

malformations. Such an infant also benefits from early intervention services and eventually an individualized education plan in school because developmental delays and eventual learning problems are common.

Initial and ongoing assessment of the family's coping abilities, resources, and support systems is vital to determine their need for additional assistance and support. As with any family who has a child with chronic health care needs, nurses must teach the family to become the child's advocate. Nurses can help families locate agencies and clinics specializing in a specific disorder or its consequences that can provide services (e.g., equipment, medication, and rehabilitation), educational programs, and parent support groups. Referral to local and national support groups or contact with a local family that has a child with the same condition can be helpful for new parents. Privacy and confidentiality are imperative, and both families must give permission before their contact information is given. Nurses can also be instrumental in helping parents start a support group when none is available.

Parental attachment and adjustment to the baby can be supported and facilitated by nursing interventions. Assessing the parents' understanding of the child's disorder and providing simple and truthful explanations can help them begin to understand their child's health issues. Guiding the parents in recognizing their child's cues, responses, and strengths can be helpful even for experienced parents. A caring attitude conveys the value of their child and, by extension, their value as parents. The nurse can help the parents identify their strengths as a family and identify support that is available to them.

Giving birth to and raising a child with a genetic disorder is not necessarily a lifetime burden. It is important for nurses to ask parents to describe their experience raising their child with a particular genetic condition. What has been the impact on their family? Although parents may initially experience negative outcomes, such as shock, emotional distress, and grief, families can adapt and thrive. Resources for managing stress and restoring balance in the lives of families affected by a genetic condition can help. [Van Riper's \(2007\)](#) research has identified nursing interventions that can promote resilience and adaptation in families of children with Down syndrome. Van Riper's recommendations