot be rushed. Staff training requires time to be allocated and cover available while staff are being trained.

1. Sufficiency of staff such as midwives, hospital social workers, specialist health visitors et al.
2. Quiet room to be available for uninterrupted discussions with parents e.g., in maternity unit or child development centre.
3. Services needed by child and family e.g., short term care, Portage, extra help in integrated nursery, play group or school.
4. Library of information with adequate space for storage and display and a system for checking loans.
5. Secretarial assistance for correspondence.
6. A panel of interpreters who are trained for this task should be available.
7. Appropriate materials are required e.g., leaflets in braille for visually impaired parents, and in different languages.
8. Training resources e.g., video, budget for guest speakers (including parents).
9. Monitoring, evaluation and review need to be planned. An audit system to include medical, nursing and management audit arrangements needs to be designed.
10. Time for staff (with parents involvement) to discuss and agree and review policy, procedures and good practice.

Much good practice does not cost anything e.g., treating parents and child with respect. However, there may be costs implied e.g., staff training to assist staff towards being respectful.

## Monitoring, Evaluation and Review

Once procedures have been agreed and written and training been done it will be necessary to keep track of how it is all implemented. What are the outcomes in terms of parent satisfaction? Are there new problems arising? There will need to be mechanisms for monitoring and evaluation of outcomes for parents and children as well as practice. Then there needs to be some means of arriving at decisions for updating procedures.

Some things to think about at this stage are:

1. Written *Service Deficiency Reports* to be sent to the manager of children's services in the district.
2. Follow-up of a cohort of parents' experience by an independent person, possibly every 2-3 years. This could be done by questionnaire or interview in which parents are invited to tell their story (see Appendix 2 for an example). Lessons for good practice can then be identified.
3. Report of each case to audit meeting.
4. Peer review.
5. External evaluation of the complete procedure to check what procedures have been agreed and written down and whether they are working as intended. This would include:
  - review of documentation, mechanisms for development and review of policies and procedures, including membership of working groups and committees
  - discussions with relevant staff and managers
  - discussions with parents who have had recent experience of the service
  - analysis
  - formulation of recommendations
  - feedback - both verbal and written.

This is a way for independent practitioners to discuss their practice with a colleague for feedback and comment.

## Appendix 1: Checklist

This checklist is intended as an aide memoir summary of the section on Early Counselling.

- |   |                       |
|---|-----------------------|
| 1. Parents told at first suspicion.   | p3#1, p10#1           |
| 2. Parents told together. (If father not available, arrangements made to see him later).                                    | p5#1, p10#2           |
| 3. Disclosure in private place without interruptions.   | p10#3                 |
| 4. Not more than one additional staff present.  | p5#1, p10#4,          |
| 5. Colleague present to make notes to be typed and subsequently given to parents.   | p10#4                 |
| 6. Baby present and picked up.  | p5#1, p11#6           |
| 7. Tried to convey warmth, understanding and respect for mother and child.  | p11#8, p13            |
| 8. Told honestly.   | p10#1, p11#7          |
| 9. Uncertainty acknowledged (if appropriate).   | p10#1                 |
| 10. Explanation not too technical.  | p11#7                 |
| 11. Negative predictions only made with great caution.  | p11#7                 |
| 12. Invited questions.  | p11#9                 |
| 13. Offered to introduce another parent.  | p11#11                |
| 14. Leaflet on child's condition given.   | p5#7, p7#7,<br>p11#10 |
| 15. Offered to help break news to family and friends.   | p11#12                |
| 16. Second interview scheduled for within 2 days. Parents invited to keep a note of any questions to ask at next session.   | p11#9                 |
| 17. Parents given privacy at end of interview.  | p11#13                |
| 18. Before leaving hospital, parents provided with appropriate written information on community services and parent groups. | p5#7, p7#7,<br>p12#14 |
| 19. Schedule up to an hour or more.   | p11#5                 |
| 20. Letter to parents following hospital consultation.  | pp8-9                 |
| 21. Interpreter present if needed.  | p12#15                |

## Appendix 2: Learning from Experience

One way to improve practice is to listen to parents' experiences and be guided by the lessons which that experience teaches. This needs an independent person to whom parents are willing to talk. The local Early Counselling Working Group can then identify from the story the recommendations for changing practice. Following is an example.

### One Mother's Experience

"I didn't see him for 12 hours after he was born. I knew something was wrong. The staff were avoiding me. With my first two children it wasn't like this. When I did get to see him, he had tubes up his nose and he was blue. He looked awful. Well, I wasn't prepared for this. They hadn't told me anything. When I asked why he had the tubes the doctor said he wasn't feeding. Then she did a very thorough examination of him but she didn't speak to me."

"Then she asked to look at my hands which seemed peculiar, so I asked what that was for and I was told 'It's routine'. I really had to press her to tell me what was wrong. She asked me 'Have you ever heard of Down's Syndrome?' I just screamed. I don't know what else she could have said but it seemed so harsh. She said he had a heart defect and needed special care."

"When my husband came, he didn't know anything about it. He had his suit on and a big bunch of flowers. He was so pleased to have a boy. And I was left on my own to tell him. No-one helped. He didn't know anything about Down's Syndrome and I had to do my best to explain."

"They put me in a side ward for the rest of my stay."

"The paediatrician was very good. He explained things to me. It was a pity my husband wasn't there though. And I was still so upset that I didn't hear what he was saying. I couldn't take it in."

"You know, I felt totally isolated. The nurses avoided me. Even the midwife wouldn't come near me. And I had no contact with anyone outside. I just wanted to talk to someone who would listen. But there was nobody."

"When I got home the special care midwife visited me. She was marvellous, one in a million."

"I got a book out of the library and read it in one night."

"When he was six weeks I went to the parents group and I discovered that other parents understood. They had gone through similar experiences. It was nice to know I wasn't alone."

"He's four years old now and he's very much part of the family. We love him but why did we have to go through all that at the beginning?"

### **Good Practice**

- paediatrician explained
- special care midwife visited mother at home
- access to parents' group to share experiences

### **Practice Needing Improvement**

- baby separated from mother for 12 hours
- staff avoiding mother
- mother not prepared for seeing baby in special care
- no explanation from the start
- junior doctor does not treat mother with respect - doctor more concerned with technicalities of identifying child's defects
- mother not offered help in breaking the news to her husband
- father not given opportunity to learn from competent professional
- parents not invited to think of questions
- mother isolated without being asked
- mother had no one to unburden to
- no literature provided or information in writing
- opportunity to meet a parent who has experience of bringing up a child with a similar disability not offered

### **Recommendations Arising From This Experience**

- parents to be told at first suspicion
- try not to separate mother and baby if possible
- if necessary to separate mother and baby, provide explanation to mother
- staff to comfort mother and be available to answer her questions and listen to her concerns

- junior doctor to recognise mother as a person and treat her with respect
- senior paediatrician to be called when abnormality identified or suspected
- parents to be invited to ask questions
- news to be broken, if possible, to both parents together
- husband to be seen by senior paediatrician
- mother to be given choice of side room
- literature on child's condition and resources available to be provided before leaving hospital
- information about parents group to be given before mother leaves hospital
- opportunity to be made available to meet a parent of a child with a similar disability

## Appendix 3: Working Group Membership

<b>Barbara Bergin</b>	Social Worker, Royal Manchester Children's Hospital, Pendlebury.
<b>Ian Brown</b>	Consultant Community Paediatrician, Burnley.
<b>Mary Eminson</b>	Consultant in Child and Adolescent Psychiatry, Salford, and Lecturer, University of Manchester.
<b>Chris Gathercole</b>	North Western Training and Development Team.
<b>Evelyn Hepburn</b>	Clinical Midwife Specialist, Neonatal Unit, Stockport.
<b>Veronica Kilasi</b>	Parent, Bolton.
<b>Lynn O'Hagan</b>	Neonatal Nurse Manager, Neonatal Unit, St Mary's Hospital, Manchester.
<b>Pat Thean</b>	Specialist Health Visitor, Bolton.
<b>Godfrey Travis</b>	Project Leader, Barnardo's Families Project, Salford.
<b>Joe Whittaker</b>	Lecturer, Bolton Institute of Higher Education.