2. Communication

In relation to the communication of the child’s diagnosis to the family, the Guidelines recommend that:

2.1 The news is communicated with:
- Empathy
- Sensitivity
- Honesty
- Respect
- Compassion
- Understanding

2.2 It is important that positive, realistic messages are conveyed, and hope is given along with the diagnosis. Positive messages can include describing support and assistance that will be available to the family and focusing on the individual child as a person, with the disability secondary. Rather than listing all possible negative implications of the diagnosis and presenting only the worst case scenario, parents have indicated that where possible it is helpful to be informed of the range of possible outcomes of the disability or condition, and the percentages of children who experience different aspects of the syndrome.

2.3 Staff members giving the news use language that is:
- Simple
- Understandable
- Straightforward
- Appropriate

2.4 Prior knowledge of parents is assessed before explaining a diagnosis. (Parents have suggested that open questions such as ‘Have you any concerns?’ or ‘What have you heard so far?’ are helpful, but closed questions such as ‘Does he look like anyone else in the family?’ are not.)

2.5 Any medical terminology used is clearly explained, along with the implications and significance of any information given about the child’s diagnosis.
2.6 Explanations are given at a level parents can understand, taking into account socio-economic, linguistic and cultural factors.

2.7 Listen to parents. Listening to parents allows for communication to be tailored to the individual needs of the family.

2.8 Parents are encouraged to ask questions.

2.9 Staff members check that parents have understood what has been discussed.

2.10 The child is shown respect; the child’s name is always used, and they are not referred to by their diagnosis. For example, instead of saying ‘this Down Syndrome baby’ staff members say ‘Ben, who has Down Syndrome’.

2.11 The appointment is not rushed. Families and professionals agree that informing parents of their child’s disability should be seen as a priority, and consequently adequate time must be allocated, including time for the parents to ask questions and express emotions without interruption.

2.12 Pagers and mobile phones are switched off.

2.13 Team members reinforce the information already given, at appropriate times, so that families have several opportunities to absorb and clarify information provided.

2.14 Staff members are aware of their body language and how this can be interpreted by parents. Avoid whispering in front of parents, or giving negative non-verbal signals that could raise concerns with parents before the news has been communicated to them.

2.15 Parents’ concerns are acknowledged, treated seriously and followed up.

2.16 The reaction of parents is acknowledged, supported and taken into account when communicating with the family. (Parents will have different reactions and different coping mechanisms. Some may feel the need to ‘walk away’ for a period of time to come to terms with the news, others may be in shock and take in very little, still others may wish to have significant interaction, information and support from staff members.)

2.17 Dismissive, impatient, aggressive or judgemental language is never used when speaking to parents or children.