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**Abstract**

This pamphlet recognises that the occasion of the birth of a child with a disability needs special management by hospital and medical staff, who should remain sensitive and non-judgemental. It outlines a procedure for telling parents, the basic management of the family in hospital and the creation of links for the family with relevant community workers. The importance of the family receiving emotional recognition and help first is stressed. **Keyword:**  
**Professionals**

*Guidelines to follow...*

*WHEN A CHILD  
WITH A DISABILITY  
IS BORN*



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In May 1984 a seminar was convened by ASSID (formerly AGSSOMD) to discuss procedures adopted and decisions made about young children identified as having a disability; especially for those who could not live with their parents. A major issue raised at this seminar was that the decisions made by parents were greatly influenced by how they were given the initial information about their child's disability. A sub-committee was set up to establish guidelines to be followed in these situations. A large number of people have contributed to the formulation of these guidelines, which has involved extensive consultation with a broad cross section of people from parent groups, government agencies, and private and voluntary associations.

Special thanks are due to those ASSID members who organised the original seminar, especially De Helen Beange. Others who have significantly contributed include Virginia Ryan and Barbara McCann (social workers), Dr George Soutter, Dr Barbara Field, Dr Henderson-Smart (paediatricians), Marie Jolley (program officer). The valuable input of the various committee members is also gratefully acknowledged, along with the many practical comments and suggestions about the implementation of those guidelines by experts, workers and parents, who are too numerous to individually mention.

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## INTRODUCTION

The birth of a child with a disability is very often a traumatic occasion. There are obvious and real reasons why this is the case. Hence the management of such an occasion by hospital and medical staff is crucial in assisting the parents in coping with, and adjusting to, this situation.

The protocol outlines a procedure for telling parents that their new baby has a disability, the basic management of the family in hospital and linking them with community services who will take major responsibility for supporting the child and the family,

People will react to the birth of a child with a disability in many different ways, including differences because of ethnic or cultural background. Hospital and medical staff needs to remain sensitive and non-judgemental and need to recognise and support **the child's right**

- to life
- to treatment
- to love, care and support

- to a family

### **and the parent's right**

- to care and support
- to information immediately or as it emerges regarding the child's condition and treatment
- to information relating to their own or child's needs
- to be recognised as parents of a new baby and equal partners in all informed decisions.

Hospital and medical staff and persons offering support need to ascertain and respect the social and religious values and culture of the parents.

It is acknowledged that this work is very stressful, and staff's support and consultation is essential.

### **GUIDELINES**

#### a) The initial Interview

It should be entered in the knowledge that little of what is said will be remembered, but the way that it is said will likely never be forgotten. Much of the success of the first interview does not lie in the volume of factual information imported, but in the climate which is established as a sound basis for future sessions.

The following points have been identified as a framework of how parents should be told of the diagnosis of their baby's disability.

1. By two Health Workers, one of whom (e.g. Paediatrician, Obstetrician) would give the factual information. The other worker (e.g. Nurse, Social Worker) would be available to work with the parents towards acceptance of this information.
2. As soon as possible.
3. Together.
4. In a private place, with no "audience" of medical students, nurses, etc, and where no disturbances are likely.
5. With the baby present - except if very ill and in special care,

6. In a straightforward way with as much time as needed to ask questions. A balanced viewpoint would be aimed for rather than a catalogue of the child's potential problems.
7. Information of community resources to be given, It may be appropriate to arrange for a worker from one of these services to meet the parents and give them further information.
8. Available written material should be provided

b) During the First Few Hours

1. The child, where possible should stay with the mother from the moment of birth. Every opportunity needs to be provided for mother/father and hospital/ medical staff to interact with and/or hold the baby, *(Staff/doctors need to be aware that their initial reaction with/without words will have an important and lasting impact on the parents)*.
2. The parents may be in shock and may not be able to hold the baby straight away. Doctors and staff need to be sensitive to parents' needs and while remaining positive and non-judgemental, work towards point 1 above. *(Parents will react in different ways including differences caused by socio-economic, cultural or ethnic factors)*.
3. The Paediatrician is, in most cases, the most appropriate and qualified person to convey information to the family. A senior member of nursing staff should also be involved.
4. When parents are seen:
  - If English is not the first language of the family an interpreter should be present,
  - Parents should be seen together in a private place, with no extraneous people present (e.g. students) and where they are unlikely to be disturbed.
5. The diagnosis or information should be straightforward and clearly explained, This information, including confirmation of a condition, needs to include positive as well as negative information. *(Lack of information raises anxiety. This will provide a clear barrier to communication between staff and parents)*.
6. It is essential to acknowledge any doubts the parents may have, e.g. "We can see you're worried about the baby - we'll ask the doctor to see him/her". *(Avoidance of doubts will maximise the parents' anxiety not reduce it)*.

7. It is important to acknowledge the family doubts, concerned or lack of information that doctors/hospital staff may have and the next step needs to be explained clearly. The "next" step may mean next few minutes or next day,  
*(Acknowledgement of doctors' doubts, fears etc may help the family accept the equality of partnership. Explaining what will happen next can show the parents that they are not alone and that there are people who have the information or will provide assistance and that positive things are happening).*
8. If the diagnosis or need for concern is not evident at the time of delivery, but becomes evident within the first few hours/days, the above principles, at the appropriate time still apply.  
*(This would include telling both parents together, baby present, if possible, and being held; straightforward information, positives as well as negatives; and the "next" step).*
9. The senior nursing and medical staff needs to ensure a common understanding of the Situation by all people having contact with the family. Confidentiality should be maintained. *(Conflicting messages will cause confusion for parents and staff. Senior staff should ensure that all persons in contact with the family have clear guidelines regarding needs and rights of both, parents, the siblings and the baby).*

**c) During the next Few Days in Hospital**

1. The hospital Social Worker is available to work with the family and appropriate hospital staff and community team members.  
*(It is very important to ensure there is communication to and between the family and the workers).*
2. The parents need access to information, support and counselling to assist them in making decisions, This help should include information about resources, e.g. financial, supportive, and medical; and referral to specialist help as needed. Services for people with disabilities become involved according to the family's needs. *(The family needs to feel secure in the knowledge that there are services and other parents to support them).*
3. Although the parents should have access to information about their child, workers need to be aware of where the family is at, and not to bombard them with too much information all at once. Families need accurate answers to questions as they come up even if they have already been given the information before. *(At times of stress it is very hard to absorb painful information, so it may need repeating a number of times, Some people may continue to deny what has happened).*
4. It is important to consider the needs and rights of the infant, and the needs of the family (Including siblings, and at times extended family members);

as Individuals and as a unit. Workers must also recognise that the family may be unable to support each other at this time.  
*(Families need emotional recognition and help first - prior to advice and information in a neutral manner to help the baby).*

**d. Prior to, and following Discharge**

The family should be aware of the local Developmental Disability Team and/or other on-going services, Depending on the needs of the family, a worker from the team may visit before the baby leaves hospital. Otherwise, a worker should be available to contact the family shortly after the baby comes home.

If the family does not wish immediate contact with community services, they can be provided with clear written information in their own language if possible, with contact addresses and phone numbers.

The family is advised of routine follow-up with the Baby Health Centre. Appropriate hospital staff must ensure that the resource list is updated, and services and organisations for people with disabilities should also ensure that hospital staff has the information, *(Information to families needs to be clearly given. Many families experience frustrations, as they are unaware of services. Written information where possible should be given to families).*

**CONCLUSION**

These general principles for counselling parents of a newborn child with an identified disability are put forward in order to help those who are in a position to counsel the families and perhaps lessen the trauma of the event for them by outlining positive options for the future,