

Establishing a Support System

The diagnosis of a child with a complex chronic condition is a major situational crisis that affects the entire family system. However, families can experience positive outcomes as they successfully deal with the many challenges that accompany a child with chronic illness ([Hungerbuehler, Vollrath, and Landolt, 2011](#)).

One nursing goal is to assess which families are at risk for succumbing to the effects of the crisis. Several variables—available support system, perception of the event, coping mechanisms, reactions to the child, available resources, and concurrent stresses within the family—influence the resolution of a crisis. Although most families cope well, the needs of families at risk are great. If they receive emotional support and guidance early, there is an increased likelihood that they will also cope successfully.

Although it is easy to assume that families of children with the most severe illnesses or disabilities would have the poorest adjustment, the severity of the condition reflects only one part of the overall picture. The level of adjustment is significantly influenced by the **functional burden** on the family ([Stein, 1985](#)). This concept considers the issues related to caring for and living with the child in relation to the family's resources and ability to cope ([Box 17-5](#)). The family of a child with a high level of technology dependence demanding complex care yet having many resources and coping skills may adjust more successfully to the child's situation than the family of a child with a less serious condition and few resources to counterbalance.

Box 17-5

Concept of Functional Burden

Impact of the Child with Special Needs

The child's need for medical and nursing care

The child's fixed deficits

The child's age-appropriate dependency in activities of daily living

The disruptions in the family routine caused by the care