



## Birth Defects Surveillance Toolkit

### Appendix F: Suggestions for delivering the news of a congenital anomaly diagnosis to a family

*Note:* It is important to remember that abstractors, those individuals who will be extracting information from hospital logs or medical records for the identification and classification of congenital anomalies, do not give information to parents about a diagnosis or services. This is to be done by a health-care provider.

- Parents are told about the diagnosis as soon as possible, even if it is suspected but not yet confirmed.
- The diagnosis is communicated in person, by a health-care professional with sufficient knowledge of the condition. Health-care providers should coordinate the message to ensure consistency in the information provided to the family.
- Begin the conversation with positive words and avoid using value judgments when starting the conversation, such as “I’m sorry”, or “Unfortunately, I have bad news”. Parents remember the exact words of the first contact with the health-care provider even after many years.
- The family is informed of the diagnosis, treatment and prognosis, in their preferred language. If possible, a professional medical interpreter is present at the time of disclosure.
- Discuss the diagnosis, treatment and prognosis in a private, comfortable setting, free from interruptions. The infant may be present in the room unless he or she is ill. Allow time for questions and make plans for a follow-up conversation. Stop, when possible, to assess for comprehension.
- Parents should be provided with accurate and up-to-date information. Information is normally given with a balanced perspective, including both positive aspects and challenges related to the congenital anomaly.
- Provide the information on diagnosis, treatment and prognosis in a sensitive and caring, yet confident and straightforward manner, using understandable, non-medical terms, and language that is clear and concise.
- Use sensitive language and avoid outdated or offensive terminology. In the neonatal setting, the baby is to be present, and to be referred to by name.
- Assess for knowledge of that specific congenital anomaly, including etiology. Because there may often be guilt or blame associated with congenital anomalies, often placed on the mother, it is important to discuss these issues with the parents.
- Informational resources can be provided, including contact information for local and national support groups, up-to-date printed information or fact sheets, and books. When appropriate, referrals to other specialists may also be helpful (e.g. medical geneticists, genetic counsellors, cardiologists, neonatologists).

*Source:* suggestions modified from Sheets et al., 2011 ([56](#)).